

CHAPTER 43

Autism Across Cultures: Perspectives From Non-Western Cultures and Implications for Research

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“Your child has autism.” Hearing this short phrase is likely to have a profound impact on any parent. The implications of this phrase are wide-reaching and lead to a broad range of consequences for the future. For some parents, their reaction may be one of shock, worry, and confusion. For others there may be a sense of relief, improved understanding, and renewed optimism for the future. It is evident that each parent will interpret the implications of this phrase differently. However, the disparity becomes even more apparent when implications of culture are taken into consideration. For parents from certain cultures the immediate implication may be that as a result of formal diagnosis their child will be eligible for additional support and will have easier access to services; whereas for parents from other cultures the implication may be that their child will have less access to services, in certain circumstances their child may no longer be

eligible to attend the parent’s chosen school, and the parent may also feel ostracized from their extended family or community due to the perceived stigma of having a child with developmental disorder. In short, cultural context has a profound effect on the interpretation and implications of a diagnosis of autism.

Not only are there differential effects of culture on social acceptance, understanding and the provision of services for individuals with autism, but also certain behaviors exhibited by individuals with autism may have differing cultural interpretations. For example, a tendency not to make direct eye contact with caregivers may be interpreted as very unusual in Western cultures; in contrast, this may be viewed as polite and respectful in certain Eastern cultures, such as in China and South Korea, thus rendering this behavior somewhat less maladaptive. Other behaviors, such as poor communication, are

likely to be problematic in all cultures. It is also important to consider that different cultures may have different cultural norms in terms of general cognitive style. Attention to detail may be aspired to, and generally more common, in certain cultures, whereas in others the ability to perform tasks rapidly and being able to quickly switch between tasks may be more strongly revered. The culture in which we are raised has a profound influence on the way we view and interpret the world. It is useful to take these cultural norms into consideration when attempting to understand the implications of autism within a cultural context.

This chapter is split into two broad sections. First we discuss general perspectives of autism from non-Western cultures. We highlight some of the pressing issues facing individuals, families, service providers and the wider community who are affected by autism in non-Western cultures. We aim to identify some of the current disparities and to provide some cultural context to the effects of autism. The second section focuses on the contribution of research in different cultures to understanding autism. We discuss the contributions of research to understanding the influence of culture on cognition and behavior relevant to autism. We then go on to discuss issues that researchers should be aware of when embarking on autism research with non-Western populations or cultural minorities. As will become clear throughout the chapter, there are more publications on the topic of autism in peer-reviewed journals from certain non-Western cultures than others; hence some aspects of discussion focus on certain cultures more than others. In particular, a broad range of work has emerged from South Korea and India in the past 10 to 15 years, raising the profile of autism in those cultures. Also, there is a growing literature from China and Japan, as well as some recent publications from the Middle East. Currently there is little published work from Africa but hopefully this will change in the future. The overall goal of this chapter is to provide an overview of the current state of understanding of autism within a cultural context.

PERSPECTIVES OF AUTISM FROM NON-WESTERN CULTURES

Culture and Autism in Context

In recent years the emphasis on understanding autism within a cultural context has drastically increased, especially with regard to the emergence of prevalence studies in different cultures (see Elsabbagh et al., 2012 for a review). However, it is noted by Zaroff and Uhm (2012) that systematic cross-cultural comparative studies relating to autism are rather sparse in general. Indeed until relatively recently the relevance of culture to autism was largely ignored (Daley, 2002). It seemed that initially some researchers believed that autism was intrinsically linked to modernity and Westernization and was rare in other cultures; in fact, the misheld belief that autism is the result of modernity and Westernization still exists to a certain extent in non-Western cultures (Daley & Sigman, 2002; Hudec, 2012). Other researchers assumed that because autism was described as a neurobiological disorder, its expression would be exactly the same everywhere so there was no need to take any aspect of culture into consideration. However, it is becoming increasingly clear that culture is relevant to autism in many ways and further cross-cultural work is required to gain a broader understanding of the issues.

There is a complex relationship between culture and developmental disabilities. The importance and benefit of this work is endorsed in numerous recent reviews and empirical papers (e.g., Bernier, Mao, & Yen, 2010; Daley, Singhal, & Krishnamurthy, 2013; Norbury & Spars, 2013). A recent review on Korean culture and autism spectrum disorders (ASD) by Kang-Yi, Grinker and Mandell (2013) argues that culturally informed research on ASD is vital for increasing awareness of the importance of early intervention and the need for educational and psychological services in countries like South Korea, a country in which autism can be stigmatized and left undiagnosed or misdiagnosed. Additionally, cross-cultural autism research may

yield useful information on “protective” environmental and/or societal factors in relation to autism. Indeed, Grinker et al. (2012) proposed that cross-cultural community-based research studies or studies of subcultures within a single community can advance knowledge of interactions among genetic, environmental and cultural factors on the expression of ASD. If it is possible to adequately ascertain whether there are real prevalence differences between cultures or real differences in severity, this might lead us to identify potentially protective environmental factors.

An ASD diagnosis is currently based on whether behavior deviates from what is regarded as typical. However, what is typical may differ between cultures. The saliency of symptoms may be culturally shaped (Daley, 2004). There is little doubt that ASD exists worldwide, is biologically influenced, and crosses country and cultural boundaries. However, there is far less consensus on exactly where the boundary between difference and disorder lies. As mentioned earlier, behaviors that are seen as extremely maladaptive and unusual in some cultures may not be particularly atypical in other cultures due to differing cultural norms. Therefore using diagnostic tools and procedures that have been developed and standardized in the West may not necessarily be a valid method for diagnosis when applied in non-Western cultures. Kang-Yi et al. (2013) report that as yet there has been little attention to the effects of cultural context on the presentation, diagnosis and treatment of ASD. It could even be argued that attempting to introduce standardized tests developed in the West into non-Western countries might do more harm than good as they could produce a systematic bias in responding. Perhaps it would be better for clinical professionals and health service providers to focus on an individual's ability to function within society and associated problems with daily living rather than their scores on standardized tests.

