Section I: Background Information

Terminology and Perspective
If you ever felt perplexed by whom the term “Chinese people” refers to exactly, you have every right to feel so. People of Chinese descent are members of a heterogeneous group, though their origins can be typically traced back to China (a geographic rather than a political term here), Hong Kong, Macau, and Taiwan. Given the sociopolitical complexity throughout Chinese history, it is always advisable to ask how your patient self-identifies. While some may self-identify in general as Chinese or Chinese American, many may prefer to be identified with the geographic region to which they feel most connected, such as Taiwanese American, Hongkongers, and Singaporean Chinese. For this chapter, though, the broad terms of Chinese and Chinese American are used, we focus on those who identify their place of origin as China, Hong Kong, and Macau.

AUTHOR'S NOTE [MIMI K.W. WONG]: My perspective is that of a bilingual (Cantonese/English) Chinese American neuropsychologist who was born in Guangzhou, China, and immigrated to the United States as a young child. I trained in neuropsychology on the West Coast of the United States, where I currently practice in a teaching hospital inpatient/outpatient setting.

AUTHOR'S NOTE [ESTHER CHIN]: I identify myself as a “Hongkonger” who was born in Hong Kong and completed my college degree there. I then received my master’s degree in London and subsequently practiced psychology in both Hong Kong and Boston. My doctoral/postdoctoral training in clinical psychology with specialty in pediatric neuropsychology was mainly in California and later in the Midwest. I currently practice in a neurosciences institute of a teaching hospital in an outpatient setting in the suburb of Chicago.

AUTHOR'S NOTE [YUE HONG]: I identify as a first-generation Chinese in the United States. I grew up in Chengdu, China, completed my undergraduate education in Hong Kong, and received subsequent training in clinical psychology and neuropsychology on the East Coast of the United States. I currently practice in a hospital in Massachusetts.

Geography
The total area of China is estimated to be around 3.7 million square miles and is similar to that of the United States. The term “mainland China” commonly refers to the 32 first-level administrative divisions (i.e., provinces, autonomous regions, and municipalities) that are under the direct jurisdiction of the People’s Republic of China (PRC). This term typically excludes the Special Administrative Regions (SARs) of Hong Kong and Macau, which are former colonies of the

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Britain and Portuguese Empires, respectively, and were returned to Chinese rule in 1997 and 1999, respectively. Although the PRC considers Taiwan to be its 23rd province, Taiwan has identified itself as the Republic of China since 1949 and rejected the PRC’s claim of sovereignty.

**History and Society**

China has the longest continuous history in the world of over 5,000 years and is considered one of the four cradles of civilization. It is impossible to summarize Chinese history in any meaningful way in a few paragraphs; instead, we focus on significant events over the past century that may help create a broad context to understand the drastic changes the Chinese population has witnessed. To make things easier to follow, we invite the readers to join us for a walk-through of the life of a centenarian, S, who was born in 1920.

Eight years before S was born (1912), the last imperial dynasty of China had collapsed. It was during this tumultuous dynasty that Hong Kong and Macau were ceded, and they have since been under Western administrations until the late 1990s. S was born into the Republic of China founded in 1912. S’s early life was filled with political and military instability. He witnessed two civil wars (1927–1937; 1945–1949) between the two major parties in the Republic of China, as well as the Second Sino-Japanese War (1937–1945) between China and Japan. At age 29 (1949), S and his family finally saw an end to the wars, marked by the establishment of the PRC by the Communist Party and the evacuation of the Nationalist Party to the island of Taiwan.

The first three decades of the newly founded PRC were marked by a series of highly controversial reforms and movements. The country endured extreme economic difficulties marked by a nationwide famine between 1959 and 1961, right around the time when S’s children were born. A few years later came the Great Proletarian Cultural Revolution (1966–1976), during which S and many of his friends and colleagues were politically persecuted. It was an extremely difficult time for S and his family, but these memories were such a taboo that he rarely talked about even to his grandchildren.

Since the late 1970s, leadership of the PRC has implemented significant economic reforms that were proven successful. The Chinese society has since undergone drastic changes due to rapid economic growth and globalization that at times overwhelmed S. Fifty years ago, he was struggling to feed his family; by comparison, present-day China has had the world’s second-largest economy. Had S left the country during different times, his memory of China would depict a different world. S has his concerns about the current society. The rapid economic growth is accompanied by a high degree of economic inequality, resulting in a significant urban-rural disparity in terms of accessibility to resources in education, healthcare, and employment opportunities. The younger generations seem to be struggling with their traditional value and beliefs challenged by the swirling globalization. For S, at age 100, he is ready to hand over the challenges to the next generation.

**People**

According to the national census of 2010, the population of the PRC is approximately 1.37 billion. Since the 1950s, China has established a series of family planning policies to address the concerns of overpopulation. These policies reached their most strict form, the one-child restriction, in the late 1970s and have gradually loosened up over the past two decades. These policies, though effective in controlling population size, created many unintended consequences on the composition of the population. For instance, there is a huge gender imbalance in China, with the male population exceeding the female population by more than 30 million, underlined by a patriarchal preference for sons over daughters. Girls, particularly those who are less socio-economically resourceful, often struggle with issues surrounding self-worth. Additionally, with the decreasing
birth rate, China is now faced with an aging society that will challenge the system's ability to care for its people. On the family level, one sees a typical 4:2:1 (4 grandparents, 2 parents, 1 child) structure that funnels all resources and attention to this one child, who eventually becomes the sole caregiver for their entire aging family.

It is also important to note the ethnic and religious composition of the Chinese population. Besides the largest ethnic group of the Han people (approximately 92% of the population1), China recognizes other 55 ethnic minority groups, most of which reside in areas bordering other countries. Whereas in Hong Kong and Macau, though the majority (92%-95%) of the population are ethnic Chinese, the ethnic minorities are often from Southeast Asian countries and descendants of British and Portuguese. In terms of religious affiliation, the majority of the population in mainland China identify as atheists and agnostics. Five religions are currently acknowledged in mainland China, including Taoism, Buddhism, Catholicism, Protestantism, and Islam. In Hong Kong and Macau, there is a higher rate of reported religious affiliations with Buddhism, Taoism, and Christianity.

