Culturally Specific Diagnostic Practices for Austism Spectrum Disorder (ASD) Among Asian Children in Canada

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Introduction

By the age of 17, one in every 50 Canadian children will be diagnosed with Autism Spectrum Disorder (ASD) [1]. Experts claim that ASD is population indiscriminate, affecting all individuals with the same frequency, regardless of biological dispositions. Yet, recent research may be working to refute this position. A Los Angeles-based pediatric study found that adjusted "risk" rates for ASD in children were 43% and 25% higher than the general population when mothers were foreign-born Vietnamese and Filipino respectively. This same study also found that having a foreign-born Chinese or Japanese mother reduced ASD "risk" by around 30% [2]. The critical question that must be addressed here is whether these results indicate that ASD has etiologic heterogeneity or whether thresholds for diagnosis vary. This paper takes the latter position, positing that practitioners' perceptions of children's racial and cultural identity and language-use impact diagnostic efficacy. Further, it argues that ASD diagnostic tools are not universal, with these tools being calibrated to Western cultural-behavioural norms and white Anglo children. By examining the experiences of Asian children with ASD and their parents in Canada, we may be able to develop more nuanced diagnostic and treatment processes that will allow for culturally appropriate care. Through the implementation of culturally sensitive diagnostic mechanisms and treatment approaches, we may not only begin to bridge the gaps in racialized healthcare disparities but, also, provide a more holistic and overall positive experience for Asian children with ASD and their families.

Background

The definition of ASD is intentionally vague, being recognised as "a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave," [3]. Indicators of diverse neurocognitive functioning tend to appear in early childhood,

hence why ASD is considered a developmental disorder, however, many individuals may be diagnosed later in life, especially those whose external presentations of ASD deviate from the expected characteristics of the disorder. This is why ASD is under- and misdiagnosed in certain populations, like women and girls, who tend to receive implicit socialization that teaches them to camouflage or "mask" supposedly abnormal behaviours [4]. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM[-5]), a preliminary assessment tool used by practitioners, ASD is often characterized by challenges with communication and social interactions and limited (or niche) interests and repetitive behaviours. These challenges, interests, and behaviours must appear in early childhood and, to some degree, impair daily living, for an ASD diagnosis to be given [5]. There are several diagnostic tools that practitioners may utilise to assess for ASD, though ideally, a good practitioner will utilise multiple assessment tools before making a diagnosis, observing the patient directly and conducting interviews with the patient's primary caregiver(s).[6][7]

Cultural Understandings of Disability

It must first be acknowledged that Asia is a vast continent with a multitude of different societies, cultures, beliefs, and practices. Broadly speaking, existing research on Asian experiences of ASD tends to exclusively focus on a particular Asian subgroup (i.e. Han Chinese) or multiple populations originating from a wider region of Asia (i.e. South/South East Asians or Central and West Asians). There are limitations to both of these research focuses. While focusing on a particular Asian subgroup allows for more cultural specificity, it limits the applicability of the research. Conversely, focusing on multiple populations originating from a larger region of Asia may make research more broadly applicable but does not allow for nuance, especially given the significant cultural variations that exist between countries. Given this paper's focus on the

experiences of Asians with ASD in Canada, it is important to note that the country's new immigrant population is dominantly Asian, with seven of the top ten "immigrant sources" in Canada being Asian countries [8]. Additionally, Canadian census data shows that over seven million Canadians identify as having Asian "ethnic or cultural origins," comprising a significant portion (18%) of the Canadian population [9]. This paper will primarily focus on those of East Asian origin, though some discussion of South Asian culture may be relevant given certain similarities that arise from Confucian and Hindu values engrained in sociocultural practices (for this reason, Central and West Asians will not be focused on given certain Islamic cultural differences).

Perceptions of 'disability' vary across Asian cultures, though there seems to be a common thread of pathologising disability as a consequence of parental/familial behaviour. Of course, no cultural group is a monolith, and understandings of (dis)ability differ from person to person, however, certain cultural or religious values help shape the dominant social attitudes. In Chinese and South Korean culture, a child's divergence from the norm, be it physical or socioemotional, may be blamed on poor or incorrect pre-natal health practices, and result in parental guilt or shame [10]. Dominant Confucian values and worldviews in Chinese (and, to a lesser extent, South Korean) culture may also lead to pathologising disability as a predetermined fate stemming from past-life wrongdoings of ancestors, the parent, or the child. Similarly, in Indian culture, in which Hinduism is the dominant religion, understandings of Karmic justice (the philosophy that deeds of previous incarnations of the self inform how future incarnations of the self will exist) may result in the sociocultural perception of a person with disabilities as intrinsically evil or having done something wicked in a previous life [11] [12]. Given the Asian cultural emphasis on familial ties and collective social contribution, a child's ASD diagnosis may

bring great shame to their family, with prevailing stigma contributing to social isolation and increased emotional challenges as the child ages [13].