The role of societal expectation and cultural norms is clearly very important to the field of mental health. Practitioners should take account of the family and caregivers' perspectives, viewpoints,

and capabilities when deciding how to address an individual with autism's needs, thus ensuring the best possible outcome for the individual. As discussed by Norbury and Sparks (2013), it is important to establish what family members are worried about and what they value or disvalue about their child's language, behavior and education. There may be multiple end goals for parents and caregivers. With these issues in mind, it is important to determine research priorities based on issues emerging on the ground, aiming to improve the lives of family members and loved ones as well as those with autism. It is vital to ensure that research, diagnosis, and any proposed intervention is always rigorous, empirical, family-centered, culturally grounded, and methodologically sound.

Awareness of Autism in Non-Western Cultures

The first step in the process of seeking a diagnosis of autism is the recognition that some aspect of development is not proceeding as expected. For parents who are not particularly familiar with autism, this can be difficult. In some cases the saliency of a characteristic of autism may not be fully observed until a child is put into a new environment outside of the family home, such as a school. Learning to interact with new people or having changes made to the daily routine may be particularly distressing and may be the first sign that something is wrong. A recent estimate of average age of diagnosis of autism conducted in the United States revealed a mean age of initial parental concern of 19.6 months and mean age of diagnosis of 47.6 months (Rosenberg, Landa, Law, Stuart & Law, 2011). However, age of diagnosis of children from low-income families in the United States has recently been estimated to be much later, at a mean age of 64.9 months (Mandell et al., 2010). Studies conducted in non-Western cultures have also indicated a significant time lag between age of initial parental concern and age of diagnosis of autism. A study conducted with parents of children with a diagnosis of autism in India found a mean age of initial parental concern

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of 25.7 months and mean age of diagnosis of 59 months (Daley, 2004), which is not vastly different to the delay reported in the US. However in the 81 Indian families interviewed, there was a wide age range at which a diagnosis was first made (15 months to 228 months). There is no national screening for autism in India and, as in many other countries, it is probable that a high proportion of individuals with autism remain undiagnosed. A recent study conducted in Japan reported that the mean age of initial parental concern was 55 months (Fujiwara, Okuyama & Funahashi, 2011), the mean waiting time before a first appointment at a hospital in the Japanese study was another 35 months, significantly longer than the waiting time reported in a U.S. study where the waiting time in the city of Atlanta was found to be 13 months (Wiggins, Baio, & Rice, 2006).

Regarding awareness of symptoms associated with autism, Daley's (2004) report from India on 81 families who had a child with autism found that 45% of the parents of children diagnosed with autism noticed social difficulties first, such as a lack of interest in people, poor eye contact, not playing with other children, general social incompetence, withdrawing from family members, or the sense of being "in a world of his own." Thirty-one percent reported concern over a delay in speech or limited speech. Twenty-six percent of parents raised concern over behaviors not specifically related to autism, such as excessive crying. Twenty-three percent of parents noticed medical or developmental difficulties not specific to autism. Parents who noticed autism-specific behaviors first tended to receive a diagnosis of autism for their child significantly earlier than parents who noticed behavior, medical, or developmental problems not specific to autism. In India, pediatricians are typically very busy and they tend to address the specific problem for which a child is brought to them rather than running an objective overall assessment of difficulties. As a result children brought in for concerns that are not exclusive to autism may not be rapidly diagnosed with autism, if at all. Daley (2004) reported that many children later diagnosed with autism were initially given an incomplete diagnosis

of "mental retardation." A diagnosis of mental retardation in India can lead to access to further services for families as services are provided based on the level of intellectual functioning of the child. In certain cases pediatricians and psychiatrists in India use the terms autism, autistic traits, and PDD interchangeably and a diagnosis is not necessarily systematic and based on standardized tools. This is possibly due to there being less need for a specific diagnosis, as a diagnosis of autism will not provide any additional services to the family. Many families fall short of seeking a diagnosis of autism for their child.

Culture shapes how individuals who are considered different from "normal" are treated. Grinker (2008) argues that different cultures have differing ideas regarding which types of behavior are considered proper, tolerable or violating, thus differentially construing the disorder of autism. As an example, Grinker et al. (2012) report that ASD is underdiagnosed in South Korea and South Africa and propose that this could partially be the result of parents engaging in less help-seeking behavior than occurs in other cultures. Parents often prefer to deal with any problems "within the family." It is important to consider that, within certain communities, perceived social stigma and fear may be great enough to discourage any form of disclosure of a child's special needs to health professionals. Grinker and Cho (2013) report South Korean mothers' resistance to accept a diagnosis of autism for their child. Mothers want to define their child as "normal"; if this is not possible there is a stigma attached. A mother of an autistic child may fear that other mothers will prevent their children from playing together and that her family will become the topic of gossip. In addition, what happens to the child happens to the mother. If the child is isolated and stigmatized, so is the mother. In South Korea there is also a desire to localize the child's problems in a discrete area rather than as a global, pervasive impairment. There is a general desire to reject labels that insinuate a permanent impairment. Rather than accepting a diagnosis of autism, South Korean mothers prefer the concept of "border children," which characterizes the child as having

a temporary, nonpervasive deficit that is defined by a single domain—social impairment. Mothers dislike the objectification entailed in psychiatric labeling. Children are considered to change very quickly as they grow so mothers do not find a fixed label, such as autism, appealing. Rather, parents embrace terms that infer categorical instability. If a child is meeting the intellectual goals their society has set for them, for example being able to attend a mainstream school and keeping up with other children in certain subjects such as mathematics, then to parents in South Korea a label inferring a developmental disorder, such as autism, seems implausible and is therefore rejected.

