

Cultural variations in behaviours related to ASD in South African children

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Objective: This article attempts to draw attention to the variable ways autism presents across cultures. If the assumption that ASDs manifests similarly across all cultures, then the Autism Diagnostic Observation Schedule (ADOS), the western gold standard for diagnosing ASDs, will be able to accurately discriminate those children that have ASDs from those that do not, regardless of a child's cultural background.

The study on which the article is based is part of a larger international research project, entitled the KwaZulu-Natal-ASD (K-ASD)¹ study, which aimed to explore the diagnostic ability of the ADOS in special needs schools in a non-western context.

Method: The study used a matched blinded sample comprising of an atypically developing ASD and non-ASD group from Black, White and Indian ethnicities. The sample came from special needs schools in the greater eThekweni area. The experimental group comprised people with ASD and the control group was a learning disabled group that did not have ASD. This study explored the Autism Diagnostic Observation Schedule (ADOS) algorithm subcategory scores of a sample of 26 children (6-11 years of age) who were administered modules 1-3 of the ADOS.

Results: An ANOVA revealed significant differences in the communication and the reciprocal social interaction algorithm's.

Conclusion: This indicated a cultural variation in behaviours, since Black participants behaved in various gestural ways that were significantly different to the manner in which White children behaved to the ADOS testing. The results of this study indicate potential for misdiagnosis if ethnicity and cultural variables are not considered.

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Introduction

Autism Spectrum Disorders (ASDs) are one of the most severe childhood disorders having devastating long term effects on a person's functioning (Matson & Konst, 2012); Shur-Fen Gau, Liu, Wu, Chiu & Tsai, 2013). Typical behavioural patterns involve social withdrawal, communication deficits, rituals and stereotypical repetitive behaviours (Blaurock-Busch, Amin & Rabah, 2011). There is growing consensus that the world wide prevalence of ASDs is increasing, currently prevalence is approximately 1% (Malcolm-Smith, Hoogenhout, Ing, Thomas & de Vries, 2013; Moolman-Smook, Vermoter, Buckle & Lindenberg, 2008).

Although the global burden of ASDs is unknown, the cost to society in the United States and the UK is in the billions which makes one consider the impact of ASDs on South African society (Elsabbagh et al., 2012). However, very little ASD research has been conducted in South Africa. Since ASDs significantly impact on the individual, family and society, research is needed in the South African context that will assist in bridging the gap between evidence and practise (El-Gouroury & Krakow, 2012).

ASDs are considered to be a universal disorder yet researchers are questioning whether behavioural differences occur across cultures (Sipes, Furniss, Matson & Hattier, 2012; Chug et al., 2012). There are studies that identify disparities between ethnic groups, arguing that a reason for this is the lack of standardised assessment instruments (Mandell et al., 2002).

Hence, the need to have a universal, reliable, culture-fair diagnostic tool (Mandell et al., 2002), such as the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). The ADOS is considered to be the gold standard for ASD diagnosis in the West and as a result it was used in this study to diagnose ASDs most effectively (Reaven, Hepburn & Ross, 2008; Lord et al., 2000).

This study aimed to answer uncertainties regarding ethnicity and whether there were significant differences in the ways cultural groups respond to the assessment subtests of the ADOS. Cultural variability was observed in terms of behaviours across Black, White and Indian children.

Research methodology

This pilot study was part of a larger study (K-ASD) which aimed to explore the behavioural and gestural patterns of children with ASD, across cultures. The study followed a quantitative experimental design, and using the ADOS the study hypothesised that there were no significant differences in the behaviours and gestures displayed by atypically developing South African children from varying ethnic backgrounds who had ASD, compared to those atypically developing children with other special needs who did not have ASD as a developmental disorder. This hypothesis thus considered differential behaviours across cultures for the ADOS subtests.

Sample

The sample was drawn from two special needs schools in the greater eThekweni area since this is where ASD children would likely be schooled. Access to schools was authorised through the Department of Education and the gatekeepers for this research study were the Department of Education and the Principals of the special needs schools.