Immigration and Relocation

Depending on the definition of the “Chinese diaspora,” population estimates vary between 10 million and 45 million.3 The number of Chinese individuals residing in the United States is estimated to be around 5.2 million, with California and New York hosting the largest Chinese communities.4 Immigration of Chinese into the United States mainly consists of two waves: the mid-19th century and the 1970s to the present. In the 1800s, Chinese immigrants were primarily male, low-skilled manual laborers in agriculture, mining, and railroad construction who migrated to the West Coast. As US–China relations improved in 1979, the second wave of Chinese migration to the United States began. From 1980 to 1990, the number of Chinese immigrants nearly doubled and has been growing since. For older generations of immigrants, the principal reason for migration was the search for jobs and/or political asylum, whereas younger generations of immigrants are largely seeking to enhance employability and academic background. The context of immigration can shed light on socio-economic status and immigration-related stressors.

Language

Just like the term “Chinese people,” “Chinese language” is also a hugely heterogeneous umbrella term. There are hundreds of dialects spoken in China typically classified into seven groups; many of these dialects are not mutually intelligible from a linguistic perspective.5 Of the seven groups, a dialect of the Mandarin group became the official language in mainland China in the 1950s (known as Putonghua). Though Mandarin is generally spoken across most of northern China, southern Chinese of older generations or those from rural areas may not be familiar with the official dialect. Of note, another variation of Mandarin (Guoyu) serves as the official language in Taiwan. The Yue group, consisting of at least 14 dialects including Cantonese and Taishanese, is a group of Chinese dialects primarily spoken in the provinces of Guangdong and Guangxi, as well as Hong Kong and Macau. For the Chinese immigrant population in the United States, Mandarin/Putonghua and Cantonese are reported to be the most commonly spoken dialects.6

It is also important to differentiate two writing systems of Chinese, the traditional and the simplified Chinese characters. The simplified Chinese characters were introduced in the 1950s and have become the preferred writing system for most mainland Chinese. However, traditional characters continue to be used by Chinese living in Taiwan, Hong Kong, and Macau. For example, a Cantonese-speaking Hongkonger can communicate freely with a Mandarin-speaking Taiwanese by writing since both adopt the traditional characters, whereas a mainlander who uses
simplified written Chinese may not understand a Taiwanese's writing as easily even though both are Mandarin-speaking. It is worth noting, though, that both simplified and traditional writing systems of Chinese follow the same vocabulary and grammatical structure of Mandarin. Therefore, while there may be immediate challenges with a mainlander who uses simplified written Chinese not understanding a Taiwanese's writing, this could be overcome with some effort and time, and vice versa. Yet the linguistic differences between different groups of spoken Chinese languages (e.g., Cantonese and Mandarin) are much more difficult to overcome.

In short, “the patient’s primary language is Chinese” provides very little information for a culturally informed neuropsychological evaluation. Primary dialect, familiarity with the most commonly used Chinese dialects (Mandarin and Cantonese), preferred writing system (traditional vs. simplified) should be assessed to guide clinical decision-making.

Education

The level of literacy grew substantially over the last half-century in China, from 20% in 1949 to 96% in 2018. Since the 1980s, China has implemented the nine-year compulsory education system, consisting of six years of primary school and three years of junior secondary school, whereas education in Hong Kong is largely modeled after the English system. The average years of schooling in China were estimated to be 7.8 years in 2017, though the education quality likely differs depending on when and where one is educated. Those who went to school before the 1970s in mainland China likely experienced disruptions to their education given the socio-economic upheaval, and those who received education in rural areas are likely at a disadvantage for education quality.

In the United States, over half of the Chinese American population has a bachelor’s degree or higher, and the average education attainment of the US-born Chinese is remarkably higher than that of the first-generation immigrants.

Culture

Though Chinese culture is diverse given the enormous temporal and geographic spans, some themes are generalizable given the profound impact of Confucianism. Most notably, Confucianism promotes two principles of Li (social rituals) and Ren (humanism). The former is considered more conservative, promoting respect for authorities and conformity to established social roles. The latter is more idealistic and highlights universal values that allow two individuals to coexist in a humane manner. Most germane is how these general principles manifest themselves in the contemporary Chinese society and how they could impact a neuropsychological evaluation. We would like to remind our readers, though, that these summaries are not meant to perpetuate stereotypes and that each individual is unique and should be respected as such.

Harmony and Stability

Harmony is highly valued by Confucianism to maintain the stability of a society and its units. On an individual level, Chinese people are taught to behave in a way that maximizes the interests of the group and obeys those in authority. Should conflicts arise, one is expected to forgo their own personal preferences if they are of a minority/lower status on the social hierarchy. In fact, it is often considered rude and selfish to be vocal about one’s own needs without acknowledging the group’s preference. On a more societal level, while the sense of belonging is maximized for the majority, deviation from the social norm is discouraged, and the needs of minority groups are often drowned out. In a clinical setting, this can manifest as a particularly agreeable
patient who will likely hesitate to ask for clarification or to question a provider in fear of jeopardizing the patient–doctor relationship.

Communal and Familial Orientation

The communal and familial orientation is closely intertwined with the valuation of harmony and stability, as family is considered the basic building unit of a society. Altogether, they enhance commitment to familial/communal relationships because these relational networks are expected to be long-lasting. If used properly, one could find safety and support in a resourceful and nourishing relational network that spans several generations.