It can also be argued that there is a general lack of awareness and understanding of autism and other developmental disorders within the educational system in South Korea. However, a positive aspect is that education for children with disabilities is mandatory in South Korea, under the special education act of 1977 (as reported by Kang-Yi et al., 2013). Nevertheless, there are reports that the quality of education provided for children with disabilities is substandard (J. Y. Shin, 2002); indeed, Grinker and Cho (2013) argue that educational programs in South Korea have not kept pace with the growing awareness of special education needs in ASD. However, as parents tend not to disclose problems experienced by their children, there may be less opportunity for professionals to objectively assess needs and construct appropriate education programs. Grinker and Cho (2013) highlight the problem that if parents are not willing to seek or disclose a diagnosis of autism then there is little pressure on the government or private sector to build services. Although the preferential label of “border children” serves an important function for parents, lessening the perceived pain that would come from a diagnosis of ASD, it does not solve or even address many of the underlying problematic issues.

Perceived stigma is, of course, not only a problem in South Korea; it is also prevalent in other cultures. Mak and Kwok (2010) report that in Hong Kong parents often feel there is a family stigma if a child is diagnosed with autism and

the internalization of stigma within families who had a child with ASD was reported to be severe. A method of combating the stigma is by parents themselves setting up advocacy groups to increase awareness of ASD in society. Mak and Kwok (2010) report that the establishment of mutual support groups enhanced parents’ sense of control and social support, thus reducing stigma internalization. They also proposed that public education and exposure to ASD are necessary to reduce stigma towards children and their families.

At present, acceptance of a label of a developmental disorder for a child differs between cultures. For example, Lau et al. (2004) found that Asian/Pacific Islander and African-American parents were less likely than Caucasian parents to agree with teachers that their child’s behavior was indicative of an underlying disorder. In addition Yeh, Hough, McCabe, Lau, & Garland (2004) found that Asian/Pacific Islander, and Latino parents were all less likely than Caucasian parents to endorse personality, relational or family issues, or trauma as causes of children’s problems. These issues are discussed further by Mandell and Novak (2005), who propose that cultural factors assume a major role in the way families subscribe to intervention strategies.

Awareness of autism within the health profession is generally high in Western cultures. However, this level of awareness is not existent in all cultures. For example, Kang-Yi et al. (2011) report that in South Korea there are children whom American clinicians might diagnose with autism, but who are instead diagnosed with Reactive Attachment Disorder (RAD), which is thought to arise from a failure to form normal attachments to primary caregivers in early childhood. RAD is recognized in the *DSM-IV* (American Psychiatric Association [APA], 1994) and is considered to “mimic” autism in certain ways but be caused by very poor parenting habits (Y. J. Shin, Lee, Min, & Emde, 1999; see also Hong, 2006), Shin et al. (1999) reported on a small group of 25 out of 140 children who had been given a preliminary diagnosis of autism. Following assessment, it was claimed that instead these children should be diagnosed

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with RAD. It was reported that the mothers of these 25 children “lacked skills,” “failed to join in play with their children,” “appeared insensitive to their children’s cues,” and “engaged in parallel play.” This accusation of poor parental style has alarming parallels with the 1970s “refrigerator mother” theory which gained no empirical support and was extremely damaging to mothers who, as a consequence felt extreme guilt, worrying that their child’s autism could be a result of their ineffective interaction style. Autism can be difficult to diagnose accurately, especially due to its high comorbidity with other disorders. However, it is very important that autism is not misdiagnosed as an attachment disorder. Treatments for the two disorders should be very different, likely outcomes will be very different, and a misdiagnosis can be extremely damaging to caregivers who are doing their best to care for their child. It is therefore vital that accurate information regarding the current conceptualization and understanding of autism reaches all clinicians and practitioners involved in diagnosing autism and providing information to families.

In summary, awareness of autism and its associated traits and behaviors, and reactions to a diagnosis of autism, can be highly variable both within and between cultures. Delays in access to accurate information and services can be extremely frustrating to parents of children with autism, especially as early intervention has been widely shown to be associated with better outcomes (Dawson, 2008; Howlin, Magiati & Charman, 2009). Such delays can also lead to further distress and confusion and can lead parents to feel alone or ostracized from their communities, in which awareness of autism and the implications of autism may not be widely prevalent.

