

**SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM
SPECTRUMDISORDERS AMONGST HEALTHCARE
PRACTITIONERS IN SOUTH AFRICA**

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DECLARATION

I hereby declare that the master's degree mini dissertation that I herewith submit in a publish-able manuscript format for the master's degree in Paediatrics at the University of the Free State is my independent work, and that I have not previously submitted it for any qualification at another institution of higher education.



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ABSTRACT

Background: There is a global increase in Autism spectrum disorders (ASD) prevalence, awareness and its effect on the burden of disease. It is crucial that ASD is recognized and diagnosed timeously for early intervention during the age of high neuroplasticity for optimal outcomes. We do not know if Health Care Practitioners (HCPs) in South Africa working in paediatric departments are able to diagnose and manage these children with complex medical needs.

Objectives: This study was done to determine how paediatric HCPs in South Africa screen for, diagnose and manage autism spectrum disorders in both the public and private sector. Paediatric healthcare workers, general practitioners and primary level personnel are typically the first point of contact for family members concerned with ASD traits.

Methods: A cross sectional descriptive analytical study design was conducted over a period of 11 months, from 1 March 2020 to 31 January 2021. An in-depth questionnaire was sent out via an electronic platform, namely Chatbot to eligible participants. A random sample of 116 completed questionnaires were captured on Google spreadsheets by Dekode IT Company and used for statistical analysis.

Results: The majority of HCPs (70.7%) do not routinely screen children for ASD between 18-24 months as recommended by the American Academy of Paediatrics.¹⁰ Common methods used for screening ASD were; milestones, development and occasionally the checklist for Autism (CHAT)/Modified-CHAT.

There was lack of knowledge about diagnostic tools used for ASD in 40% of HCPs that made ASD diagnosis. HCPs opted for developmental history, medical examination, unstructured behavioural observation, parental concern and DSM 5 criteria to make the diagnosis, which might under- or overestimate ASD statistics. Following the diagnosis 78.5% of HCPs referred patients to another discipline. Common referrals to speech therapists and occupational therapists for coordinated multidisciplinary assessment were noted. Hearing screen was a frequent investigation undertaken when making the ASD diagnosis. Other investigations occasionally used were CT/MRI, EEG, fragile X and genetic microarray analysis.

Of the HCPs that managed ASD patients, less than 25% initiated treatment by prescribing risperidone followed by methylphenidate and valproate respectively. Supplements used were multivitamins, omega acids and Vitamin B6. Barriers to diagnosing and managing ASD identified in this survey were lack of experience, educational resources, referral centers, family support, specialists in the field, therapists, time and parental denial. In 85% of cases a HCP would provide information to the caregiver about autism.

Conclusions: HCPs in SA lack knowledge, awareness, and training to diagnose and manage children with ASD. Autism is not screened for routinely or as recommended in practice. There is a lack of knowledge about the diagnostic tools to diagnose ASD. Not all suspected Autism cases were referred for multidisciplinary assessment and a hearing screen. There were multiple barriers contributing to making an early diagnosis of Autism noticed.

KEYWORDS

Autism spectrum disorder (ASD), Autism, Screening, Diagnosis, Management, South Africa, Healthcare workers, Paediatrics

LIST OF ABBREVIATIONS AND DEFINITIONS

Abbreviations

ADOS- Autism Diagnostic Observation Schedule

ADI-R -Autism Diagnostic Interview Revised

ASD - Autism Spectrum Disorder

DSM 5-The fifth edition of the Diagnostic and Statistical manual of Mental disorders)

HCP - Healthcare Practitioner (In this study, this refers to any Medical Doctor working with children)

LMIC- Low- and Middle-income countries

M-CHAT- Modified Checklist for Autism in Toddlers

NICE - National Institute of Health and Clinical Excellence

CDC - Centre for Disease Control and Prevention

SA- South Africa

Definitions

ASD- is a life-long neuro-developmental disorder that presents with difficulties in social communication, restricted interests, and repetitive behaviours.¹

Screening- is a brief, formal, standardized evaluation, the purpose of which is the early identification of patients with unsuspected deviations from the norm. Screening does not provide diagnosis; it helps determine whether additional investigation by clinicians with special expertise in ASD is necessary.¹

Diagnosis- the use of scientific or clinical methods to establish the cause and nature of a person's illness or injury and functional impairment it produces. This will follow the DSM 5 diagnostic criteria.

Management – an approach to health care delivery that focuses on the complex needs of the patient and emphasizes the coordination and prioritization of all needed services.

South Africa - is a country on the southernmost tip of the African continent, marked by several distinct ecosystems. It has 9 provinces.

CHAPTER 1: ORIENTATION OF THE STUDY

Introduction and literature review:

Autism spectrum disorder (ASD) is defined as a life-long neuro-developmental disorder that presents with difficulties in social communication, restricted interests and repetitive behaviours.¹

Autism was first described in the medical literature in the early twentieth century and since then there has been an explosion of research, interest, and debate about this disorder. The World Health Organization (WHO) estimated the international prevalence of ASD to be at least 0.76%.² The diagnosis is suspected in approximately 3% of children according to the National Institute of Health and Clinical Excellence (NICE). ASD was said to affect one out of every 160 people worldwide in 2013, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease making it a common condition for the primary healthcare practitioner (HCP) to encounter, and thus, important to know about.³

The prevalence as described in the literature has since risen and varies substantially across studies in different countries. According to a March 2020 report by the American Centre for Disease Control and Prevention (CDC), approximately 1 in 54 children in the United States are currently affected by ASD.⁴ The prevalence in many low- and middle-income countries (LMIC) is unknown thus far. The true prevalence of ASD in Africa is unknown,

with no proper epidemiological studies in sub-Saharan Africa. The perceived rise in ASD prevalence in South Africa (SA) could be attributed to increased awareness among practitioners, parents and broadening of the diagnostic criteria since 2000.⁵ Furthermore, there are very few studies describing the presentation, features, and management of autism in developing countries. While international guidelines for ASD management are available, little is known about the actual clinical practice.⁶

ASD results from early-altered brain development and neural reorganization.⁷ The mechanism underlying autism is not fully described but a variety of approaches to identify brain differences in ASD such as neuroanatomical and genetic differences are being studied. Neuroanatomical abnormalities include volumetric changes in particular regions, as measured by magnetic resonance imaging (MRI) while genetic focuses on defects in a number of synaptic proteins that alter synaptic structure and function, as well as neural circuits.^{8,9} Factors identified to increase the risk of Autism include hereditary, environmental and genetic factors as advanced maternal and paternal age, maternal autoimmune disease, gestational diabetes, maternal infection or immune activation during pregnancy, shorter and longer pregnancy intervals, infants born prematurely, maternal drugs i.e., valproate and neuropsychological factors such as parental stress level. The complexity of risk factors lead to the conclusion that genetic and epigenetic factors that affect the central nervous system may interfere with normal developmental processes and gene expression, immune sensitivity, and environmental stressors all play a role in the development of ASD phenotypes within the first three years of existence.¹⁰

ASD main symptoms are deficits in social communication and the presence of restricted and repetitive interests or activities and sensory anomalies, beginning in the early developmental period. These occur in all children, irrespective of race, culture, ethnicity or socioeconomic groups.^{1,11} Lotter proposed that stereotypic repetitive behaviours are less common among African children with ASD.¹² Co-morbid conditions are common in ASD children such as sleep disorders and seizures, as well as other developmental or behavioural diagnoses like attention deficit/hyperactivity disorder and aggression, refusal to eat and self-injurious behaviours.¹³

Screening

Developmental surveillance, screening and the early recognition of ASD symptoms allow for the benefits of early intervention during the period of high neuroplasticity and should form part of the routine developmental assessment of every child.^{14,15} Previous studies examining the age of presentation of children with developmental delays, including those with autism, reflect disparities between socio-economic class and the availability of resources with those living in the lower socio-economic margin of society, being diagnosed later.^{16,17} Thus an assumption can be made that the time taken to diagnose individuals with ASD in South Africa will follow the same trend.