However, these relational networks can become entangling and give rise to boundary issues that may appear problematic to someone who is acculturated in an individualistic society. For instance, every single member of these networks is held responsible for the reputation or “face” (mianzi) of the group. One’s wrongdoing, or deviation from the norm, could be considered a disgrace (loss of face) to the entire group and, therefore, highly discouraged. Perhaps the other side of the same coin, boundary issues also arise as a way to protect an ingroup member. For instance, it is very common for the Chinese to “hide” the diagnosis of a terminal illness from their elder parents, because it is considered insensitive to tell them the diagnosis and unhelpful anyway. Vice versa, it is also common for parents to “hide” their health conditions from their children in fear of creating burden for them. The movie, Farewell, did an excellent job depicting these intricacies and is highly recommended for those who are interested.

Shame

Shame is proven to be an effective tool to guide human behavior and is a tool commonly used in child-rearing in traditional Chinese cultures. Lieber et al. define shame in the context of Chinese culture as “a socio-emotional reference and mechanism for fostering the development of children’s social sensitivities.” In other words, the goal of parenting is to achieve moral socialization in line with the traditional Chinese values through the mechanism of shame. Implanted at a young age, the shame system operates throughout one’s life and is easily activated when one is accused of “losing face” by failing to meet expectations from authority. During neuropsychological evaluations, you will likely see the activation of this system when a Chinese examinee becomes highly anxious about their performance and overly apologetic for not knowing an answer. It is critical to note and address these reactions, because one could end up evaluating the power of shame rather than cognitive functioning.

Mental Health Views

Stigma toward individuals with mental illnesses is pervasive in China and is, unfortunately, sustained by many of the traditional Chinese values. People with mental illness are often depicted as dangerous and unpredictable and are considered a threat to a harmonious and stable society. These public stigmas can become internalized, activating the shame system and further prohibiting individuals from seeking help and advocating for themselves. A survey revealed that the number one coping mechanism endorsed by Chinese individuals with severe mental illness is maintaining secrecy about the illness. Moreover, concealing mental illness often becomes a communal act. As previously noted, one’s deviation from the norm (in this case, having a mental illness) causes the entire family to lose “face” and, therefore, takes everyone’s effort to cover the tracks. The incentive is amplified by common beliefs about the hereditary nature of all mental illnesses, implicating the
family as pathogenic. Conversely, family members may participate in the deception and “hiding” as a way to protect their loved ones from being discriminated against. In either case, the secrecy often leads to an extreme lack of information and support and, at times, an unbearable burden for the entire family. In addition, individuals with mental illness become increasingly invisible, resulting in biased media coverage that focuses on the most extreme cases, which in turn further fortifies the stereotypes of mental illness being dangerous and unpredictable. The Chinese government passed a new mental health law in 2013 to improve mental health literacy and reduce stigma. However, it will likely take decades before individuals with mental illness become visible in a respectful light.

Health providers are often seen as authorities. A Chinese individual may, thus, conceal mental health history of themselves or family members from medical providers for fear of being sanctioned or discriminated against. A red flag may be raised even higher when one gets introduced to a neuro-psychologist. A standard question of “any history of psychiatric illnesses in your family?” will most likely get an answer of “no.” It is thus important to build rapport and gain trust before proceeding with those questions, including, but not limited to, clearly explaining the role of a neuropsychologist, proving one’s credibility by revealing one’s training background, carefully reviewing the confidentiality terms, and explaining the rationale for questions that may feel intrusive or offensive. It is also important to maintain vigilance to reports of somatic symptoms such as chronic pain and general malaise as these are often comorbid with affective symptoms and are considered “safer” options to report.

Health Status

Life expectancy in China has increased steadily over the past half-century, reaching about 76 years and is above the world average. However, significant rural-urban disparity is observed at birth and widens with age. Being a woman and being born during periods of societal instability (e.g., famine cohort (1959–1961), later cultural revolution cohort (1971–1976) are risk factors for worse health outcomes. There is also a rising rate of obesity and high smoking prevalence among Chinese men. The prevalence of neurodevelopmental disorders in Chinese children is reported to be lower than in highly industrialized countries, which is likely an underestimate. Evidence suggests that, with different methodology for data collection and reporting, the prevalence of Autism Spectrum Disorder (ASD) in China is at least comparable to that of Western societies. Individuals with neurodevelopmental disorders are another “invisibilized” group in China due to similar reasons outlined in the Mental Health section. I (YH) remember having a classmate in primary school who would constantly stand up in the middle of the class, for which he was criticized by teachers and bullied by fellow students. It never occurred to me until many years later that this person may have had attention-deficit/hyperactivity disorder. Similarly, autism, to this day, is still used in a nonchalant way by mass media to refer to social anxiety (e.g., “Nah, I’m gonna skip the party, my autism is flaring up lately”). The reason for sharing these stories is simply to remind our readers that, when you work with a Chinese family, a condition that seems common to you may not be well or accurately understood by the family. It is thus critical to take the time to explain the condition, to go the extra mile to destigmatize it, and to ensure that the family doesn’t take the diagnosis as yet another secret to keep.

History of and Approach to Neuropsychological Evaluations

Historically, a Western conceptualization of neuropsychology was introduced to mainland China in the 1980s, followed by various efforts to adapt and validate tests. However, the development of clinical neuropsychology is limited by a lack of systematic training and the healthcare system’s capacity
to afford such a time-consuming evaluation. In fact, doctoral-level neuropsychologists, who are often trained overseas, work mostly in research settings in China, whereas clinical neurocognitive testing is often performed by physicians and physician assistants, who may possess limited knowledge regarding the background and psychometric properties of testing tools. Clinical neuropsychology witnessed a comparably faster development in Hong Kong, perhaps attributable to a greater degree of Westernization. The Hong Kong Neuropsychological Association was established in 1998 and played an important role in the development of the specialty in the area.\textsuperscript{14} A large amount of indigenous test development and test translation/adaptation also took place. Yet, comprehensive neuropsychological evaluation in clinical settings is not readily accessible to everyone for whom it could be a benefit.