Prevalence of Autism Across Cultures

A systematic review of the prevalence of ASD and PDD across cultures was conducted by Elsabbagh et al. (2012), which included all data available from low-, middle-, and high-income countries. In Northern Europe recent studies (since 1999) found an average ASD prevalence rate of 18.8/10,000. In

the United States and Canada recent studies (since 2000) found an average ASD prevalence rate of 21.6/10,000. In China there was an average ASD prevalence rate of 11.6/10,000. It was noted that the prevalence estimate for China was lower than that reported in Northern Europe and North America but it did resemble estimates from older studies in these regions. Since the first diagnosed case of autism in China was recorded only in the 1980s (Tao, 1987) it may be that identification and diagnostic services are taking time to develop in this very large country. Regarding the broader category of PDD, the highest rate in the systematic review was from South Korea (Kim et al., 2011) who reported a prevalence estimate of 189/10,000. This was closely followed by a Japanese study that estimated a PDD prevalence rate of 181/10,000 (Kawamura, Takahashi, & Ishii, 2008). Elsabbagh et al. (2012) also reported that four estimates of PDD were available from Southeast Asia and the Eastern Mediterranean. These were: 100/10,000 in Sri Lanka (Perera, Wijewardena, & Aluthwelage, 2009); 29/10,000 in the United Arab Emirates (Eapen, Mabrouk, Zoubaidi, & Yunis, 2007); 1.4/10,000 in Oman (Al-Farsi et al., 2011); 6.3/10,000 in Iran (Samadi, Mahmoodizadeh, & McConkey, 2012) which compare to recent PDD prevalence estimates in Europe of between 30/10,000 (Madsen et al., 2002) and 116/10,000 (Baird et al., 2006) and in the United States of between 34/10,000 (Yeargin-Allsopp et al., 2003) and 110/10,000 (Kogan et al., 2009). There is currently no prevalence data available on ASD or PDD in Africa.

It is important to consider the methodologies used to estimate prevalence. Elsabbagh et al. (2012) argue that if prevalence estimates are based solely on the diagnosed population, there is a distinct possibility that a sizeable proportion of the ASD population will be missed as not all individuals with ASD or PDD will already have received a diagnosis or even be in touch with health services. Using this method alone can lead to a significant underestimation of the true prevalence. To date, few investigations have relied on systematic sampling techniques that would ensure a near complete coverage of the target population. When considering all

available research together, Elsabbagh et al. (2012) concluded that the current available evidence *does not* support systematic differences in ASD or PDD prevalence by geographic region, nor a strong impact of cultural or socioeconomic factors on prevalence. The average of all studies found a worldwide prevalence estimate of 62/10,000 for ASD and PDD combined. Elsabbagh et al. (2012) noted that due to a lack of consistency across many methodological aspects of epidemiological studies, it was perhaps not surprising that no systematic differences in prevalence by geographic region were seen.

In another review of prevalence studies, conducted by Matson et al. (2011), it was reported that rates of ASD have been growing steadily over time in both Western and non-Western nations. Sun and Allison (2010) report on prevalence data collected between 1971 and 2008 in six Asian countries (China, Japan, Indonesia, Israel, Iran, and Taiwan), noting a general increase in prevalence rates over time. Matson et al. (2011) argue that the relatively frequent change in diagnostic criteria and increasing awareness of ASD over time in both Western and non-Western nations appear to be at the core of the increasing prevalence of ASD. Changing diagnostic criteria are likely to have further effect on prevalence with the introduction of the *DSM-5* (APA, 2013).

The Expression of Autism Symptomatology Across Cultures

Standards and methods of diagnosis of autism vary drastically across cultures due to differing standards of training and experience of those administering the diagnostic procedures. There is also variability in the availability of tools that are generally normalized for specific countries and cultures (Daley & Sigman, 2002; Ravindran & Myers, 2012; Samadi et al., 2012). It is therefore possible that a slightly different cross-section of society is diagnosed with autism in different cultures (see also Zaroff & Uhm, 2012). Clinical characterization has increasingly relied on standardized measures in Northern Europe and North America (Elsabbagh et al.,

2012); however, use of measures for diagnosis may not be as standardized elsewhere; indeed standardized normalized measures may not even exist. For a diagnosis of a disorder to be valid, it is important to take cultural norms into consideration. A behavior that is very unusual in one culture may be far less so in another. Therefore a behavior indicating a difference from the norm in one culture may not be a reliable indicator of atypicality in another (see Matson et al., 2011; Norbury & Sparks, 2013). Carter et al. (2005) recommended taking five variables into consideration when attempting to ensure the validity of assessment: cultural influences on test performance, familiarity with being tested, the effect of formal education, test content, and the use of pictures in test materials. Norbury and Sparks (2013) summarized these as assessment *context* and assessment *content*.

In a study comparing autism symptomatology in Israel, South Korea, the United States, and the UK, symptom expression differences were found on nonverbal communication/socialization, verbal communication, and insistence on sameness and restricted interests in those diagnosed with autism (Matson et al., 2011). It was reported that children from the UK had significantly more impairments across all domains compared to children from the other countries, whereas children from Israel had significantly fewer impairments compared to children from the other countries. It is suggested that certain behaviors that are early markers of ASD and are generally picked up in some cultures may not be viewed as abnormal by parents in other cultures. Another potential reason for differences between cultures in symptom reporting is that there are vastly different screening procedures in different countries. For example, in some areas of the United States, toddlers are routinely screened during pediatric appointments with measures such as the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 1999) whereas in the UK young children are not universally evaluated with regard to the possibility of ASD, but rather are assessed for ASD only after signs are identified by clinicians or family members (Tebruegge, Nandini, & Ritchie, 2004). Therefore children may be

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identified and enrolled into intervention programs at different developmental points in each country.

In a recent paper (Freeth, Sheppard, Ramachandran, & Milne, in press) we compared the expression of behaviors considered to be autistic traits (as measured using Baron-Cohen et al.'s (2001) Autism-Spectrum Quotient) in neurotypical samples from one Western culture (UK) and two Eastern cultures (India and Malaysia). Behaviors associated with autistic traits were reported to a greater extent in the Eastern cultures than the Western culture, thus indicating that certain behavioral characteristics of autism identified in the West may be less unusual in the East. We suggest that cultural norms, in reference to these traits, are shifted in India and Malaysia. In particular, Indian participants reported significantly poorer imagination than participants in both other cultures; Malaysian participants reported significantly more difficulty with attention switching than participants in both other cultures. We propose that differences in social structure and cultural interpretation strongly contribute to the observed differences between groups. It is important to note that elevated numbers of behavioral characteristics associated with autism did not appear to be detrimental to academic success in these cultures as all participants were studying at university.