As a vulnerable population, letters of informed consent were signed by parents/legal guardians of potential participants in the study. Non-probability purposive sampling was used in recruitment.

Initially 40 students (6-11 years) were enrolled into the study. However due to participant drop-out and challenges associated with the study design, the sample was reduced to $N=26$

(Males=18, Females=8). Ultimately, the experimental group comprised ASD children ($N=13$) and the control group comprised non-ASD children ($N=13$). This final sample comprised 10 paired Black children, six paired Indian children and ten paired White children. Although a small sample, recent ASD studies in reputable journals have used similar sample sizes (Overton, Fielding & Garcia de Alba, 2008). All participants were tested on the ADOS with both the administrator and the co-coder being blinded to the diagnosis of the child, for the purpose of avoiding coder collaboration and bias in observations.

Measures

Three measures were used in this study: the ADOS and two additional tools which were designed by the study team. The 'biographical form', which recorded family history etc. and the 'behaviour during assessment' form. Their use ensured accurate diagnosis and the reduction of false positives.

ADOS

The ADOS aimed to provide information about the participant's social and communication abilities, beyond mere expressive language delays (Lord et al., 2011). This allowed the instrument to control for language ability as a possible confounding variable in diagnosing ASD. The raw scores obtained by an ADOS administration were understood to indicate the severity of the ASD that the child had (de Bildt et al., 2011). The ADOS yielded a diagnostic algorithm using scores from social and communication domains and provides error cut-off scores for two diagnostic categories: Autism and ASDs (Reaven et al., 2012). The algorithms were based on the DSM-IV-TR and ICD-10.

Only one ADOS module was administered to a participant at any one time. The decision about which Module to administer was based on the clinician's judgement of which module

was most suited to the expressive language abilities of the child, as well as some consideration of their developmental level.

The assessment process

A rigorous, child-centred approach was used in assessments. Researchers' went through intensive training on the ADOS, they coded independently of each other; all ADOS prompts were translated and back-translated into isiZulu for Zulu speaking participants; each participant assessment was video recorded and viewed by a panel of experts ensuring accurate coding of behaviours and diagnosis.

Standardisation and cultural fairness

Assessment tools such as the ADOS are subject to cultural biases (Norbury & Sparks, 2012). Hence, every effort was made to standardise the ADOS to the South African context without changing the assessment procedure. Some adaptations were however necessary. For example, the pictures on the original ADOS kit are Americanised and represent activities many South African children are unfamiliar with. To avoid un-relatedness, the Westernised pictures were substituted for scenes that are more African. Namely, a picture including activities such as water skiing, paragliding, playing tennis and sailing, were replaced with illustrations of a rural home environment with people flying home-made kites, corn growing in the garden and chickens running around with a pet dog on the scene, since these are features that were more likely to be familiar to most Black African families.

Similarly, dolls in the form of a Caucasian family with children and grandparents, were substituted for an African family with brown skins. Likewise the doll used in the birthday party task was replaced with a brown-skinned doll.

The purpose was to ensure equivalence across races in administration of the ADOS and thus avoiding bias. According to Van deVijver and Leung (1997) attaining equivalence is the most central issue in cross cultural research.

Further, the demonstration task was simplified to a dish and the soap, without too much focus on hot and cold taps. If children were unable to perform the demonstration gestures simultaneously with verbal comments, they were provided a bar piece of soap and a face cloth with which to demonstrate the task. If this task was unsuccessful, the child was asked to show and describe how they brush their teeth, using imaginary tooth paste and tooth brush.

Although the ‘birthday party’ routine was not problematic, a more culturally accepted alternative of ‘bathing the baby’ was suggested in the manual.