There has been no evaluation of current screening practices in either the public or private sector in South Africa. The current recommendation by the American Academy of Pediatrics is to screen all children at 18 and 24 months, as some children will start to show deterioration around that age. However, diagnosis can be made earlier if parental concerns are taken into consideration.^{18,19}

The screening tools are based on early manifestations of symptoms of core deficits related to social communication which may alert the provider to the risk for ASD, the so called “red flags”²⁰ (see table 1).”

TABLE 1 Red Flags: Early Symptoms of ASD

Symptoms	
By 12 months	• Does not respond to name
By 14 months	• Does not point at objects to show interest
By 18 months	• Does not have pretend play
General	<ul style="list-style-type: none"> • Avoids eye contact and may want to be alone • Has trouble understanding other people’s feelings or talking about their own feelings • Has delayed speech and language skills • Repeats words or phrases over and over (echolalia) • Gives unrelated answers to questions • Gets upset by minor changes • Has obsessive interests • Makes repetitive movements like flapping hands, rocking, or spinning in circles • Has unusual reactions to the way things sound, smell, taste, look or feel

Information from this table is adapted from:
<http://www.cdc.gov/ncbddd/autism/signs.html>

Those with red flags must undergo formal screening as milder symptoms or the subtle ASD presentation in children with normal intelligence may not be obvious. Research suggests that paediatricians identify more children with ASD when using formal screening tools rather than during informal surveillance.²¹ Various autism-specific screening tools are available (see table 2), but not all of them are equally sensitive or user friendly and there is uncertainty about which tools work best in non-Western cultures or low-resource settings.^{12, 14,22}

Table 2
 Summary of screening methods available for infants and children.²³

METHOD	TYPE	ITEMS	TARGET	AGE	TIME / MINS	SENSITIVITY	SPECIFICITY
Q-CHAT-10	Questionnaire	10	Toddlers	19-24 mo	5-10	91%	89%
CAST (Childhood Asperger Syndrome test)	Questionnaire	37	Children	5-11yrs	15-25	100%	97%
DBD-ES (Developmental Checklist-Early Screen)	Questionnaire	17		18-48mo	10-15	83%	48%
ESAT (Early Screening for Autistic Traits)	Questionnaire	14	Toddlers	16-30mo	10 to 15	88%	14%
PDDST-II (Pervasive Developmental Disorders Screening Test-Second Edition)	Questionnaire	22	Toddlers	18 - 48mo	10 - 20	92%	91%
ITC (Infant toddler checklist)	Questionnaires	24	Toddlers	6-24 mo	10 to 15	89%	85%
FYI (The First Year Inventory)	Questionnaire	63	Toddlers	12mo	20 to 35	NA	NA
ASIEP-3 (autism screening Instrument for Educational	Questionnaire	47	Toddler and children	2 to 13yrs	Varies	100%	81%
CSBS-DP	Questionnaire	24	Toddlers	6 to	10 to		

(Communication and Symbolic Behavior Scales Developmental Profile)	ire			24mo	15	78%	84%
STAT (Screening Tool for Autism in Toddlers and Young Children)	Play activities	12	Toddlers	24-36	15 to 20	95%	73%
ESAT (Early Screening for Autistic Traits)	Questionnaire	14	Toddlers	16-30mo	10 to 15	88%	14%
(CARS)-2 Childhood Autism Rating Scale	Questionnaires	15 X 2	Children	6years	10-20mo	81%	87%
ABC (Autism Behavior Checklist)	Questionnaire	57	Children	6-13year	20 to 30yrs	77%	91%

In wide populations of children, the Checklist for Autism in Toddlers (CHAT) for 18 month old babies and the Autism Screening Questionnaire for children 4 years and older have been verified. Modified Checklist for Autism in Toddlers (M-CHAT) has slightly better sensitivity and specificity compared to CHAT, and is preferable to use as a developmental surveillance- screening instrument.²⁴ It is also relatively time and cost effective.²⁵ The M-CHAT was revised to reduce the number of cases who initially screened positive and needed the follow-up questionnaire, while maintaining high sensitivity. M-CHAT -Revised (M-CHAT –R/F) has been translated into many languages besides English and can be completed by parents within 5-10 minutes achieving around 91% sensitivity and 96% specificity.²⁶

However, screening tools need to be developed for populations of individuals whose primary language is not English and who are sensitive to cultural barriers that may limit

reporting of ASD symptoms.²⁷ Establishing guidelines for the reporting of cultural adaptation and community collaboration procedures as well as screening instrument psychometrics and screening methodology will enable the field to develop best practices for autism spectrum disorder screening in low-resource settings.²⁸ Validation of screening tools, such as the Social communication questionnaire and M-CHAT, for the South African population is under way, but results are yet to be published.²⁹ A 2021 Ghanaian study using the M-CHAT showed it to be a useful ASD characteristics screening tool in a different cultural environment implying that it may be useful in the South African context.³⁰

Diagnosis

Autism symptoms can be identified by 12 months but the mean age of obtaining diagnosis is 4 years 3 months.^{31,32} Diagnosis is often delayed if there are co-occurring conditions such as anxiety, hyperactivity, or mood disorder.³³

Following the release of the DSM 5 with its revised diagnostic criteria for ASD, there has been renewed interest in the diagnosis and impact thereof on the prevalence of autism.^{34,35} The recommended practice parameter by the American Academy of child and adolescent psychiatry uses the DSM 5 criteria as the clinical standard to diagnose individuals with ASD.¹⁴

The DSM 5 criteria focus on persistent deficit in each of the three areas of social communication and interaction as well as some forms of limited, repetitive activities. The social communication concentrates on lack of emotional reciprocity in social situations, nonverbal communicative behavior that is used for social interaction and problem with forming, sustaining and comprehending relationships. The restrictive and repetitive pattern criteria is characterized by two of the following: stereotyped or repetitive motor movements, insistence on similarity, fixed interest restriction, and hyper- or hypo-reactivity to sensory input.

Although the criteria are clear, it is recommended that only practitioners with relevant training and experience in the field should make the diagnosis of autism.¹⁵ There are many tools to make the diagnosis but the gold standard tests for diagnosing ASD are the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview Revised (ADI-R) which have challenges of instrument and training cost, time required to complete them and the need for substantial training to use them reliably.^{35,36} The ADI-R is a structured interview with the caregiver in which developmental and behavioral symptoms are reviewed in children with a mental age above 18 months. The ADOS is a semi-structured, standardized assessment of social interaction, communication, play, and imaginative use of materials for individuals' suspected of having ASD. The observational schedule consists of five 45-75-minute modules, each designed to be administered to different individuals according to their level of expressive language.³⁷

The ADOS/ADI-R assessment package has been demonstrated to differentiate children with autism from those with other developmental disabilities.^{38,39} Only a few tools have been validated for use in Africa.⁴⁰ Due to time constraints in busy clinics, these tests may not be suitable in a South African environment. Smith and colleagues assessed the ADOS's cultural suitability by developing an Afrikaans translation and concluded that it was only suitable for use in urban population samples from Cape Town.⁴¹

Several diagnostic instruments are available to improve diagnostic accuracy, especially in doubtful cases. As part of the diagnostic process, children with ASD should be referred for multidisciplinary assessment, which may include a medical assessment, genetic, neurologic consultation, psychological and communication assessment. Evaluations by occupational and physiotherapists are important to assess for sensory and motor difficulties. Coordinated multidisciplinary assessment ensures that all aspects are fully evaluated and included in the treatment plan.^{14,42}