In summary, autism symptomatology may differ across cultures due to differing procedures and methods of diagnosis, perhaps resulting in a slightly different cross-section of people receiving a diagnosis on the autism spectrum in different countries. Differing cultural norms on how maladaptive or atypical certain behaviors are deemed to be may also have an effect on diagnosis. We suggest that diagnoses should reflect the cultural norms of the country in which an individual lives and behaviors should be assessed with reference to how problematic they are for everyday living.

Education and Interventions for Autism in Non-Western Cultures

It is very important that any diagnosis of a developmental disorder is coupled with accurate,

understandable information and support. Merely providing a diagnosis without any further information or guidance could actually be detrimental to a family as it will naturally cause further questions and issues to emerge. Increased awareness of autism is clearly beneficial overall but it is important to ensure that increased awareness of autism is not coupled by increased misconceptions. Parents will always want to do their best by their child but paucity of information following a diagnosis can lead parents towards reliance on unproven methods and practices (McCabe, in press). There is often great interest in complementary and alternative treatments from parents. Therefore, up-to-date impartial information from health professionals is required (Lofthouse, Hendren, Hurt, Arnold, & Butter, 2012). A recent paper by Daley et al. (2013) reports that in India parents often have the misconception that if an intervention is "being researched," then it is known to be effective. This can lead to a lot of expense and effort being spent to engage in a program with no proven benefit. Miller, Schreck, Mulick, and Butter (2012) report that in the United States the history of autism treatment has been plagued with fad therapies that waste parents' and children's time, energy, and money. They reported that less than half of the 400 parents surveyed chose a scientifically supported treatment for their child. Recent reviews of the literature indicate that very few interventions actually have a solid research base and even those with the strongest evidence base do not have a universally positive impact (Howlin et al., 2009; Mills & Marchant, 2011). Therefore the parental task of searching out and implementing an effective intervention or education program for their child is incredibly difficult, a difficulty that is not merely experienced in non-Western cultures. However, in certain non-Western cultures there is the added complication that some treatments considered "alternative" in the West have gained the status of an established medical practice. For example, in India there are government-run ayurvedic and homeopathic colleges that use complementary and alternative medicine for the treatment of autism rather than scientifically supported evidence-based

practices. There may also be a tendency to view alternative approaches as “natural” and therefore not having side effects. In addition, differing cultural beliefs about the cause of a disorder can influence families’ decision-making regarding what type of treatment to go for and what outcome to expect (Ravindran & Myers, 2012).

The availability of resources and services following receipt of an autism diagnosis can be extremely variable. It has been reported in the Middle East, for example, that knowledge of autism is extremely poor and services for children with developmental and psychiatric disorders are not well developed (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009). A study of autism in Oman (Al-Farsi et al., 2011) reported that there was only a single child psychiatry unit in the country, based in the capital city of Muscat. The majority of the population in Oman would likely find it logistically and/or financially challenging to reach the child psychiatry clinic in order to take a diagnostic assessment or to access intervention programs.

Regarding treatments or interventions for autism in China, there is an emphasis on providing everything available. This may include using multiple methods and equipment that have unclear value (McCabe, in press). There are continuing challenges to providing effective services that relate to the desires of parents, where the driving force is to provide “more” treatments, which is seen as better. However, a focus on quantity may prevent a focus on quality. McCabe (in press) calls for a greater focus on evidence-based practice, rather than trying to provide everything at once.

In summary, access to information regarding the latest understanding of autism and recommendations for education and intervention programs is often not as easily accessible as in non-Western countries. It is important to improve public awareness of autism in order to reduce misunderstandings and mischaracterizations of autism and to aid acceptance. If parents have access to the latest impartial information regarding recommendations for education and intervention, improved outcomes for their child are likely to follow. It is vitally important that interventions are based on evidence

rather than hearsay as a multifaceted, confusing, highly stimulating intervention program could be worse than no intervention at all. It may be, in the future, that culture-specific interventions are developed. It is not necessarily true that Western-style interventions will be most effective in all cultures. As previously discussed, the behaviors associated with autism that are most maladaptive are likely to differ between cultures. Therefore a culturally specific intervention would seem most appropriate.

THE IMPACT OF CULTURE ON AUTISM RESEARCH

Cultural Influences on Behavior and Cognition

The vast majority of psychology research is conducted with participants from the United States, a country that houses only 5% of the world’s population (Arnett, 2008). However solely conducting research with populations who are Western, Educated, Industrialized, Rich, and Democratic (WEIRD) is not a useful strategy if we wish to make inferences about other cultures (Henrich, Heine, & Norenzayan, 2010). Differences on a range of constructs have been observed between Western and Eastern populations. Individuals from Western cultures, and in particular individuals from the subset of Western culture that can be described as WEIRD, tend to have independent social orientation, emphasizing self-direction, autonomy, and self-expression; whereas individuals from Eastern cultures tend to have interdependent social orientation, emphasizing harmony, relatedness, and connection (Markus & Kitayama, 1991; Triandis, 1989; Varnum, Grossman, Kitayama, & Nisbett, 2010). Compared to individuals in Western cultures, individuals in Eastern cultures tend to place more emphasis on the situation than on internal attributes of a person (Choi, Nisbett, & Norenzayan, 1999). These differences in behavior between cultures are also coupled with differences in cognition, described as “cognitive habits” (Varnum et al., 2010).