Further, the frog in the functional play section was also not used as a toy in the ADOS subtest as many Black children fear frogs. The “Tuesday” book with flying frogs was also avoided with the Black children. The DSM IV acknowledges specific phobias associated with frogs, termed Ranidae phobia. Frogs also superstitiously represent bad omens in the Zulu culture (Gordon, n.d.; Psychiatry speciality board review for the DSM IV, 1996).

These adaptations aided in bridging the obvious cultural and social gaps that existed in using the ADOS in a Western context as opposed to the South African context. An expert panel of psychologists (across race), paediatricians and researchers corroborated and decided upon these adjustments relative to their findings in the broader K-ASD study.

Analysis

The different ethnicity scores across all ADOS sub-categories were compared using one-way analyses of variance (ANOVA) using SPSS (version 19) to observe whether there were

systematic differences present in the sample (Durrheim, 2002; Sheskin, 2007). A Levene's Test was run to test for homogeneity of variance across the populations.

Results

An F-statistic found that systematic differences were found. Thus the null hypothesis stating equal means between groups was rejected, indicating that ethnic groups responded differently on the ADOS subtests (Table 1).

Post-hoc tests revealed that the significant patterns of variance between ethnic groups lay in the sub-categories of communication and reciprocal social interaction ($p = .043$ and $p = .005$ respectively).

Table 1: ANOVA summary table for analysis of data

		ANOVA				
		Sum of Squares	df	Mean Square	F	Sig.
Communication	Between Groups	31.405	2	15.703	3.607	.043
	Within Groups	100.133	23	4.354		
	Total	131.538	25			
Reciprocal Social Interaction	Between Groups	106.128	2	53.064	6.621	.005
	Within Groups	184.333	23	8.014		
	Total	290.462	25			
Imagination/Cre ativity	Between Groups	5.785	2	2.892	2.247	.128
	Within Groups	29.600	23	1.287		
	Total	35.385	25			
Stereotypical Behaviours/Res tricted Interests	Between Groups	.328	2	.164	.134	.875
	Within Groups	28.133	23	1.223		
	Total	28.462	25			

Tukeys Honestly Significantly Difference test (HSD) of multiple comparisons further revealed that significant differences were noted between the Black and White/Indian ethnic groups (communication sub-category = 0.034; at the significance level of $p = 0.05$ and reciprocal social interaction = 0.004 at the significance level of $p = 0.05$).

Table 2: Multiple comparisons using Tukey's (HSD) test results

Multiple Comparisons							
Tukey HSD							
Dependent Variable	(I) Ethnicity	(J) Ethnicity	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Communication	Black	White	2.500	.933	.034	.16	4.84
		Indian	1.067	1.077	.590	-1.63	3.77
	White	Black	-2.500	.933	.034	-4.84	-.16
		Indian	-1.433	1.077	.393	-4.13	1.27
Reciprocal Social Interaction	Black	White	4.600	1.266	.004	1.43	7.77
		Indian	2.033	1.462	.362	-1.63	5.69
	White	Black	-4.600	1.266	.004	-7.77	-1.43
		Indian	-2.567	1.462	.207	-6.23	1.09
Imagination/Creativity	Black	White	.700	.507	.368	-.57	1.97
		Indian	-.500	.586	.674	-1.97	.97
	White	Black	-.700	.507	.368	-1.97	.57
		Indian	-1.200	.586	.123	-2.67	.27
Stereotypical Behaviours/Restricted Interests	Black	White	-.200	.495	.914	-1.44	1.04
		Indian	-.267	.571	.887	-1.70	1.16
	White	Black	.200	.495	.914	-1.04	1.44
		Indian	-.067	.571	.993	-1.50	1.36
Indian	Black	.267	.571	.887	-1.16	1.70	
	White	.067	.571	.993	-1.36	1.50	

*. The mean difference is significant at the 0.05 level.