Management

The management of ASD is challenging and an individualized treatment plan catering for the patient and family alike is important.⁴² Research on comprehensive treatment models is flawed by methodological errors, but some behavioural interventions are supported by evidence as cited in Fuentes-Biggi et al (2005).⁴³ Interventions can be divided into medical, educational, behavioural, family and complementary or alternative treatments.¹⁴

Despite intensive research efforts, no drugs are yet registered to treat the core deficits of autism. Oxytocin shows promise but studies were underpowered and have not reached phase 3 trials. Drugs targeting specific molecular pathways in syndromes are being developed but even in the condition with the most research evidence, tuberous sclerosis, the use of Mammalian target of Rapamycin (M-Tor) drugs have had mixed results in its effects on improving autism behavioural traits. The strongest evidence for medication is found in the use of co-occurring conditions like irritability, attention deficit disorder and to a lesser extent anxiety. Parents and caretakers will often use alternative substances or dietary interventions like cannabidiol products or the gluten and casein diet.⁴⁴ The atypical antipsychotics risperidone and aripiprazole are approved by the Food and Drug administration of the United States of America to treat irritability, which may include behaviours like aggression and self-injury.⁴⁵ Both these drugs may cause significant weight gain, as well as sedation. Dystonia if used for a prolonged period in high doses is a concern. Metformin can be added to the atypical antipsychotics to ameliorate the weight gain.⁴⁶ Methylphenidate, Atomoxetine and guanfacine (which is not available in South Africa) improve symptoms of an attention hyperactivity disorder in autism, but the stimulants have more side effects when used in children with ASD than in typical children. The efficacy of serotonin reuptake inhibitors like fluoxetine, sertraline and citalopram is less established in autism than the general population.⁴⁷ Although fluoxetine was efficacious in reducing obsessive symptoms in autistic adults with an obsessive compulsive disorder, citalopram has not been of benefit for children's repetitive behaviours.⁴⁸ Cannabidiol reduces seizure

in severe myoclonic epilepsy of infancy and may be of benefit in drug resistant epilepsy in autism, but there are real concerns about the effects on immature brains and it should not be used for behavioural challenges.⁴⁹

It is important to assess behaviour from the perspective that it is as a form of communication e.g., a child being overwhelmed by sensory issues or wanting to avoid demands. In South Africa, the shortage of trained professionals who can use applied behavioural analysis may lead to medication being used earlier and off-label for challenging meltdowns.

In the past few years interventions in children with autism has moved away from historical and often rigid approaches to a more natural approach of teaching. These approaches share common features and use principles of both applied behavioural analysis (ABA) and the underlying forces of typical child development, which are then combined to reinforce the idea that normal development should drive the learning process.⁵⁰ Skills are taught in a natural environment and integrated across domains to prevent learning to become too context bound or prompt dependent. The key concept is that all learning is enhanced if it occurs during meaningful social affective interactions. Teaching is often initiated by the child and occurs during child-preferred activities using materials the child finds motivating. Natural reinforcers are used to strengthen the child's motivation. Although behavioural and educational treatments for the core symptoms of ASD were established as the standard of care, they require time to show improvements and not every patient benefit from them.

Natural developmental behavioural interventions (NDBI) programs can be delivered by both parents and therapists but there are also some differences between the Early Start Denver Model (ESDM) where there is a comprehensive focus on functioning in all domains vs JASPER (Joint attention, symbolic play, engagement, and regulation) which is more targeted to pivotal responses. The process starts by securing the attention of the child, being sensitive to the child's level of arousal, optimizing motivation and offering multiple opportunities for communication. The process should be fun driven with engagement trying to "find the social smile". The language used should be at the child's level, with the principle of using one word more than he/she (one up expansion). Joint activities should be planned with careful transitions. The process redirects the child's focus of attention to people rather than things and promotes affective engagement, which enhances learning, as we know that affect plays a key role in learning. These NDBIs recruit the brain's plasticity that is its ability to learn from experience. It may influence synapse formation that early in development occurs at a rate of 700 per second. The amount of effort necessary to influence plasticity increases with age, emphasizing the importance of early intervention.⁵¹

According to studies, low-intensity interventions that teach parents how to communicate with their young children have immediate effects on social interaction and communication. The interventions focus on teaching parents and caregivers on how to maintain joint treatment by avoiding to be too directive, build opportunities for mutual attention and

balanced play.⁵² No systematic studies that explicitly varied the intensity of interventions or compared one strategy to another have been conducted.⁵³ These therapies are generally non-intrusive for families, low in cost and adaptable for clinic or home or groups and individuals. They may be beneficial even for families with very young and at-risk children who in the end may not grow ASD but may experience other delays.⁵⁴

Although not evidence based, complementary and/or alternative medicines (CAM) are often used as an adjunct and may include modified/special diets, vitamins/minerals and food supplements.⁴⁴ CAM therapies are targeting the proposed pathophysiological mechanisms related to ASD, which are immune dysregulation and inflammation, environmental toxin exposures, oxidative stress and mitochondrial dysfunction.⁵⁵ Assessing the Gluten-free/casein-free diet in experimental studies suggested improvement of symptoms for a proportion of people with ASD but conflicting study results make it difficult to recommend.⁵⁶ The ketogenic diet is beneficial for treating epilepsy but not ASD.⁵⁷ Vitamin B12 is an antioxidant cofactor that aids in the regeneration of methionine from homocysteine in the body. It has been proposed that methyl cobalamin deficiency and impaired methylation can play a role in the development of ASD.⁵⁸ Another antioxidant which is currently in vogue is camel milk, which is close to human mother's milk since it has high vitamin C, A and E levels and rich in antioxidants. It is thought to have a positive effect on autism symptoms and to lower the effects of oxidative stress. There are however no proper double blind studies done for any of these dietary manipulations.⁵⁹ Chelating therapy is another form of CAM treatment where chemicals are administered in order to bind heavy metals but the risk associated with this therapy is bigger than the potential benefits.⁴⁴

Research on different treatment modalities in the South African context is sparse. A small study done in the Western Cape showed that, in keeping with international data, our autism population frequently uses prescription and over-the-counter drugs.⁶⁰ The management of ASD in South Africa is further undermined by the lack of available autism-specific specialized education.⁶¹

A growing population of people with ASD necessitates increased service and resource availability which should include the training of professionals, as well as the development of additional trans disciplinary resources to cope with the rising numbers of children identified with the condition.⁶² As paediatric healthcare workers will see most children with red flags for ASD at some stage in the diagnostic process, we undertook this study to understand how HCPs in South Africa screen for, diagnose and manage ASD.

Research question:

How do healthcare practitioners in South Africa screen for, diagnose and manage autism spectrum disorder?

Aim:

The aim of the study was to determine how healthcare practitioners in South Africa screen for diagnose and manage autism spectrum disorder in their respective workplaces.

Objectives of the study:

The objectives of the study were:

- To determine and document screening practices for autism spectrum disorders by healthcare practitioners in South Africa:
 - Calculate the percentage of healthcare practitioners that routinely screen for autism
 - Document the age at which they screen patients for autism
 - List the tools that they use to screen for autism
 - To document the diagnostic process used by healthcare practitioners when considering the diagnosis of autism spectrum disorder.
 - To list the different methods used by healthcare practitioners to diagnose autism.
 - To calculate the percentage of healthcare practitioners that use an autism-specific diagnostic tool to diagnose autism.
 - To calculate the percentage of healthcare practitioners that use multidisciplinary input to diagnose autism.
 - To list special investigations done when assessing a child for ASD
- To document the management plan for autism spectrum disorders used by healthcare practitioners in South Africa:
 - To list the referral pattern of children with autism
 - To list the general management of patients with autism and to calculate and document which treatment modalities are most frequently prescribed.
 - To compare practices relating to autism spectrum disorder between the healthcare practitioners in the private and state sector.