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The degree to which the literature on cross-cultural variations in cognition overlaps with the literature on cognition in ASD is striking. An area that has received significant attention in the ASD literature and in the cross-cultural literature is visual perception. It is well-known that individuals with ASD display Weak Central Coherence (WCC), a visual perceptual style in which local details are relatively more salient compared to the global percept. This can result in reduced processing of contextual information (Happé & Frith, 2006). The 2006 version of the WCC account exclusively cited experimental studies conducted with individuals from Western cultures. In the subsequent 7 years many more studies looking into WCC and ASD have been published. However, to our knowledge only one of these has considered the issue of culture directly (Koh & Milne, 2012). In this study, participants with and without ASD in the UK and Singapore completed the embedded figures task and the framed-line task. Both of these tasks require visual perceptual skills and provide an indication of how relatively salient local details are to an individual compared to global information, thus providing a measure of WCC for each individual. As expected, participants with ASD in the UK displayed a more local processing style (more WCC) than the typically developing matched control group from the UK. However participants with ASD in Singapore did not display a more local processing style (more WCC) than the matched control participants from Singapore. Koh and Milne (2012) therefore raised the possibility that WCC in ASD may not be universal. This finding is supported by a broad literature indicating cultural variation in constructs implicated in central coherence. For example, cultures which value interdependency and group values, such as many East-Asian cultures, encode information more holistically (Nisbett & Miyamoto, 2005) and are more sensitive to contextual changes, as opposed to focused object changes, than their Western counterparts (Masuda & Nisbett, 2006). In support of these findings of the existence of visual perceptual differences across cultures, Kühnen et al. (2001) found that participants in Russia and

Malaysia detected fewer embedded figures in a visual perception task (thus indicating less WCC) than participants from Germany and America. This collection of studies highlights the need for further work to establish the extent to which the cognitive phenotype of ASD is culturally invariant.

It is important to bear in mind that the extent to which performance on any cognitive task is “atypical” bears direct relation to the performance of the control group. If cultural variations occur across control groups, it stands to reason that the benchmark against which performance of individuals with ASD is compared will influence the interpretation of results; this is applicable to all aspects of behavior and cognition. This is particularly relevant to social attention, which has been shown to vary greatly across cultures. A study by Blais, Jack, Scheepers, Fiset, and Caldara (2008) demonstrated different patterns of visual inspection of faces across cultures. While Western Caucasian participants displayed the standard triangular pattern of fixating mainly on the eyes and mouth when they learned, categorized, and recognized faces, East Asian participants tended to look more at the central region of the face. Following this, a recent study by Tan, Stephen, Whitehead, and Sheppard (2012) reported that Malaysian Chinese participants, when attempting to recognize faces, tend to use a mixed strategy of focusing on the eyes and nose more than on the mouth. This combination of Eastern and Western strategies proved advantageous in the ability to recognize East Asian and White Western faces, suggesting that individuals learn to use fixation patterns that are optimized for recognizing the faces that they commonly see day to day. It has been proposed that reduced fixation on the mouth in Eastern cultures may explain reports of poorer emotion recognition within these cultures (Jack, Blais, Scheepers, Schyns & Caldara, 2009). A recent study by Senju et al. (2013) that tracked the eye movements of British and Japanese viewers while looking at faces, found that British participants’ eye movements were less affected by an observed person’s gaze shifts than Japanese participants’ eye movements were. The results seem consistent with the proposal that the

Western cultural norm is to value maintenance of eye contact, in contrast to the Eastern cultural norm requiring flexible use of eye contact and gaze aversion.

Regarding social attention in live interactions, a study by McCarthy, Lee, Itakura and Muir (2006) measured the eye gaze patterns of Canadian, Trinidadian, and Japanese participants as they answered questions for which they either knew, or had to derive, the answers. When they knew the answers, Trinidadians maintained the most eye contact, whereas Japanese participants maintained the least. Further, McCarthy, Lee, Itakura and Muir (2008) found that when being observed while thinking, Canadian participants tended to look up while Japanese participants tended to look down. However, when Canadian participants thought they were not being observed, they also tended to look down while thinking, perhaps in an attempt to reduce their cognitive load (cf. Doherty-Sneddon & Phelps, 2005). This tendency for Canadian participants to maintain eye-contact when participants thought they were being observed could be due to gaze avoidance being perceived as insincere in Western cultures. Gaze aversion does not have such a negative value in Eastern cultures and can even signal respect in certain contexts (Argyle, Henderson, Bond, Iizuka, & Contrello, 1986). This series of studies looking at patterns of social attention across cultures clearly has implications for autism, as individuals with ASD generally display "unusual eye contact," as referred to in the Western sense; indeed this is one of the diagnostic criteria for autism in the *DSM-IV*. It remains to be seen whether the social attention patterns of individuals with ASD in non-Western cultures, where maintenance of eye contact is not as widely expected, is as markedly different from individuals within those cultures who do not have a diagnosis of ASD, as it is observed to be in Western cultures.