One of the biggest barriers for neuropsychologists who are interested in serving the Chinese population is the accessibility of testing instruments. As most neuropsychologists work in research settings, the end goal of test development, adaptation, and validation are often not for clinical application, making the tests difficult to locate. Practical barriers such as the high price of commercialized tests in China and the need to be credentialed through a local professional organization to purchase tests can also impede these local tools/norms from appreciation by a wider audience. A recent systematic review\textsuperscript{15} provides detailed information on non-commercialized test validation in mainland China and provides a list of available instruments and normative data that may be of interest to readers of this chapter.

Taken together, providers should bear in mind that a neuropsychological evaluation can be particularly foreign to a Chinese patient. They may find it highly intimidating given the “psychology” root in combination with the testing setting that creates a rather explicit social hierarchy. It is advised that a provider actively seeks ways to enhance rapport and motivation and adopts a communication style that maximizes the patient’s comfort level. Extra time is likely required to explain the purpose and procedures of the evaluation. During the evaluation, it is important to watch for signs of when a patient tries to maintain harmonious relationships by not being direct and forthright. In those situations, the patient may instead communicate indirectly with a greater emphasis on nonverbals (e.g., reduced eye contact, closed-off body posture), of which a culturally sensitive neuropsychologist should be mindful.

Section II: Case Studies — “Overcoming Shame in the Family”

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

The following two case studies were selected to illustrate some of the cultural considerations mentioned in Section I. Please note that the pediatric case is from Dr. Esther Chin, and the adult case is from Dr. Mimi K.W. Wong.

Pediatric Case

Background

Xiaomin Chan was a 4-year-10-month-old Chinese female with a right-handed preference who immigrated to the United States eight months prior to the evaluation. Her family was referred to me by her social worker at a community center for a neuropsychological evaluation due to concerns with global cognitive delays. In addition to the standard components of a pediatric evaluation, an extensive clinical interview was performed with not only Xiaomin’s parents but also her grandparents, homeroom teacher, and school social worker. [Author’s note (EC): In the context of communal culture, both Chinese parents and grandparents are likely to be the main caregivers.
Her teacher and school social worker provide additional information in order to validate the consistency of information and prevent cultural biases. Cantonese and Taishanese dialects (referred to as “Cantonese” for the rest of this case study for simplicity) were Xiaomin’s primary languages used at home, while English and Cantonese were used at school.

Xiaomin’s parents, grandparents, and teachers were concerned about her overall cognitive functioning. According to their report, she demonstrated an inconsistent level of attention, depending on the nature of the activity. With respect to her language functioning, she mainly used physical guidance (e.g., pulling an adult’s hand), vocalization (e.g., babbling), and gestures to make requests or express herself. She occasionally communicated with single words and simple phrases in Cantonese. Her ability to follow simple 1-step instructions in Cantonese and English was inconsistent. In terms of her adaptive functioning, she was able to feed herself with utensils and dress herself with assistance. However, she needed help to bathe herself, wash her hair, and button her shirts. She could scribble but couldn’t trace lines. She could walk up and down stairs and ride a bike with training wheels. She was also toilet trained. [Author’s note (EC): I was pleasantly surprised by the fact that both her parents and grandparents appeared to have no hesitation to accurately report what she could and could not do. This was a positive sign for me to access their readiness to process any diagnostic information during the feedback.]

Xiaomin’s parents and teachers also reported concerns related to social and emotional difficulties. She struggled to initiate social interactions and maintain social reciprocity, even when the engagement was facilitated in Cantonese. Her eye contact was inconsistent, and affect tended to be flat. Her ability to engage in pretend/imaginative play was limited. Echolalia and behavioral rigidity (e.g., difficulty with transitions) were reported. Excessive interests in specific toys and sensory atypicality (e.g., disliking getting wet, visual examination, looking up at the ceiling lighting) were observed. Emotionally, separation anxiety with her mother was reported. She also easily became frustrated at home, resulting in crying with variable durations. No therapy services had been initiated.

At the time of the evaluation, Xiaomin attended the pre-kindergarten program organized by a Chinese community center. Reportedly, she did not demonstrate knowledge of pre-academic skills (e.g., recognition of color, numbers, or shapes). Of note, she received no formal education prior to her immigration to the United States. Her social worker had been assisting the family in navigating resources provided by their school district in preparation for her attendance to kindergarten in the next academic school year. An Individualized Education Program (IEP) evaluation was initiated; however, she was deemed ineligible as her language delay was attributed to her recent immigration. [Author’s note (EC): Upon record review, her school did not appear to conduct a thorough interview with her family to gather information regarding her development prior to immigrating or involve culturally competent specialists to differentiate between a true language delay and a lack of language proficiency due to recent immigration.]

Xiaomin’s mother reported that she was diagnosed with pre-eclampsia in the last month of her pregnancy. She was otherwise reportedly born full term via cesarean section without postnatal complications. During infancy, she was diagnosed with pulmonary arteriovenous malformation, for which two surgeries were performed at four months and nine months old. The rest of her medical history was unremarkable. Cognitively, her attainment of early gross and language skills was delayed. While she crawled at approximately eight months, she started walking at age two. She started using single words in Cantonese at age two and word phrases at age 4.5. No concerns with her sleep, appetite, functional hearing, or vision were reported.

In May 2018, Xiaomin and her mother immigrated to the United States to reunite with her father, who had been living here. At the time of the evaluation, Xiaomin lived with her parents and paternal grandparents. Her father graduated from high school in China and worked as a busser in a Chinese restaurant. Her mother completed nine years of education in China and was
Behavioral Observations

Xiaomin’s mother and grandmother accompanied her to the clinic on the day of testing. Due to her separation anxiety, her mother had to be present in the testing room throughout the evaluation. Xiaomin presented as a pleasant girl, but her social engagement was limited, and eye contact was inconsistent. Her mood was mostly indifferent, but she appeared to show brief moments of pleasure when activities caught her interests (e.g., blowing bubbles). To communicate, she used vocalization, physical guidance/gestures, and simple vocabulary in Cantonese. She wasn’t able to follow 1-step instructions consistently and needed frequent redirection and prompting to keep her on task. Despite support, her attention span was short. She struggled to remain seated and tended to walk around in the testing room. She also demonstrated echolalia, visual examination, and repetitive looking up at the ceiling lighting during testing. She was able to walk independently and scribbled with color pencils. Her short attention span and limited social engagement most definitely impacted her testing performance, but these results are likely an accurate representation of her typical functioning.