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CHAPTER 2: Publishable journal Article.

Prepared for the South African Journal of Child Health

Title:

Screening, diagnosis, and management of autism spectrum disorders amongst healthcare practitioners in South Africa

Abstract

Background: There is a global increase in Autism spectrum disorders (ASD) prevalence. It is unknown whether Health Care Professionals (HCP) in South Africa (SA) working in paediatric departments, can manage these children.

Objectives: To determine how paediatric HCPs in SA screen, diagnose and manage ASD. They are generally the first point of contact for concerned family members.

Methods: A cross sectional descriptive analytical study was done. Quantitative data was collected using an in-depth questionnaire sent through an electronic platform

Results: A random sample of 116 completed questionnaires was collected.

Overall, $n=82/116$ (70.7%) of HCPs do not routinely screen for ASD. Preferred screening tools were developmental milestones and occasionally the checklist for Autism (CHAT)/ Modified-CHAT.

There was a lack of knowledge about diagnostic tools. Developmental history, medical examination, unstructured behavioural observation, parental concern, and DSM 5 criteria were used for the diagnosis. Patients were commonly referred to someone for coordinated multidisciplinary assessment and a hearing screen was a frequent investigation of choice.

Approximately a quarter of patients were given medicine. Lack of expertise, educational services, referral centers, family support, specialists in the area, therapists, time and parental denial were all barriers to diagnosing and treating ASD.

Conclusions: HCPs lack knowledge, awareness and training in ASD. Screening for ASD is not routinely done. There is lack of knowledge about diagnostic tools. Not all suspected ASD cases are referred for multidisciplinary assessment and a hearing screen. We identified multiple barriers to making the diagnosis.

Introduction

ASD is defined as a life-long neuro-developmental disorder that presents with difficulties in social communication, restricted interests, and repetitive behaviours.^[1] Globally, in 2013, one in every 160 persons was estimated to live with ASD accounting for 7.6 million disability-adjusted life years, making it a common condition for the paediatric HCP to encounter.^[2]

Prevalence has since risen and varies substantially across studies in different countries. According to the CDC approximately 1 in 54 children in the United States are currently affected by ASD.^[3] The true prevalence of ASD in many low- and middle-income countries

(LMIC) and Africa is unknown. There are no proper epidemiological studies in sub-Saharan Africa. Furthermore, there are few studies that describe the presentation, characteristics, and management of autism in developing countries.^[4] Although many international guidelines are available, little is known about what actually takes place in clinical practice.

Developmental surveillance, screening and the early recognition of Autism symptoms allow for the benefits of early intervention during the period of high neuroplasticity. These should form part of the routine developmental assessment of every child.^[5,6] Previous studies examining the age of presentation of children with developmental delays, including those with autism, reflect disparities between socio-economic class and the availability of resources with those living in the lower socio-economic margin of society, being diagnosed later.^[7,8] As a result, it is expected that the presentation of children with ASD in South Africa will follow the same pattern.

There has been no evaluation of current screening practices in either the public or private sector in South Africa. The current recommendation by the American Academy of Paediatrics is to screen all children at 18 and 24 months.^[9] Diagnosis can be made earlier if parental concerns are taken into consideration.^[10] Various autism-specific screening tools are available, but not all of them are equally sensitive or user friendly.^[5,11] Screening tools need to be developed for populations of individuals whose primary language is not English and who are sensitive to cultural barriers that may limit reporting of ASD symptoms.^[12] Validation of screening tools for the South African population is under way, but results are yet to be published.^[13]

The American Academy of child and adolescent psychiatry uses the DSM 5 criteria as the clinical standard to diagnose individuals with ASD.^[5] Only practitioners with relevant training and experience in the field should make the diagnosis of autism.^[6] The two tests that are considered to be the gold standard for diagnosing ASD are the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostics Interview-Revised (ADI-R).^[14] Smith and colleagues evaluated the cultural appropriateness of the ADOS and concluded that it was appropriate for urban samples from Cape Town only.^[15] There are very few tools that have been validated for the African context.^[16] Children with ASD should be referred for multidisciplinary assessment. This may include a medical assessment, genetic and/or neurologic consultation, as well as psychological and communication assessment. Coordinated multidisciplinary assessment ensures that all aspects are fully evaluated and included in the treatment plan.^[5,17]

The management of ASD is challenging. An individualized treatment plan catering for the patient and the family alike is of utmost importance.^[17] Interventions can be divided into medical, educational, behavioural, family, and complementary or alternative treatments.^[5]

Since most children with early signs of ASD would come into contact with a paediatric healthcare worker at some point during the diagnostic phase, we conducted this study to learn how HCPs in South Africa screen, diagnose and manage this common condition.

Research method and design

We carried out a cross-sectional descriptive analytical study where quantitative data was collected using an electronic administered questionnaire to participants/ HCPs. HCPs who met the inclusion criteria were doctors registered with Health Professions Council of South Africa (HPCSA) and working in either a private or state sector paediatric environment in South Africa.

A questionnaire was formulated in English, and included summarized information of the study for completion by HCPs at leisure. It consisted of 111 questions translated into an electronic format focused on the following aspects: 1) demographic data; 2) screening and surveillance; 3) diagnosis and tools used; and 4) planned management. If the answer to a category question was 'NO' exposure, Chatbot skipped the subsequent questions to the next category.

The questionnaire was sent to paediatric HCPs around SA in all nine provinces using an electronic platform, Chatbot using emails from the existing departmental mailing lists, provincial health departments after acquiring provincial ethics approval and by site visit and from personal requests.

The Health Sciences Research Ethics Committee at the University of the Free State (HSREC nr 2019/1336/2411) and the Department of Health gave their approval. Consent was implied by the completion of the questionnaire. The questionnaires were returned anonymously. Data was captured on Google spreadsheet by Dekode IT Company and stored in a password-protected electronic format on a research laptop (see attached form). Data was collected over an 11-month period, beginning on March 1, 2020, and ending on January 31, 2021, before being submitted for analysis.

Results

Demographics

A total sample of 116 completed questionnaires across the 9 provinces in both private and government sector was collected. Of the 116 HCPs, 81% (n=94/116) worked in the government sector, 5.2% (n=6/116) worked in private, 12% (14/116) in both sectors and 1.7% (2/116) do not practice but previously worked in paediatrics. The percentage of provincial contribution figure 1 varied with limitations and strengths alluded to under methodology.