Discussion

Approximately 85% of the world's youth reside in developing countries, thus South Africa has a large portion of youth in the population (Rutter, 2011). Since about 1% of the world's youth have ASDs, it can be surmised that ASDs pose a severe economic burden to the country. However the lack of research and knowledge regarding how ASDs present in South Africa across cultures and ethnicities results in them largely going unnoticed (Elsabbagh, 2012). Given that ASDs affect the individual, family and the larger community, this pathology extends the responsibility of an accurate diagnosis of this disorder to the national and international community at large.

As a study which spanned two very different socio-economic communities in the greater eThekweni area, it was obvious that access to resources in terms of clinician expertise and assessments, were not evenly weighted. The one school servicing a more affluent community was able to have comprehensive personal files and assessment results at the researcher's disposal. Whereas the other school in a low income area struggled to have their learners adequately assessed.

In terms of gender, ASDs do not manifest in equal proportions across males and females (Rivet & Matson, 2011). This was observed in our sample ($n = 26$), where 31% of the sample (8 participants) were female and 69% (18 participants) were male. Some studies cite boys outnumbering girls by a ratio of 4 to 1 (Ametepee & Chitiyo, 2009; Gau et al., 2013).

Children with ASDs show weaknesses in social reciprocity, communication and repetitive behaviours (Strang et al., 2012; Bolte et al, 2013). The ADOS does increase the likelihood that a participant will display ASD type behaviours which typify an ASD diagnosis (Lord et al., 2000). It has a sensitivity of .80 to 1.00 in diagnosing ASD type behaviours (Lord et al., 2000).

Some studies have highlighted disparities across ethnic groups in diagnosing ASDs (El Goroury & Krackow, 2012). Thus in South Africa's multicultural context it was questionable whether different ethnicities respond differently to the various sub-categories on the ADOS, affecting algorithm scores and ASD diagnosis. The hypotheses read as such:

- **Ho1:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.
- **Ha1:** There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.

- **Ho2:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

Ha2: There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

- **Ho3:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

Ha3: There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

- **Ho4:** There is no significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

- **Ha4:** There is a significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

Results of this pilot study showed that the null hypothesis for communicative behaviours and reciprocal social interaction were rejected as significant differences were found in behaviours across Black and White cultures. This can be interpreted to mean that Black participants behaved in various verbal and non-verbal/ gestural ways that were significantly different to the manner in which the White participants behaved. These differences were picked up on the ADOS and affected the individual scores significantly.

The challenge lay in recognising these culturally embedded verbal and non-verbal behaviours observed in the spontaneity of play, the use of gestures, and in the asking and showing of objects interactively. The ADOS, in previous studies, revealed extreme accuracy in

diagnosing those who were on the autism spectrum and those who are not (Overton, Fielding & Garcia de Alba, 2008).

Since diagnosis of ASDs is based on observable behaviour patterns, variations across cultures may account for variations in diagnoses, and may result in possible false positives (Klinger, Dawson & Renner, 2003; Bernier, Mao & Yen, 2010). This notion was supported by other theorists who documented variable response patterns across cultures (Clark, 2000 as cited in Johnson et al., 2005; Bachman, O'Malley & Freedman-Doan, 2010, Scarborough & Poon, 2004 in Chung et al., 2012).

It could be argued that the children from Zulu ancestry may have misunderstood the instructions on the ADOS that were given in English. This may have resulted in variable behaviours. However, a translator was always present during assessments thus ensuring no confusion in instructions.

Variability in behaviours could have been culturally induced. Acceptable communication patterns in one culture may not be acceptable in another (Ostrosk-Solis, Ramirez & Ardila, 2004). Observations showed that the Black children were reluctant to spontaneously communicate with the researcher, in a verbal or a non-verbal gestural manner, such as talking or pointing. For example, in making a choice between sweet biscuits or savoury crisps, the Black children behaved in a shy, reserved way and never asked for additional treats. The White children were more outspoken, confident and almost always asked for more. This display of confident behaviour would be considered disrespectful in Zulu culture.