Tests and Norm Selection

The limitations surrounding availability and accessibility of tests and normative data for Chinese individuals described in previous sections are, unfortunately, prevalent in the pediatric world. The common practice, though not ideal, is to utilize measures developed and normed in the United States with reasonable adaptation, interpret results with caution, and clearly note the limitations in the report. For this case, the following tests and questionnaires were translated and administered in Cantonese.

- Stanford Binet—Fifth Edition (SB-5): Abbreviated battery IQ
- Bayley III—Scales of Infant and Toddler Development: Cognitive composite
- Wide Range Assessment of Visual Motor Abilities (WRAVMA): Drawing and pegboard
- Peabody Picture Vocabulary Test—Fourth Edition (PPVT-4)
- Bracken School Readiness Assessment: School readiness composite
- Adaptive Behavior Assessment System—Third Edition (ABAS-3)
- Social Responsiveness Scale—Second Edition (SRS-2)
- Behavior Rating Inventory of Executive Functioning (BRIEF): Parent and Teacher Report

Cognitive Test Results and Interpretation

Xiaomin’s overall cognitive functioning was below age expectation, falling within the moderately impaired range. Her cognitive development was approximately at an age equivalent of 18 months old. She was able to search for missing objects and take blocks out of cups. However, she struggled to engage in relational play (e.g., feeding a baby doll) or match shapes consistently.

Comparably, Xiaomin’s other cognitive abilities, including visual-motor integration skills, fine motor dexterity, and language skills, were below age expectation. She particularly struggled with
her language skills. In addition to her observed language deficits throughout testing, her performance on a task of receptive language skills was severely impaired, with an age equivalent below two years. A task of pre-academic skills was attempted but was incomplete due to her inattention and limited social engagement.

**Autism-Related Measures**

The ADOS-2 Module 1 was administered with the presence of her mother in the testing room. Xiaomin demonstrated atypical social communication and interaction, which was evident in Cantonese. For example, she mostly used vocalization but not words in her communication, which was considered as a delay in Chinese language development given her age. She seldom directed her vocalization to her mother/the examiner and used poorly modulated eye contact throughout the evaluation. While she directed some of her facial expressions to her mother, she did not demonstrate a responsive social smile to either her mother or the examiner. Despite her mother’s effort, she showed limited engagement in most activities. [Author’s note (EC): Compared to people raised in Western cultures, Chinese people may demonstrate less eye contact, facial expression, and/or gestures in communication and appear to be relatively reserved with new people or people in higher hierarchy. However, Xiaomin’s lack of social communication and interaction even with her mother, with whom she is familiar, was above and beyond what is expected in Chinese culture.]

In addition, atypical sensory interests (e.g., unusual visual examination, looking up at the ceiling lighting) were observed during the ADOS. She demonstrated an intense and repetitive interest in a particular pop-up toy and often fidgeted and got up out of her seat. Overall, on the ADOS-2 Module 1, her scores showed a moderate level of autism spectrum-related symptoms.

**Adaptive Functioning and Emotional/Behavioral Rating Questionnaires**

Xiaomin’s parents, grandparents, and teachers completed questionnaires assessing her overall adaptive functioning and general emotional/behavioral functioning. Xiaomin’s overall adaptive functioning was moderately impaired, mostly functioning at one year and six months to one year and 10 months old. All raters reported similar concerns but with different levels of severity. The concerning areas included lack of inhibition/hyperactivity, emotional dysregulation, atypical behaviors, social problems, and functional communication difficulties. The ratings from her parents and teachers indicated significant concerns, whereas her grandparents endorsed less severe concerns. [Author’s note (EC): As mentioned, based on the observation during intake, both her parents and grandparents appeared to be ready and likely to accept potential diagnoses. Yet, the discrepancy in severity ratings may suggest that her grandparents experience a higher level of “shame” related to the atypical neurodevelopment of their granddaughter. I made a mental note that additional explanation and education for her grandparents may be required during the feedback.]

**Summary**

Xiaomin presented as a pleasant girl with a short attention span and limited social engagement. Results of the current evaluation, performed in Xiaomin’s first language, revealed overall developmental and intellectual delay. Significant difficulties with socialization/communication, restricted interests, rigidity, and sensory issues were reported by Xiaomin’s parents, grandparents, and teachers, consistent with formal testing and clinical observation. Her cognitive delays and language difficulties could not be solely explained by her lack of formal education or English proficiency. Thus, a diagnosis of ASD with accompanying intellectual and language impairment (Level 2) was given.
Feedback and Recommendations

[Author's note (EC): In order to mitigate reactions of shame and help the family focus on strengths and therapeutic options, ongoing psychoeducation and updates on preliminary data were provided throughout the evaluation. This gradual manner was crucial to mentally prepare the family for the possible diagnosis, alleviate the feeling of shame, and cultivate realistic hope to the family by navigating services and resources in the community.] On day one, following the intake, I gently inquired of the family about any “diagnostic” thoughts in their mind and subsequently provided psychoeducation on each possible diagnosis. I also provided education on how the “diagnostic term” was not used to create stigma but to navigate and connect with the appropriate interventions. On the day of testing, I spent the last 15–20 minutes summarizing the preliminary data with Xiaomin’s mother and her grandmother. I tied the data to the diagnosis (in this case, autism) and strategically pointed out Xiaomin’s relative strengths and areas of potential improvement. With all the mental preparation starting at the intake, the oral feedback provided in the last session became a smooth and constructive discussion with relatively open-minded reception from Xiaomin’s family. [Author’s note (EC): Xiaomin’s mother and grandmother were both closely involved throughout the evaluation. This was crucial in Xiaomin’s case to alleviate her mother’s burden to convey the “bad news” and communicate unfamiliar information to members of the higher familial hierarchy. Additionally, having the whole family on board, the strong relational network within the family became an excellent asset to maximize the benefits from appropriate interventions.]