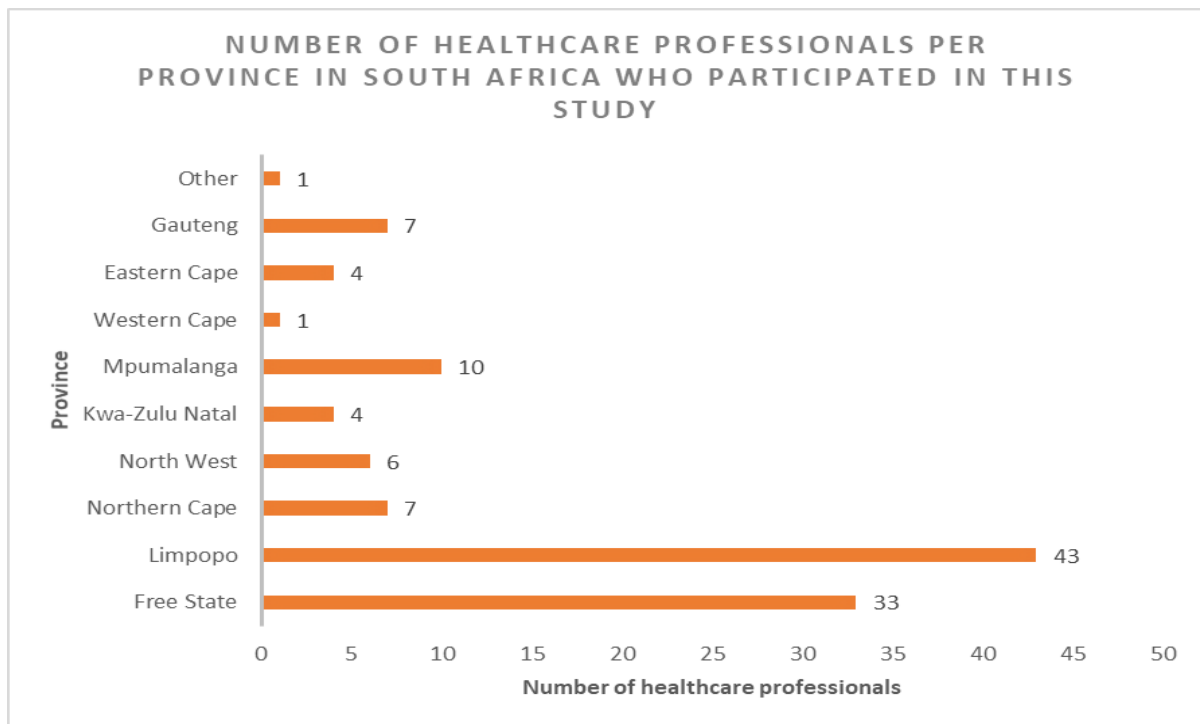


Figure 1: Graph showing the number of healthcare professionals who participated in this study from each of the 9 provinces in South Africa (n=116)

The majority of HCPs are not exposed to ASD training. 61% (n=71) had never attended a course/workshop on ASD, 17.4% (n=20) had never encountered ASD and 41% (n=41) had never diagnosed ASD. Approximately 58% of HCPs often encounter ASD in their practice. Only 29.3% of HCPs screen for ASD routinely and of that percentage, 35% screen on every visit.

Most HCPs are not confident (37%) to moderately confident (49.1%) to diagnose and manage ASD and felt that training at both undergraduate and postgraduate level was inadequate. Figure 2

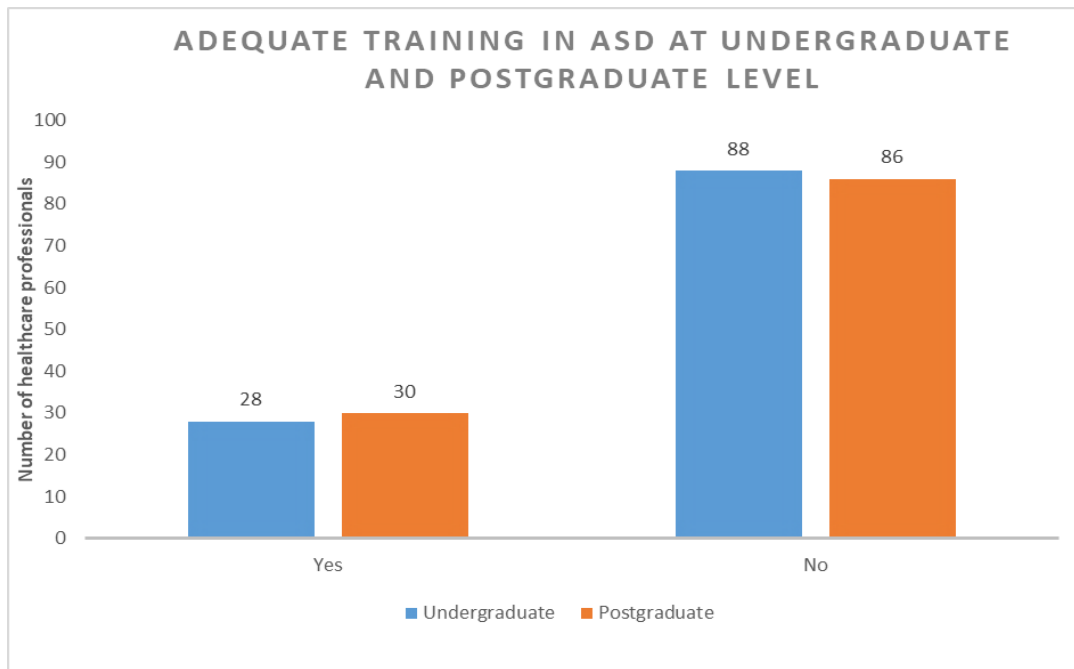


Figure 2: Graph showing adequacy of training at both undergraduate and postgraduate level

If the HCPs replied ‘NO’ exposure to any of the following categories, they were excluded from answering follow-up questions and skipped to the next.

Screening

A minority of HCP screened for ASD $n=34$ (29.3%) but the majority did not $n=82$ (70.7%). Of those that screened for ASD (29.3% of the sample participants), 82% did not screen routinely with every routine visit. Lack of training and lack of time for screening were mentioned as barriers to diagnosis (50% for both). HCPs commonly used milestones (84.6%) and developmental levels (76.9%) as a form of screening. A tool that was sometimes used for screening is the Checklist for Autism in Toddlers (CHAT) (73.1%), followed by the Modified Checklist for Autism in Toddlers (M-CHAT) (70.8%). Figure 3