Further aspects of cognition that are often discussed in relation to autism are executive function and inhibitory control, as individuals with ASD are generally prone to struggle with these skills. Young children from South Korea have recently been

shown to have advanced inhibitory control (Oh & Lewis, 2008). It was proposed that the enforcement of proper etiquette and strict rules of social engagement between children and elders could contribute to the development of enhanced inhibitory control in young children in South Korea. In support of this proposal, Vinden (2001) found that authoritative parenting in South Korea is positively associated with a more developed theory of mind in children, a pattern opposite to that observed in America. It seems that culturally different parenting styles may achieve similar developmental goals, thus reinforcing the idea that a "one-size-fits-all" model of recommendations for parenting across cultures would be incorrect. Evaluation of parenting strengths and needs should be based on the complex interaction between attitudes and behaviors within particular sociocultural contexts as well as family dynamics and parent-child interactions. It is clear that when deciding on appropriate parenting recommendations, practitioners should be mindful of the parents' culture. Importing methods and tools from another culture without consideration of cultural norms could be detrimental.

Another aspect of culture that is known to have effects on cognition is bilingualism. Children who speak two languages from a young age have been shown to display better executive function (Bialystok, 2003, 2009). Bilingualism has also been shown to be associated with better theory of mind performance in young children (Goetz, 2003). There are a few explanations for these findings. One is the suggestion that people who are bilingual are required to be more aware of tailoring their language to meet the needs of others, making mental states more salient. Another suggestion is that having to understand that one object or concept corresponds to two different words facilitates the development of metarepresentation, which also underpins Theory of Mind. A further option is that increased inhibitory control in the linguistic domain in people who are bilingual underlies their superior performance. Bialystok and Martin (2004) suggest that this is because people who are bilingual need greater executive control in order to inhibit the opposing language to

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the one that they are currently using. It is perhaps worth investigating the impact of the relationship between cognition and bilingualism for children with autism. Bilingualism may help to develop skills such as executive function or theory of mind in those with ASD. The relationship between ASD, cognitive skills, and bilingualism is one that could provide great insights into understanding the nature of problems faced by individuals with ASD in the future.

In summary, there are many aspects of cognition and behavior in ASD that have been shown to differ among cultures. It is important to explore the complex relationship between culture and autism and to establish cultural norms in order to characterize the ASD profile accurately. It may be that autism is expressed differently across cultures and that certain aspects of cognition and behavior associated with autism will be shown to be less maladaptive in some cultures. Specific areas relevant to autism in which cultural differences have been demonstrated are visual perception (involving implications for weak central coherence), social attention (involving implications for theory of mind), inhibitory control and bilingualism (involving implications for executive function). Further research into the cultural influences on cognition and behavior associated with autism may also identify certain protective environmental factors that either modify maladaptive behavior or deem behavior less atypical.

Issues for Researchers Working With Non-Western Populations and Cultural Minorities

There are a number of methodological and ethical issues that arise when conducting research crossculturally, and many of these are highly pertinent to ASD. One of the key challenges faced in cross-cultural research is obtaining informed consent from participants, especially in the more rural communities of non-Western countries. Individuals who have not had access to a Western education may not have any framework within which to understand the nature, purpose, or benefits

and risks of the research in which they have been invited to participate. This undermines the ability to give fully informed consent (Ekunwe & Kessel, 1984; Samadi & McConkey, 2011). This is true for all cross-cultural research but is especially problematic for health-related research involving interventions, where some individuals may agree to participate in an intervention under the misunderstanding that the intervention must work for people to be researching them (Daley et al., 2013). Individuals may even participate in a study that does not involve intervention at all, under the mistaken assumption that it would have some kind of therapeutic benefit. Therefore, researchers need to take considerable care when approaching potential participants to ensure that they understand exactly what is expected of them in the study, and how they may or may not benefit.

Another general issue in cross-cultural research is the question of equivalence. It is important to know whether the same methods, procedures, tools, or scale items mean the same thing in different cultures. A number of studies have attempted to use tools developed in the West for autism diagnosis or screening in non-Western cultures, with mixed evidence on their reliability. For example the M-CHAT (Robins et al., 1999) screening tool for ASD has been translated into 40 different languages and is widely used across cultures, Seif Eldin et al. (2008) reported the M-CHAT to be an applicable screening tool in nine Arab speaking countries. However, in Sri Lanka it was found to lack specificity (Perera et al., 2009). Problems of tool validity implemented in cultures other than those for which it was designed is not just problematic for epidemiological research but also more generally. It is often regarded as good practice to incorporate diagnostic confirmation via the ADOS and/or ADI-R in all studies of individuals on the autism spectrum (Lord et al., 2000, Rutter, Le Couteur, & Lord, 2003). The ADOS has been translated into 16 different languages, the ADI-R has been translated into different 17 languages. However, certain aspects of these tools may be less applicable and therefore less valid when used outside the United States, the country in which they were designed.

Thought also needs to be given to what happens after individuals participate in research. There is increasing recognition worldwide that researchers have a responsibility to disseminate the findings of publically funded research beyond the academic community. For example, Research Councils UK have launched a variety of initiatives aimed at increasing public engagement with research including the requirement that all future research funded by RCUK must be published open access from April 2013; meanwhile the American Association for the Advancement of Science (AAAS) focuses on public engagement and communication of research findings to the public. The need to communicate research findings is magnified further in non-Western communities, as highlighted by Daley et al. (2013), as such communities may have limited access to academic journals and some may have limited access to any form of media. Indeed Darou, Hum, and Kurtness (1993) suggest that not only the results but the data ownership itself should be shared with the participants. Hence, efforts need to be made to communicate key findings of research studies after they have taken place through modes that are appropriate for the context. There may also be ethical implications for the disclosure of findings to individuals who participate, especially for studies involving screening and diagnosis. There is a good chance that such studies may reveal previously unidentified cases on the autism spectrum and there should be mechanisms in place to support such individuals and their families after the study has taken place.

