

Global Health and Inequalities:

ASDs In South Africa: Behavioural presentations; culture-fair tools and access to services

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HSD



26 - 27 september
birchwood conference centre

inequalities and justice:

influences, effects, intersections and evidence



2013 HSRC SOCIAL SCIENCE RESEARCH CONFERENCE



Autism Spectrum Disorders

Autism Spectrum Disorders (ASDs) : lifelong neurological & developmental disorders.

- Heterogeneous disorder
- Clinical diversity
- Conceptualisation of core ASD symptoms = complex

Autism Diagnostic Observation Schedule (ADOS).

- Standardised semi-structured diagnostic instrument
- Increases the likelihood that a child with ASD will display behaviours that typify disorders on this spectrum

Prevalence & Global Burden

- World wide prevalence: 1%
- Mismatch between local and global perceptions
- Global burden is unknown: cost to society in UK and USA is in the billions.
- Statistics South Africa (2013) currently 15 million youth (0-18years): 150 000 possibly have ASDs
- Under researched – mental health disorder
- 85% worlds youth reside in LMICs
- “Autism Speaks” – K-ASD

Global perspective of ASD

Our **1 in 88** can't wait!

It's time for the President
and Congress to listen.

SIGN THE PETITION



South Africa's children are also vulnerable



Study Aims

Explore the diagnostic ability of the ADOS in a non-western context through exploring the behavioural and gestural patterns of children with ASD in comparison to non-ASD controls, in so doing understand local manifestations of ASD symptoms across Black, White and Indian cultures.



Study design

Special Needs Schools

A quantitative, blinded, matched experimental design.

- Initially N = 40

Methodological Challenges

- The experimental group (n=13) and the control group (n=13).

Matching

- based on age (6-11 years), gender and ethnic origins.

Comparative, Child-centred approach

- To assessment was carried out using the ADOS, in an attempt to explore the diagnostic ability of the ADOS across ASD and non-ASD participants.

ADOS

Sensitivity of diagnosis is
0.8 – 1.00

Accurate in diagnosis of
ASDs

- Social withdrawal
- Communication deficits
- Rituals
- Stereotyped repetitive behaviours



4 Modules which control for expressive language level

14 sub-tests that are scored to provide quantitative results on an algorithm.

TEST ADAPTATIONS

- Azenze study
- Test adaptations in consultation with test developers



ORIGINAL	CHANGES MADE
Caucasian family	Black family
White doll	Brown doll
Demonstration task- hot/cold taps	Washing of face in basin with cloth and soap
Frog	Dog
Pictures - Westernised	Rural community/homestead
Birthday party	Bathing the baby

Research Design

Hypothesis testing

Main Hypothesis

- Null Hypothesis: There will be no significant difference in the ADOS coding algorithms between atypically developing children with Zulu or English as their home language, diagnosed with ASD and children with other needs for special education.

Sub-hypotheses

- **Ho1:** There is no significant difference between children of White, Black or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.
- **Ho2** Reciprocal Social Interaction
- **Ho3** Imagination/Creativity behaviours
- **Ho4** Stereotyped Behaviours and Restricted Interests

Methodology and Results

Matching of 40 students

- Experimental ($N=20$) and control groups ($N = 20$).

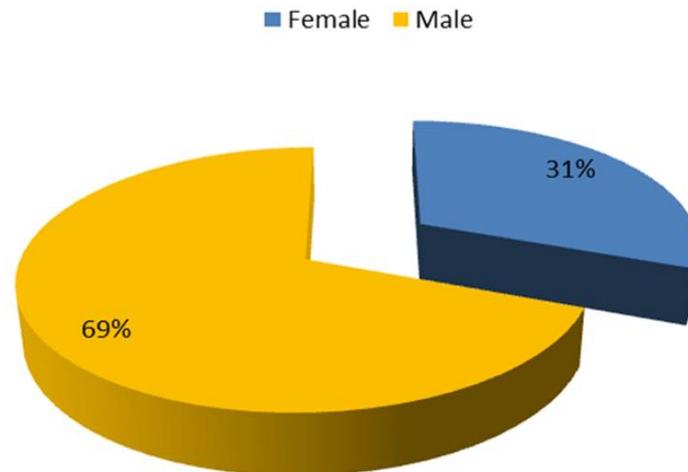
Participant drop-out, mismatching across age race and gender

- Experimental ($N=13$) and control groups ($N = 13$).

ADOS, Behaviour during assessment, Personal files.

Gender across sample:

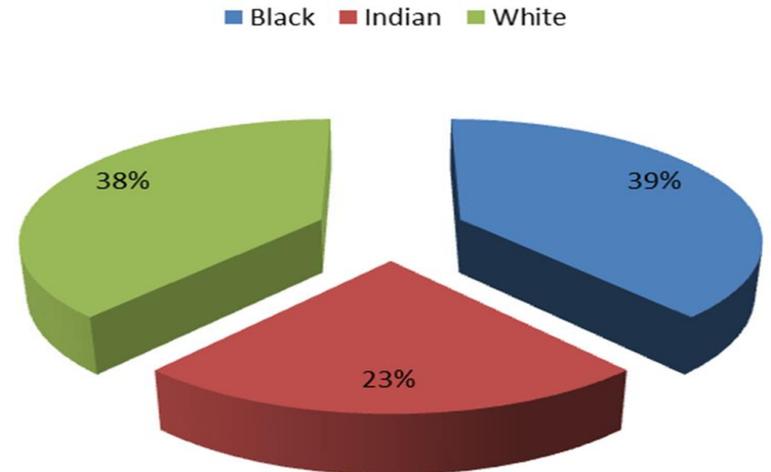
- 69% = Male
- 31% = Female



Results

Racial variations in the sample:

- 39% Black
- 38% White
- 23% Indian



ANOVA

Observe whether ethnic differences exist in behaviour presentations on the ADOS subgroups namely:

- Communication
- Reciprocal Social Interaction
- Imagination/Creativity
- Stereotypical Behaviours/Repetitive Interests

Results and Discussion

ANOVA RESULTS:

- Significance between Black and White participant scores on the sub-categories for:
 - communication ($p= 0.34$; $\alpha= 0.05$) and
 - reciprocal social interaction ($p= 0.04$; $\alpha= 0.05$).
- Thus **verbal and non-verbal gestural ways** = significantly different.
- Challenge
- People learn how to socialise within their culture. Thus, acceptable communication patterns in one culture may not be acceptable in another.

Discussion continued

Acceptable behaviour patterns:

- Less spontaneous communication
- Confident behaviour versus respectful behaviour
- Power dynamics determined by cultural perceptions

Reciprocal Social interaction:

- Eye contact
- Normality of facial expressions – variability of social overtures, relevant to context, rapport

ASD diagnosis based on observable behaviours

A person's responses to social interactions and their gestural behaviours greatly influences, individual diagnosis, prevalence and incidence rates

Discussion continued

Researchers need to recognise behavioural differences embedded in culture.

Gestures and behaviour patterns are not universal

Uninformed researchers and clinicians make errors in their diagnostic coding, resulting in inaccuracies in diagnosis

Concluding remarks

- Familial, communal and individual distress
- Responsibility of an accurate diagnosis of this disorder -international community
- Clinical presentation of ASDs in Africa ‘remains elusive’
(*Elsabbagh et al., 2013, 172*).

“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*).

- Dramatic improvements- community level in terms of service delivery