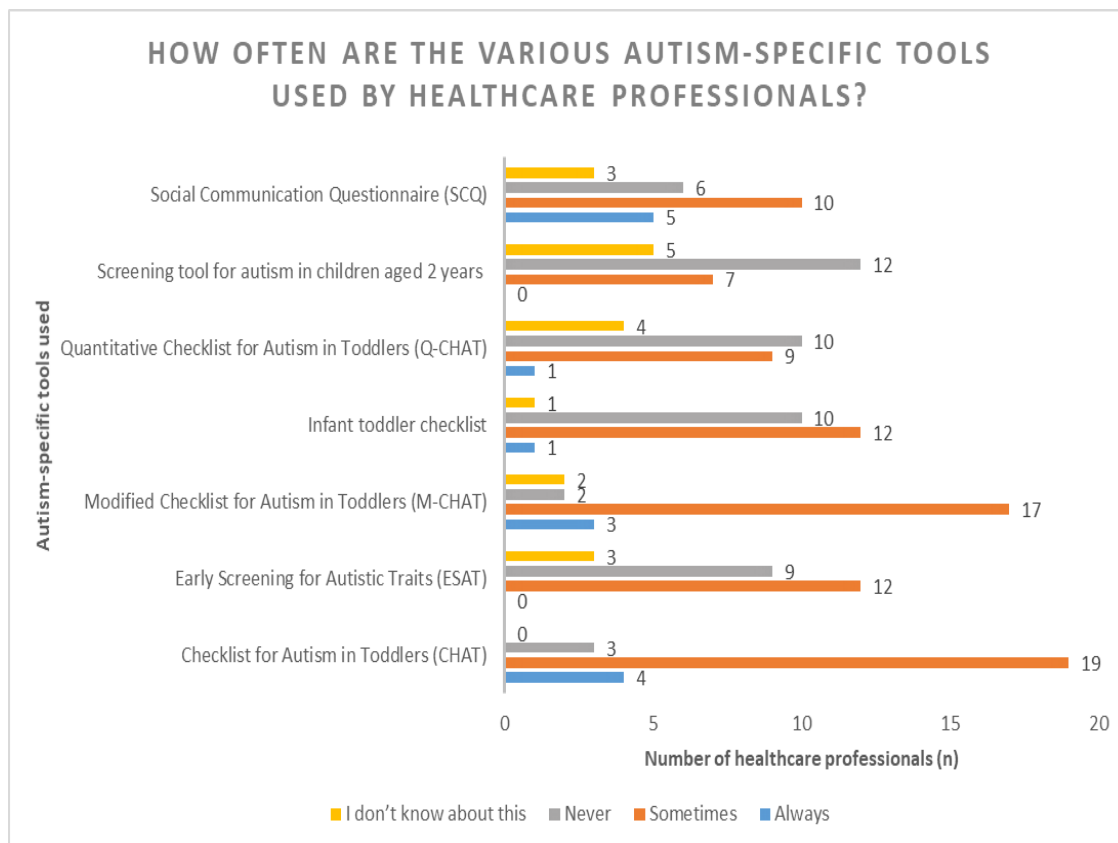


Figure 3: Graph showing screening tools used by healthcare practitioners

Diagnosis

About 64.6% of HCPs ($n=73$) have diagnosed ASD, 35.4% ($n=40$) have not, thus our data interpretation was based on the 73 HCPs. The preferred methods used for diagnosing ASD were: Use of the developmental history (89%); Medical examination (86.3%); Unstructured behavioural observation (80.8%); Parental concern (72.6%); DSM 5 (68.5%). The duration taken to make ASD diagnosis was 30 to 60 minutes in 55% of HCPs, more than 60min in 33%, and less than 30 minutes in 12% of HCPs.

More than 45% of HCPs are unaware of the common tools used for diagnosing ASD, 59.7% do not know the DISCO-diagnostic interview for social and communication disorder, 58.3% are unaware of the developmental, dimensional, and diagnostic interview (3D1), 52.8% do not know the ADI-R revised autism diagnostic interview and 45.2% are unaware of the childhood autism rating scale (CARS). Of the HCP that are aware of the tools, the following tools are used: The CARS, ADI-R, 3D1 and DISCO with 31.5%, 23.6%, 18.1% and 9.7% respectively. Figure 4

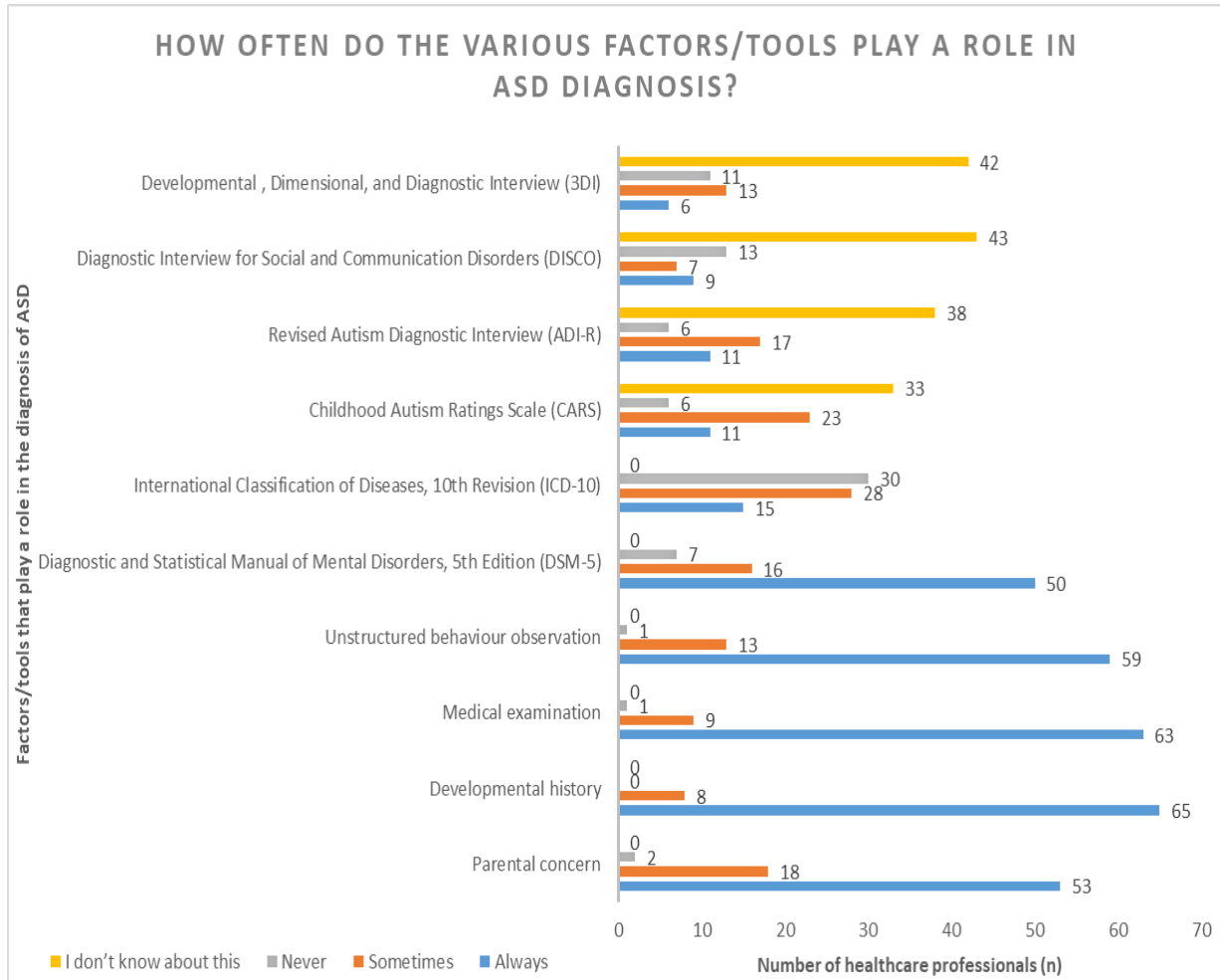


Figure 4: Graph showing various factors/tools that play a role in ASD diagnosis

Investigations used in ASD

Of the 73 HCPs, 68.1% (n=49) do recommend investigations for children with Autism. Those used were CT/MRI of the brain, EEG, Karyotyping, microarray, and Fragile X testing at 65.3%, 61.2%, 57.1%, 42.9% and 46.9% respectively. Only 69.4% (n=34) routinely screened for hearing loss and 26.5% (n=13) sometimes. Figure 5