In Zulu culture, a White adult researcher, has an elevated social status to a child. This may have accounted for the Black children's reticence (Rudwick, 2008). If the researcher were a male as opposed to a female, the researcher would have an even more elevated status. These perceptions affected behaviour patterns, enhancing quietness and reservation in the black

children. This cultural, reticence and reservation was also observed in the ways the children gained the researchers attention and the way they socialised and interacted with them.

The reciprocal social interaction sub-category also considered non-verbal cues such as the quality of eye contact that the participant had with the researcher throughout the ADOS administration. Poor eye contact, which is typical amongst individuals with ASD, may be interpreted differently depending on the societal norms of the cultural group in question (Sipes et al., 2011). In Zulu culture children are considered to be disrespectful if they gaze into an adult's eyes while they are being spoken to (Rudwick, 2008). In a White Western culture, it is considered rude to avoid eye contact with a person when communicating. Eye contact was analysed for the entire assessment process. This allowed for initial reticence and shyness in the beginning stages of the assessment, until rapport was established between the participant and the examiner.

These variances in communication patterns and eye contact may have affected the scoring on the algorithms and resulted in significant differences in the ADOS scores. Alternatively they reflect actual cultural differences.

Reciprocal social interaction as a sub-category also considered the normality of facial expressions that the participant directed to the examiner. The quality of the participant's social overtures and variable responses were considered. That is, were the social interactions appropriate to the test context and were they variable? This included a researcher's judgement call on how comfortable the interaction was and the degree of difficulty in establishing rapport.

People are most definitely influenced by their environments and learn how to socialise within their culture, and this largely affects how people behave (Grinker et al., 2011). Since ASD diagnoses rely heavily on observable behaviours a person's responses to social interactions

and their gestural behaviours greatly influences, individual diagnosis, prevalence and incidence rates (Bernier et al., 2010). Researchers need to recognise behavioural differences embedded in culture. Gestures and behaviour patterns are not universal (Archer, 1997). Uninformed researchers make errors in their diagnostic coding, resulting in inaccuracies in diagnosis (Grinker et al., 2011).

The increasing prevalence of ASDs in developing countries like our own, makes a study like this relevant and useful for mental health professionals working in South Africa (Durkin et al., 2006). South Africa needs a specific ASD-case detection tool like the ADOS which is easy to use in a community clinic, a paediatrician's or a psychologist's office. Currently, in South Africa, there are minimal provisions for screening, diagnosis and intervention strategies for ASD children especially in communal settings. There is a lack of research on gestural behaviours and expression variances between cultures. It is a fact that gestural behaviours are not universal (Archer, 1997).

People of different cultures are socialised differently. Although Black, White and Indian children in this study had English as their medium of instruction at school, their home languages differed. Black children spoke either isiZulu or isiXhosa at home and were more likely socialised to be respectful and obedient. In comparison, the White and Indian children spoke English as their home language and appeared to be socialised in similar ways. The variable perspectives on what is considered respectful behaviour may have accounted of this (Rudwick, 2008). This may have accounted for the disparity in the ADOS sub-category results.

The enormity of familial, communal and individual distress incurred by the pathology of ASDs extends the responsibility of an accurate diagnosis of this disorder to the international community at large. One cannot rely solely on parental support to do this. Many people in

South Africa do not have access to services affiliated with ASDs nor do they have the means to have lengthy expensive assessments done on their children. This was obvious in the second school used in the study which had a lower social economic status of parents than the first school. The personal files at times were quite scant in terms of assessments.

Decisions need to be taken at a national level to ensure the wellbeing of South Africa's children. This is supported by Munir and Bakare (2011) who stated that "Africa needs more policy making attention directed at child and adolescent mental health service provision, especially regarding the issues of childhood developmental disorders and intellectual disability" (Munir & Bakare, 2011). This will require dramatic improvements in the health care system especially at the community level in terms of service delivery. Further research which replicates this pilot study with larger sample sizes would be able to validate the findings, since it is acknowledged that the clinical presentation of ASDs in Africa 'remains elusive' (Elsabbagh et al., 2013, 172).

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