Based on the results of the current evaluation, a list of recommendations was provided, including therapeutic intervention, special education services, and community resources. Here I highlight the recommendations that are most relevant to this chapter.

1. Xiaomin and her family were recommended to receive applied behavioral analysis (ABA) in-home therapy to address her ASD symptoms. I encouraged participation of the entire family to support her ability to generalize the learned skills across different settings. Given the intricacies of therapy, I recommended arranging a Cantonese-speaking therapist for the family; or, at least, the presence of a medically trained interpreter to assist with communication.

2. Xiaomin’s family was recommended to share the report with her school and school district. I made it explicit in the report that her symptoms could not be solely explained by her lack of proficiency in English and/or her history of recent immigration in order to help with the qualification for IEP. In addition to intensive special education services commonly provided to students with ASD, I highlighted the importance for her IEP team to collaborate with bilingual/bicultural providers. Specifically, I recommended collaborating with a qualified bilingual (i.e., English and Cantonese) specialist or teacher to assist with understanding language or cultural factors as they relate to the student’s instructional or assistance needs and to design and implement the English as a Second Language (ESL) curriculum. I also recommended consultation with a Chinese-speaking speech/language pathologist in order to maximize her benefit from speech/language therapy at school.

3. Lastly, the following resources for ASD were provided to Xiaomin’s family and may be of interest to readers of this chapter.

- Featuring dozens of short files, the website (http://www.interactingwithautism.com) presents the latest evidence-based information on how to understand, treat, and live with people with ASD. Information is available in Chinese.
- Here is a website with autism information packet: https://www.supportforfamilies.org/autism-info-packet
Background Information

“Ms. Chan” was a 55-year-old Chinese female with approximately two years of formal education. Her primary language is Cantonese, which is used with her family and providers. [Author’s note (MW): Given that she came from rural China, it’s possible that she speaks other rural dialects such as Taishanese. I would typically ask the patient which language they use at home when communicating with family, which is helpful in determining the language to use in testing]. The patient was referred by her primary care provider for complaints of problems with cognition in general, including memory and comprehension, with a history of possible developmental delay. The provider requested an evaluation of the patient’s current neurocognitive status to assist in differential diagnosis and treatment planning.

Ms. Chan appeared to be a poor historian. Records showed contradictory self-reports about her symptoms and history. As a result, I gathered most of her history through available record reviews and collateral information from providers and siblings. Per her providers, Ms. Chan’s current cognitive symptoms included problems with memory, attention, and comprehension. She demonstrated difficulties with performing complex activities of daily living, such as shopping, filling out forms, going to unfamiliar places, and following medical directions. Arrangements had to be made for Ms. Chan to visit the primary care clinic daily to ensure medication compliance. Although Ms. Chan reported that she took care of her own finances, Adult Protective Services was involved on two separate occasions due to concerns of possible financial abuse or undue influence. She reportedly had been able to manage her simple daily activities in the past, likely with support from her parents. At the time of the evaluation, Ms. Chan was able to dress, eat, and toilet independently and could use public transportation to get to familiar places. However, records noted poor hygiene in the past. Her sister noted that she usually attempts to present herself in a positive light and was reluctant to acknowledge any cognitive problems.

Ms. Chan was born in Vietnam and raised in rural China. Per Ms. Chan’s older sister, she did not meet her developmental milestones for communication. She spoke single words at four years old, spoke two-word phrases and knew a few colors at 8–9, could count at 10, and spoke short sentences at 12. She had a high fever when she was around seven years old, was in a “coma” for three to four days with possible seizures, and was hospitalized for approximately one month in China. Her sister believed that Ms. Chan’s functioning further declined after this early illness with tremendous difficulties with communication, memory, and learning. She did not progress through school like her peers and siblings and only completed two years of formal schooling. [Author’s note (MW): Ms. Chan grew up in a rural Chinese family during the Cultural Revolution, which was a time marked by great sociopolitical turmoil. Access to quality education and healthcare was limited. All the family members had limited education and low health literacy, including poor understanding of the impact of mental health and developmental conditions on one’s behavior].

Ms. Chan had been cared for by her family since childhood. She has never worked in gainful employment. Around 25 years ago, she moved to the United States to reunite with her family. She has since lived with and been taken care of by her mother until she passed away around two to three years prior to this assessment. Soon after her mother passed away, Ms. Chan was evicted from the family residence due to increasing conflicts with her siblings, who were concerned by her behavioral problems at home, including refusing to throw away rotting food and being verbally abusive to her brother and sister-in-law. After being evicted, Ms. Chan became homeless. She was living at a shelter and was supported financially by supplemental social security income. She appeared to maintain a somewhat close relationship with her younger brother, whom she called
once per week. [Author’s note (MW): Ms. Chan’s family may have been aware of her pervasive cognitive deficits to some degree, but shame, in addition to other factors including limited health literacy, may have prevented the family from seeking professional help earlier. Ms. Chan’s mother took care of her disabled child’s needs into adulthood, which is a common cultural expectation. As mentioned earlier, in traditional Chinese families, the stigma of having a mentally ill family member may lead to overprotection and the phenomenon of being “hidden” from the world. If Ms. Chan was assessed and received appropriate services earlier, she may not have had to endure the hardship of the years of homelessness, abuse, and vulnerability as a result].