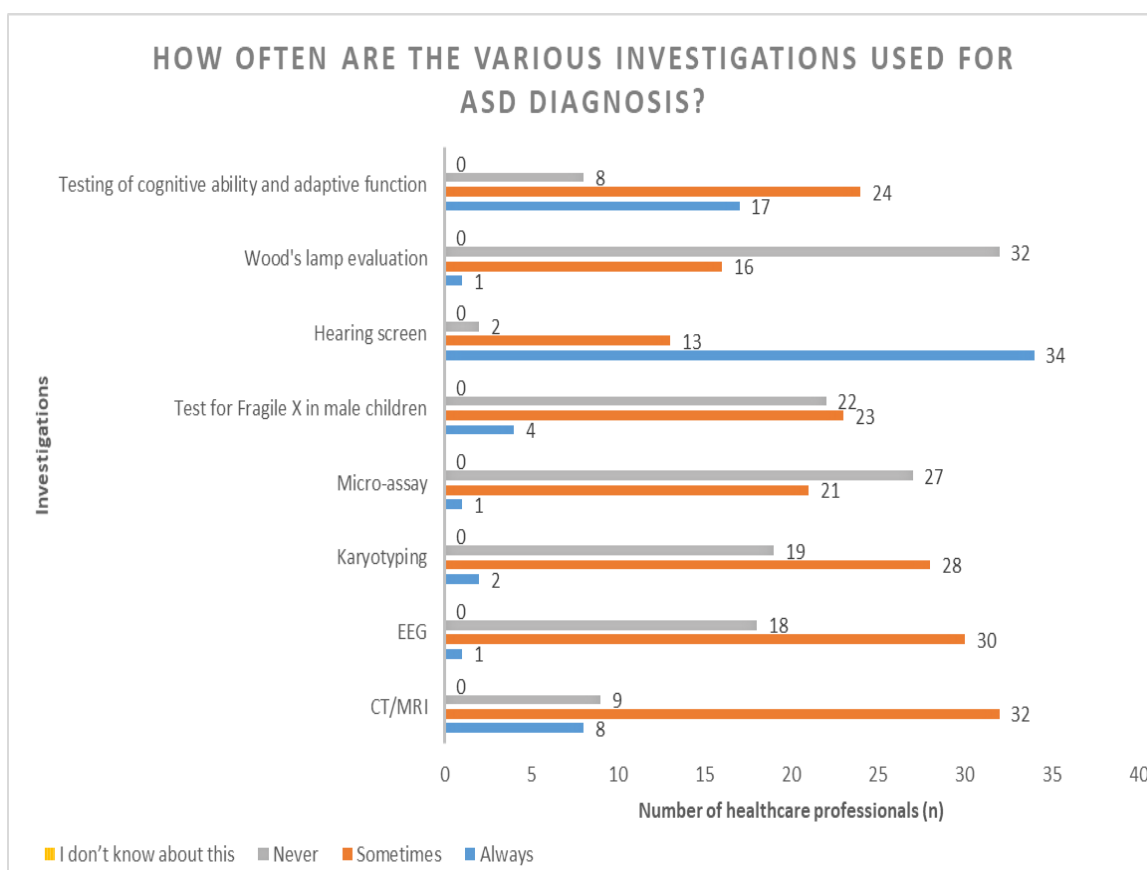


Figure 5: Graph showing investigations undertaken for ASD diagnosis

Referral of suspected Autism cases

HCPs that had referred suspected Autism children were $n=84$ (78.5%). They commonly reported referrals to a speech therapist (85.4%), occupational therapist (78.6%), and a psychologist (50%). Less common were referrals to a neurologist (31.7%), educational services (33.7%) and a psychiatrist (25.6%). After diagnosis, the HCPs gave feedback to the caregivers by providing: Information (84.8%); book references (64%); booklets (57.5%); details for support groups (54.1%); Internet sites (45.4%).

Management

Two-thirds ($n= 71$; 67%) of the HCPs have managed ASD. Most of the interventions are unknown to respondents. Recommended interventions were: Communication intervention (44.3%); Play-based interventions (37.3%); Intensive behavioural therapy (35.2%); Cognitive behavioural therapy (33.8%); Pragmatic language skills training (18.6%); Social communication intervention (14.9%); Early Start Denver or other natural behavioural intervention (8.8%); Developmental individual difference relationship-based intervention (7.4%); TEACCH programs (treatment and education of autism and related communication handicapped children program) (5.9%)

Use of Medication, complementary and alternative methods

Medication is prescribed in <25% of patients by 34.3% ($n=23$ of 71) of HCPs, 25-49% by 26.9% ($n=18$), 50-75% by 31.3% ($n=21$) and >75% by 7.5% ($n=5$). Regarding the specific medications prescribed, approximately 22.7% of HCPs always or often prescribe risperidone (59.1%), followed by methylphenidate (39%) and Valproate (24.6%). Other medications seldom used by HCW are Lamotrigine (52.3%), Fluoxetine (35.4%), Citalopram (32.3%), Levetiracetam (29.3%), Clonidine (29.85%), Haloperidol (27.3%), Olanzapine (24.2%), Clomipramine (23.4%), Alprazolam (12.5%) and Diazepam (6.3%). (Figure9) Alternative options used by patients include multivitamins (58.7%), omega acids (33.3%), Vitamin B6(15.9%), a gluten-free diet (11.1%), magnesium (6.4%), gut therapy (3.2%) and miracle mineral solution (1.6%).

Complementary treatments used by patients were cannabis oil, Biostrath, traditional and religious intervention, play therapy and stem cell transplants.

Barriers to diagnosing and managing ASD

Of the $n=85$ HCPs that completed this section, most responders indicated a lack of experience (95.3%), lack of educational resources (89.3%), lack of referral centers (82.4%), lack of family support (82.1%), lack of specialists in the field (81.2%), lack of therapists (72.6%) and time (69.4%) as well as parental denial (80.7%) as barriers to the diagnosis and management of ASD. See Figure 6 for the options used by HCPs to give caregivers information following diagnosis

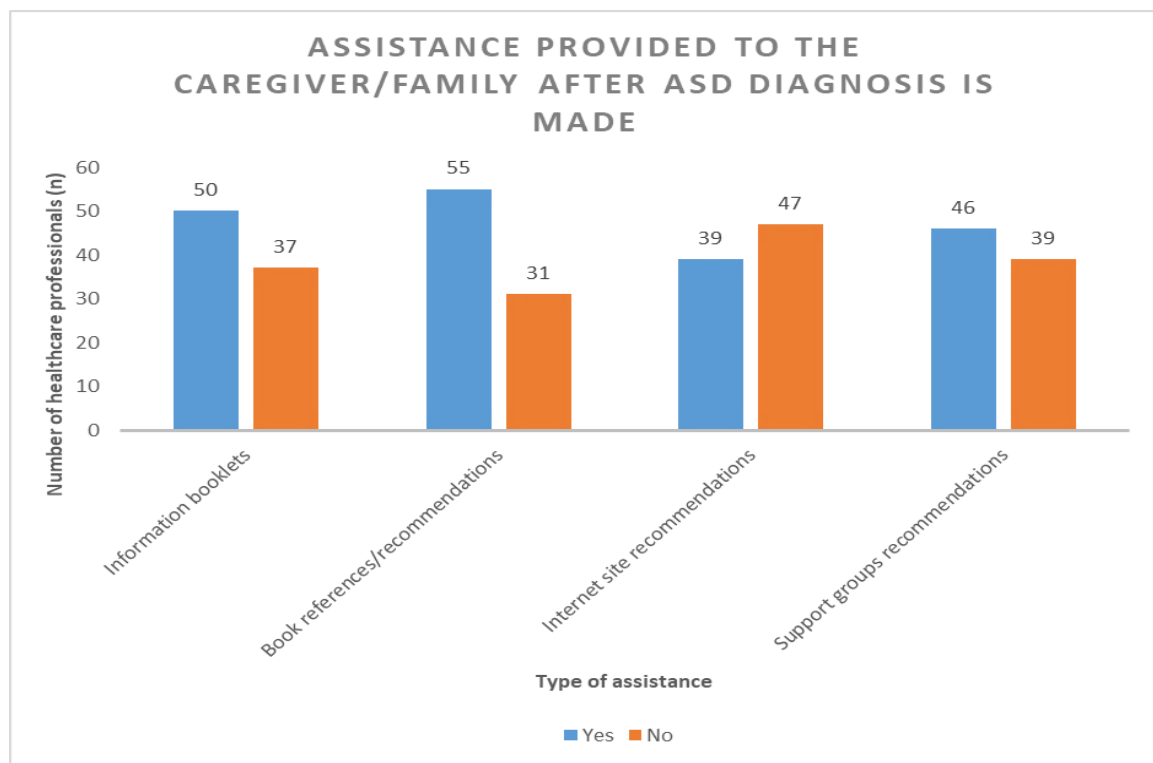


Figure 6: Graph showing assistance provided to family/caregiver after diagnosing ASD

Difference between public and private sector

We only obtained 6/116 paediatric practitioners that worked solely in private, from 5 different provinces thus could not compare the state and private sector

Discussion

Our study confirmed our suspicions that health care workers in a pediatric setting in South African are not well informed about the diagnosis of ASD, lack confidence in assessment, and have limited resources and time to make the diagnosis. These trends are in keeping with trends in the rest of sub-Saharan Africa. The literature proposes that knowledge and awareness about childhood ASD remain at a low level in Africa among healthcare workers and our findings support this.^[18,19]

The American Academy of Paediatrics' (AAP) recommends screening for ASD at 18 and 24 months but the majority of HCPs do not screen for ASD regularly or on recommended specific visits. Prompt diagnosis of ASD allows access to early intervention services, which have been shown

to improve developmental outcomes in young children because of early brain plasticity. ASD may be diagnosed by a variety of healthcare professionals, including paediatricians, therapists, and psychologists, with the best results achieved by a multidisciplinary approach.