When addressing the experiences of Asian children with ASD in Canada, immigrant status only serves to complicate the situation. Cultural perceptions of disability do not magically disappear when individuals migrate to NA, and, without established social ties, a clear understanding of the healthcare system, or linguistic proficiency (particularly of medical terminology), parents of children diagnosed with ASD may feel that themselves and their child have been doomed. Research into the experiences of Asian immigrant mothers with children with ASD found that there were frequent parental attempts to deny or refute the initial ASD diagnosis [14]. As one can imagine, moving to a new country is a drastic shift in one's life, often inherently disadvantaging new immigrants relative to the locally-born population. Attempts to deny or refute an ASD diagnosis may be rooted in the guilt that accompanies the knowledge that a new-immigrant parent may have had greater social capital, and subsequently better means of addressing the diagnosis, in their home country. Further, pervasive social stigma toward those who diverge from the norm is as much an issue in NA as it is anywhere around the globe; pre-existing parental concerns about a child's ability to integrate into a new society were only amplified by ASD diagnoses [14]. Practitioners must take the time to explain what ASD is to Asian parents, especially those of whom who have existing negative perceptions of ASD , framing the diagnosis as a diffrence in neurocognative functioning, rather than as a disability. In circumstances where there is a language barrier between the parent and practitioner, it is of the utmost importance that the practitioner undertakes the work of finding a translator given that families may not have the capacity to undertake this themselves.

Diagnostic Tools and Practicioner Sensitivity

As was previously mentioned, there is significant debate in the medical community about whether ASD impacts certain populations more than others and it seems as though every other report on ASD diagnostics takes a contradictory stance. About half of the research reviewed for this paper claimed that ASD was underdiagnosed among racial minorities, while the other half claimed overdiagnosis. Though there is not enough concrete evidence to support one claim over the other, it may be posited that both under- and overdiagnosis stem from similar problems with the diagnostic practice. As Lee and Zhu put it, “Diagnosis is not only a medical practice by doctors, but also a sociocultural practice that involves various people and their points of view on race, gender, class, and disability,” [14]. As such, overdiagnosis may be rooted in a lack of cultural understanding in which the diagnostician perceives certain ‘Asian behaviours’ as indicative of ASD, even when these behaviours are unrelated. Similarly, underdiagnosis may be rooted in a lack of cultural understanding in which the diagnostician does not recognize certain behaviours that may be indicative of diverse neurocognitive functioning, instead attributing these behaviours to cultural differences.

Across Asian cultures, there is an emphasis on collectivism, focusing on interdependence, loyalty, and contribution to the greater society. This stands in stark contrast to the capitalism-fed, highly individualistic and competitive nature of Western society. For example, North American (NA) culture places minimal emphasis on age hierarchy, instead lauding characteristics like hyper-independence as early indicators of childhood success. While talking back to one's parents may still be seen as disrespectful in NA, there is also an understanding of “sassing” as an indicator of quick wit and self-assuredness. Meanwhile, age-based hierarchy is of great significance in various East Asian countries, with the Confucian value of respect for one’s elders

shaping authority status and social interactions, like in South Korea, where honorifics specifically denote age differences in relationships [15]. Though age relations may not seem particularly important when discussing ASD, it is vital to consider when addressing cross-cultural diagnostic efficacy given that parent-child interactions and dynamics contribute to a diagnostician's assessment of Autistic behaviours. The commonly used M-CHAT diagnostic tool asks whether a child looks other individuals, particularly their parents, directly in the eyes when talking to them [16]. While this may be an apt indicator for some children, it can be a false flag in others. In Chinese culture, avoiding eye contact with authority figures is indicative of respect, thus a Chinese child may avoid eye contact as an engrained cultural habit rather than out of social discomfort (as would be seen with ASD) [17]. Likewise, the ADOS-2 diagnostic tool used by practitioners asks if the examinee initiates social interactions. In several East Asian cultures, it is considered disrespectful for a person who is younger or has less authority status to initiate an interaction, thus an Asian child being assessed for ASD may not engage in an interaction with the diagnostician until after they have been prompted, as a sign of respect for authority. Regarding underdiagnosis, Western stereotypes about Asian intelligence and parenting styles may be a contributing factor. Asian parents concerned with their child's functionality at school may be dismissed by practitioners who apply the "tiger mom" stereotype and incorrectly attribute these concerns to an Asian overemphasis on academic success. Given that cultural practices may be wholly unrelated to diverse neurocognitive functioning, a practitioner assessing an Asian child for ASD must be culturally sensitive, taking care to avoid stereotyping parents or pathologizing behaviours that may be unrelated to ASD, lest they contribute to misdiagnosis.

Conclusion

The combining factors of Asian cultural attitudes toward disability (generally), culturally uncalliberated ASD diagnostic tools, and diagnostician biases make the experiences of Asian families and their children with ASD extremely challenging. Cultural understandings of disability in tandem with the Asian cultural emphasis on family and collectivity may make parents hesitant to address sociobehavioural abnormalities they see in their children due to fear of stigmatization. If these parents have the courage to engage with the diagnostic process, they may nonetheless be met with significant barriers [18]. Academic literature on the client-practitioner dyad in ASD diagnosis tends to frame immigrant or otherwise 'foreign' parents as having antithetical goals to the practitioner, meaning practitioners may enter a diagnostic process with existing biases toward the parents that manifests in hostility [14]. This is only magnfified by pervasive medical racism that exists in the Canadian healthcare system. A lack of culturally sensitive care and resources only serves to amplify parental fears about ASD which, in turn, may strain parent-child relationships, ultimately damaging the child's understanding of their neurodiversity and negatively impacting the life-course. People on the autism spectrum, regardless of race, can live happy and fulfilling lives if they are given the correct tools to succeed. The family-oriented nature of Asian cultures may provide a rich network of supports and resources for children with ASD, but this process begins by adequately helping patents understand their child's condition and specific needs. It is the responsibility of the healthcare system and, more importantly, the practitioner, to ensure that Asian children on the spectrum, and their parents, are supported in a culturally sensitive manner throughout the diagnostic process and beyond, lest these children incur wholly unnecessary iatrogenic harm.

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