Per records, Ms. Chan has been diagnosed with schizophrenia, psychosis disorder not specified, psychosis unspecified, recurrent major depressive disorder, and severe adjustment disorder. Approximately two years prior to this assessment, Ms. Chan completed an evaluation with an English-speaking neuropsychologist with the assistance of a Cantonese interpreter for possible cognitive/intellectual disorder. During that evaluation, the family’s concerns regarding her problems with behavior and self-management (i.e., difficulties in learning about diabetes management) were confirmed, but no developmental history or other collateral information was gathered from family members. Furthermore, no formal intelligence measures or normative data appropriate for her culture were utilized during that assessment. She was diagnosed with a psychotic disorder not otherwise specified by history and a cognitive disorder NOS, mild, possibly due to a long-standing learning disorder. Following this evaluation, she was referred to the local Regional Center by her primary care provider, but her application was apparently rejected due to insufficient information regarding developmental and educational history and an under-established link between her mental illness and her ongoing symptoms. [Author’s note (MW): It is not entirely clear how the examiner arrived at this diagnosis, given the overall marked impairment demonstrated in test results. It is certainly possible that given the lack of appropriate culturally appropriate measures and normative data available at the time of that evaluation, the examiner took a more conservative stance on conclusions so as not to pathologize the patient].

Ms. Chan has historically presented conflicting self-reports on symptoms of auditory and visual hallucinations. Providers noted poor, if at all, compliance with her psychotropic medications, yet her symptoms stayed stable. Per Ms. Chan’s siblings, they have never observed and heard of any psychotic symptoms such as auditory or visual hallucinations, internal preoccupation, or delusions. They noted disorganized speech and behaviors but noted that they were not a significant change from her baseline post-childhood febrile illness. Recently, a second opinion obtained from a new psychiatrist indicated that although psychotic disorder could not be ruled out, the degree of cognitive impairment appeared to exceed the level that would be expected from psychiatric diagnosis alone. [Author’s note (MW): Gathering detailed collateral information from her siblings was essential for accurately determining the diagnosis and assessing her eligibility for certain programs. Although it was unfortunate that her siblings were unable to be more involved in her care previously, it was my hope that with greater psychoeducation regarding intellectual disability and more support through the RC, they would be more amenable to engage with Ms. Chan. I recall her speaking fondly of her younger brother and how she enjoyed his visits while she was staying at the shelter].

Behavioral Observations

Ms. Chan came to the appointment alone. She was dressed appropriately but appeared somewhat disheveled with noticeable dirt under fingernails and a report of constant “itchy skin.” She looked younger than her stated age. She knew that she was in the hospital to see me but did not know the date or the situation related to this evaluation. She spoke in a loud child-like voice, and her speech felt pressured with mostly short phrases. Enunciation of Chinese words was at times unclear, and
I had to ask her to repeat for me to understand. She also had difficulties with comprehension and following instructions, requiring multiple repetitions on more complex tasks. Reports of her own history appeared questionable after corroboration with her sister and providers. During our interaction, she had difficulties tracking the conversation and appeared impulsive despite prompting. I noticed that her affect was restricted and was not always congruent with her reported mood. For instance, she did not appear fearful or distressed when talking about her hallucinations, which she stated as distressing.

Ms. Chan reported seeing “ghosts who threaten to harm her with forks and knives.” When asked to describe this in greater detail, she stated, “they wear white and it happens both day and night,” but could not elaborate further. Other than self-reported visual hallucinations, and circumstantial speech, she did not seem preoccupied with things that were not present in the room or report any beliefs that were detached from reality. Her ability to understand and judge complex situations appeared impaired. During testing, she put forth adequate effort and task engagement, and the testing results were considered to be a valid representation of Ms. Chan’s current cognitive functioning.

Tests and Norm Selection

Given the limitations surrounding test accessibility as described in previous sections, it is often the practice to use a mix of available tests normed for the Chinese population (when possible) along with tests adapted and translated from measures developed and normed in the United States. In this battery, I used the measures listed below. The instructions for the Beta-4 and the questions for the Independent Living Scales (ILS) subtest: Health and Safety were informally translated into Cantonese. All other tests listed below were normed on neurotypical Chinese individuals. The Beta-4 provides a reliable and valid estimate of non-verbal intellectual functioning, validated on English, ESL, and non-English speaking populations as well as special groups with learning disorders and intellectual disabilities. Given Ms. Chan’s educational level and unfamiliarity with the testing situation, special attention and arrangements were made in order to optimize her comfort and participation. These included using more simplified explanations on training items in addition to the standard instructions and/or having the examiner read the Chinese word list items if she was unable to read all the words due to low literacy. Deviations from standard administration procedures and cautious interpretation were documented in the report.

- Beta-4
- Brief Visuospatial Memory Test—Revised Form 1 (BVMT-R)
- CERAD List Learning Test—Chinese
- Category Fluency
- Color Trails Test
- ILS subtest: Health and Safety
- Wechsler Adult Intelligence Scale—Revised Edition (WAIS-R)
- Selected subtest: Digit Span

Test Results

An estimate of Ms. Chan’s non-verbal intellectual functioning based on the Beta-4 suggested strong possibility of intellectual disability (Beta 4 IQ = 52; 0.1 percentile). Her ability to recall a verbal list after ten minutes appeared grossly intact, but her ability to recall visual information was severely impaired, mostly due to poor comprehension and poor encoding. A teach-back
method was used where Ms. Chan was asked to state in her own words what she understood to be the task instructions. She failed this three times with no improvement on prompting. Verbal fluency and visuospatial construction abilities were impaired (Category fluency = mild to moderately impaired; BVMT copy = unable to understand instructions). Simple attention was mildly impaired. Complex attention and executive functioning were severely impaired. She had significant difficulties understanding the instructions for a set-shifting task. Similarly, she was unable to understand how to do digits backward despite repeated teaching and prompting. Understanding of everyday health and safety scenarios assessed using the ILS Health and Safety subtest was impaired, which is typically associated with inability for independent living.

Clinical Impressions

Based on the results of this assessment and reported onset of cognitive and adaptive functional deficits since childhood, it was my impression that Ms. Chan met criteria for Intellectual Disability. She demonstrated significant deficits primarily in comprehension, complex attention, and executive functioning. In spite of the lack of records from Ms. Chan’s developmental period, information gleaned from family members and current providers was highly consistent with impaired adaptive functioning prior to age eighteen in the absence of psychiatric disorder, as well as impaired current adaptive functioning. Furthermore, recent questions regarding her self-reported psychotic symptoms had been raised by multiple providers. In fact, providers who have known Ms. Chan for many years have not reported any observable psychotic symptoms other than circumstantial child-like speech.