Looking to the future, in order to minimize any potential negative impact of ethical and practical issues created by conducting research, it is essential that research is conducted in collaborative partnerships with local stakeholders such as service providers, NGOs and other relevant groups. It is vital that these community-based partnerships are not just seen as providing ways to access communities with ASD for testing within these populations but rather they should be engaged in discussion and included in every stage of the research process to ensure that measures or procedures used are meaningful and fit for purpose (Minkler, 2005). These

partnerships will also help build up trust between the research participants and researchers. Crigger, Holcomb, and Weiss (2001) state that such partnerships can also help address the power imbalance that often arises in cross-cultural research, which can lead to participants being exploited (Daley et al., 2013).

Local communities should also take the lead in establishing research priorities. It is important to consider which types of research will yield the largest benefits for the community and whether research should focus on long-term or immediate impact. These questions can best be answered by the communities themselves, although for researchers this raises the problem of identifying who are the most relevant stakeholders to be consulted (Piquemal, 2001). Nevertheless, involving communities in decisions about research is likely to prove essential for ensuring that outputs of research have real impact within the communities in which they have been conducted.

SUMMARY AND CONCLUSIONS

From the review provided above, it is clear that the issue of culture is extremely important for ASD in terms of how it is perceived, understood, diagnosed, supported, and treated. Some excellent work over the past 10 years or so has highlighted many common issues and challenges of those supporting people with ASD in different cultures, as well as the issues and challenges faced by individuals with ASD themselves. There is a need for more autism research to be conducted in non-Western cultures as further research will lead to improved understanding of the universality of autism, the causes, the cognitive and behavioral profile, and how best to improve outcomes for those affected.

Autism exists worldwide, is biologically influenced, and crosses country and cultural boundaries (see Elsabbagh et al., 2012 for a review of worldwide prevalence). However, there is far less consensus regarding where the boundary between difference and disorder actually lies. Standards and methods of diagnosis of autism vary drastically

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across cultures. Indeed, recent evidence suggests that autism symptomatology is culturally influenced (Norbury & Sparks, 2013; Zaroff & Uhm, 2012). Behaviors that are seen as particularly maladaptive in some cultures, such as a child's failure to maintain eye contact with a caregiver, are far less atypical or problematic in others. It is clear that diagnostic tools should be culturally informed and it is important that cultural norms are taken into consideration when identifying maladaptive behaviors to target in interventions.

Practitioner recommendations in all cultures should be approached with the caregivers' perspectives in mind and it is important to be aware that caregiver needs are likely to differ between cultures. Practitioners must focus on achieving the best outcome for the individual with autism and their family rather than solely focusing on identifying the correct diagnostic label. The ultimate goal will be to provide access to a tailored education and/or intervention program involving family support, as this will likely lead to the best outcome for the child. Of course, each child will develop differently, but it is important that families are helped to establish realistic expectations for their child's development and provided with support in order that the best outcomes can be achieved. The resources and services available to an individual with autism and their family following diagnosis are extremely variable and are dependent on age and characteristics of the person with ASD; the country, county, city, and neighborhood of residence; and family advocacy. Parents often have trouble accessing resources and support they feel they need. Differing cultural beliefs can influence families' decision making regarding what type of intervention, or treatment, to pursue. This is why cultural expectations and norms must be taken into consideration by practitioners who may be looking to provide post-diagnosis support.

The vast majority of psychological research is conducted in Western nations, indeed it is typically conducted in populations which are Western, Educated, Industrialized, Rich and Democratic (WEIRD) (Henrich et al., 2010). However, as culture plays such a fundamental role in our

understanding of the world, and influences cognition and behavior, it is vitally important to conduct research across all cultures. Culture has been shown to influence visual perception, social attention, and also behaviors associated with planning and execution of actions and language. These are all areas that are highly relevant to autism, so conducting cognitive and behavioral autism research within a cultural context will lead to improvements in our understanding of autism overall.

It is important to determine research priorities based on emerging issues on the ground to ensure that research addresses the most relevant and pressing public concerns. Key stakeholders from different countries, such as practitioners, family members, and individuals with autism themselves must be involved in the decision-making process regarding identification of research questions. One of the key challenges for researchers conducting empirical work is to ensure that all methods and procedures are ethically appropriate and that informed consent is obtained prior to the commencement of any piece of research. Thought also needs to be given to what happens after participation in research, as researchers also have a responsibility to disseminate their findings in an understandable manner.

In conclusion, although the past 10 years or so has seen a rapid increase in work on autism emerging from non-Western countries, there is still a paucity of evidence from these cultures overall. There is a critical need for further research and capacity building in relation to autism in low- and middle-income countries (Elsabbagh et al., 2012). The importance of engaging the public with research and furthering understanding of ASD within a cultural context is paramount in order for researchers to understand how those affected by ASD conceive, identify, manage, and talk about the various symptoms of developmental disorders such as ASD (see also Grinker et al., 2012). Culture is integral to the way in which autism is experienced, defined, and managed. Further research in non-Western nations, in minority subcultures and cross-cultural studies will lead to improved understanding of the causes of autism, the cognitive

and behavioral profile, and how best to improve outcomes for those affected.

CROSS-REFERENCES

Issues of diagnosis are addressed in Chapter 1 and the broader autism phenotype in Chapter 2. Epidemiology is the topic of Chapter 3. Age-related issues are discussed in Chapters 5 through 8. Teacher preparation is the focus of Chapter 47 and social policy issues the topic in Chapter 49.

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