Recommendations

1. Given repeated concerns regarding possible financial abuse by current payee and prior APS involvement, I recommended that another payee other than the alleged perpetrator be identified to help Ms. Chan manage her SSI income.
2. I encouraged Ms. Chan to continue following up with a psychiatrist within her own health network who can manage her psychiatric treatment.
3. I recommended that Ms. Chan be re-evaluated for eligibility to receive services from Regional Center. Although she was previously found ineligible, it was my hope that Regional Center will reconsider her application given the newly acquired collateral information from siblings, detailed psychiatric records, and updated testing with more culturally appropriate measures and normative data.
4. Ms. Chan is fortunate that her bilingual social worker has been advocating tirelessly to help her obtain the appropriate diagnosis and services. I recommended engaging with other advocacy programs should more support be required.

Follow-Up

Feedback was provided to Ms. Chan’s primary care team per her wishes. Ms Chan’s application was re-submitted to the Regional Center, which was then evaluated by a separate team of clinicians for eligibility criteria. She underwent another eligibility evaluation, meeting with an intake social worker, and was tested by a new bilingual neuropsychologist, whose report indicated that Ms Chan met criteria for moderate Intellectual Disability and was therefore eligible for Regional Center services. She was assigned a bilingual case manager who met with her regularly and found her appropriate housing, such that she was able to transition from the shelter where she was living.
She later enrolled in a structured day program focusing on helping adults with intellectual disabilities improve both social and daily living skills. According to her social worker, Ms. Chan appeared quite happy with her new living arrangements and daily structure activities, which allowed her to meet new friends and eat “dim sum” together.

Section III: Lessons Learned

- A culture of stigma and shame surrounding mental health and neurodevelopmental diagnoses is prevalent in Chinese communities. Healthcare providers should be mindful of the following.
  - Past experience of internalized and public stigma may impact one’s mental health history.
  - Stigma may increase the patient’s suspicion about the neuropsychological evaluation. Extra time is likely required to explain the purpose, procedures, and limits of confidentiality and to build rapport and trust.
  - Stigma may prevent patients and families from accepting the diagnosis and following up with recommendations. On-going psychoeducation and destigmatizing efforts are greatly beneficial.

- The following are considered helpful to reach accurate diagnoses and to generate effective recommendations.
  - Language concordant assessment is important. In both cases, having a bilingual/bicultural neuropsychologist who could speak the patients’ native language, administer culturally appropriate measures, and navigate nuanced cultural issues, was essential to increasing confidence in diagnostic accuracy.
  - Accuracy of self-reported and collateral information should be considered in light of the possibility that patients or family members may not be fully forthright with disclosure in efforts to “save face,” avoid potential conflict, and maintain harmony.
  - Relational network, if used properly, can be a powerful tool to aid effective treatment. Inclusion and/or exclusion of certain family members should be carefully discussed with the patient (and their guardian(s) if applicable). Proper involvement of extended family members can greatly alleviate the patient’s pressure to reveal the “bad news” and communicate unfamiliar information to members of the higher familial hierarchy. Conversely, support from the important family members can in return greatly benefit the patient.
  - Better ability to differentiate culturally acceptable/related behaviors from clinical behaviors (e.g., avoidant eye contact due to the presence of elders in the context of Chinese cultural context vs. in the context of ASD) will prevent the possibility of misdiagnosis or underdiagnosis. This is particularly relevant to clinical diagnoses that take the quality of social engagement into consideration (e.g., ASD, social anxiety).

- When working with immigrants, assistance on how to navigate the dominant culture’s system of care is often necessary and critical.
  - Inaccurate diagnosis can deprive immigrants who are unfamiliar with the dominant system of the opportunity to access adequate care and services. Providers should assess how past diagnoses/healthcare has or has not made an impact on the patient’s daily living.
  - Certain services (for example, the Regional Center, a formulation of an IEP) may require specific and convoluted documentation, which often puts immigrants at a disadvantage.
The process is much easier to navigate when providers working with immigrant populations familiarize themselves with possible barriers and how to overcome them.

- Health providers who are able and willing to engage in advocacy are invaluable. In both cases, the patients were fortunate that many of their providers went above and beyond the call of duty to ensure they received appropriate care and services despite setbacks.

Glossary

Confucianism. A system of social and ethical philosophy founded by Confucius (孔子, 500 B.C.), which promotes Li (礼, social rituals) and Ren (仁, humanism). The philosophy is based on the belief that adherence to ethical social rituals enables one to maximize the fundamental goodness of humans and live a productive and ethical life. Though transformed over time, Confucianism remains one of the most influential philosophies in the Chinese-speaking world.

Cultural Revolution. A sociopolitical purge movement in mainland China (1966-1976) that began with efforts to rid the population of its “unprogressive values,” which resulted in the harassment and persecution of a large body of the country’s elderly and intellectuals. Despite the significant short- and long-term effects of this movement, it is commonly considered a taboo to discuss this topic unless a high level of trust has been established.

Mianzi (direct translation of face). A sociological concept that links the reputation and dignity of an individual, as well as the communal network to which they belong, with one’s perceived image in social contexts. Mianzi can be lost or earned and is largely determined by the collective evaluation than by the individual perspective.

Taoism. One of the five religious doctrines in mainland China. Taoism is commonly considered both a philosophy and a religion and is connected to the philosophers Laozi (老子, 500 BC) and Zhuangzi (庄子, 400 BC). It is vaguely defined by a belief in cosmic balance maintained and regulated by the Tao (“the Way”). One of the most well-known ideas of Taoism is the belief in balancing forces, or yin and yang. Taoism differs from Confucianism by its lack of emphasis on the rigid rituals and social order.

References