HCPs commonly used milestones, development and occasionally, the Checklist for Autism (CHAT) / Modified-CHAT as a form of screening. However, studies of physician estimation of the developmental status of children are considerably less accurate when only clinical impressions, rather than formal screening tools are used.^[20]

There was a connection between a lack of diagnostic tool expertise and the number of HCPs who made the diagnosis. HCPs opted to make the diagnosis based on developmental background, medical review, unstructured behavioural observation, parental concern, and DSM 5 criteria, which may result in overestimation or underestimation of ASD statistics. The average duration of 30 to 60 minutes taken while making a diagnosis of ASD may not be adequate for assessing a child with complex medical needs.

Many guidelines recommend a hearing test, and that imaging is reserved for children with focal neurological signs. In our study, imaging studies were used frequently and the recommendation for a hearing test was not universal.

Following the diagnosis, most HCPs refer patients to speech therapists and occupational therapists. This follows recommendations from the literature, in that coordinated multidisciplinary assessments ensure a comprehensive evaluation where therapy can be tailored to each individual child's needs and all aspects are fully evaluated and included in

the treatment plan.^[5,19] This comprehensive evaluation is important, as Autism is seen as a spectrum that can range from very mild to severe. It is also a heterogeneous disorder with a broad range of clinical manifestations and associated conditions.

More than 60% of HCPs have managed ASD and less than 25% of HCPs initiated medical treatment. Commonly prescribed medications were risperidone, followed by methylphenidate and valproate. Only risperidone and aripiprazole are currently United States Food and drug administration (FDA) approved, specifically to treat irritability in ASD.^[21] One can assume that methylphenidate was used for the attention deficit disorder often co-diagnosed with ASD, and valproate was used either as a mood stabilizer or for co-occurring epilepsy. Our study did not investigate this further. In a country where resources are unevenly distributed, one can assume that medication may be used more frequently than in well-resourced settings.

Other barriers to diagnosing and managing ASD were lack of experience, educational resources, a lack of referral centers, family support, specialists in the field, therapists, lack of time for assessment, as well as parental denial.

Parents used different types of complementary and alternative medications such as cannabis oil and stem cell transplants, as well as special diets, which are of questionable value or even possibly dangerous. Only melatonin supplement has been demonstrated to be a safe and effective intervention for improving sleep in children with Autism.^[21]

Limitations

The limitations of this study were that of any cross-sectional descriptive research method. The quality of respondents' answers may influence the reliability and validity of data, as a self-completed questionnaire may be subject to misinterpretation of questions and reporting errors. Data may not be representative, as not all the HCP were equally likely to respond. The questionnaire is lengthy, which might predispose to survey fatigue. The survey took place during Coronavirus disease of 2019 (COVID-19) outbreak, which influenced the time available to complete questionnaires. COVID-19 lockdown rules affected site visits and electronic glitches could occur.

Recommendations

It would be worthwhile to repeat the study and include psychiatry healthcare practitioners in South Africa. There are five South African provinces without a registered child psychiatrist in a government setting, which is of concern and needs to be addressed in future human resource expansion planning.

This study did not have enough data from private health sector thus is not representative of that specific sector. Another study recruiting solely from the private health sector where it is assumed there are more resources and specialists will add information.

If mortality rates from acute illnesses continue to decline, then child developmental delay and disability will become a larger and important part of the burden of childhood disease. Services where children with complex medical needs like autism can be assessed by a multi-disciplinary team need to be established, with priority given to younger children where therapy can make the biggest difference.

A standardized screening tool should be administered at any point when concerns about ASDs are raised. Screening tools need to be developed for populations of individuals whose primary language is not English and who are sensitive to cultural barriers that may limit reporting of symptoms of ASD.

More studies need to be done comparing private hospitals and state settings to decide on minimum standards that should be developed with the aim of having common South African guidelines.

A lack of sufficient undergraduate and postgraduate ASD training was identified and this finding should be communicated to different sectors; The Department of Health should implement the use of the developmental screening page in the road to health booklet as a standardized, Hospitals should hold recurring short course training and outreach with an aim to improve the knowledge of HCPs and enable the transfer of skills and promote trans-disciplinary education. Medical institutions should integrate information with enough practical and virtual learning to keep up to date with Autism terminology and evidence-based literature, enabling them to effectively communicate the rationale of treatment choice, and the importance of other service providers like multidisciplinary team roles.^[19]

The only scalable option for management in the South African context is to involve parents in therapy. This will enable the child to learn in different contexts as well as the family home, a stated aim of the so-called natural developmental interventions, all of which have a solid evidence base. The World Health Organization's caregiver skills training programme is being implemented with governmental support in some provinces. This intervention focuses on children with developmental delay pre-diagnosis and has a strong social and communication- teaching component that makes it suitable for children with autism.

Conclusion:

When you are committed to the idea that the first 1000 days of life matter, you cannot ignore a developmental condition with a prevalence of almost two percent. Early identification of, and intervention in, children with an ASD have proven positive effects and enable them to reach their optimal capabilities, something that in the long term will improve the lives of South African children and reduce disability-adjusted life years (DALY).

Conflict of interest: none declared.

We declare that we have no financial or personal relationship(s) that may have inappropriately influenced us in writing this article.

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APPENDICES

- Research Ethics Committee approval

23 July 2019

For attention: Health Sciences Research Ethics Committee
Faculty of Health Sciences

Title of project:

SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM
DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA

Researcher:

Dr MJ Matlou

I have given input regarding the above mentioned project's protocol on the following aspects of the protocol, namely the study design, sample, measurement, measuring instrument and statistical analysis.

The input will be implemented under supervision of the study leader Dr DJ Griessel.

Yours faithfully

m. matlou



- Provincial Department of Health approval



20 January 2020

Dear Dr MJ Matlou

**ETHICS CLEARANCE: SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA
PRINCIPAL INVESTIGATOR: DR MASEFETSANE J MATLOU
DEPARTMENT: PAEDIATRICS AND CHILD HEALTH (BLOEMFONTEIN CAMPUS)**

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance and research can commence in the following province:

- Eastern Cape (EC 201911 007)

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za. Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours faithfully

DR SM LE GRANGE
CHAIRPERSON: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE

Health Sciences Research Ethics Committee
Office of the Dean: Health Sciences
NHREC 230408-011 / IRB 00011992 / IORG 0010096 / FWA00027947
T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za
Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa
www.ufs.ac.za



01 December 2020

Dear Dr MJ Matlou

ETHICS CLEARANCE: SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA
PRINCIPAL INVESTIGATOR: DR MASEFETSANE J MATLOU
DEPARTMENT: PAEDIATRICS AND CHILD HEALTH (BLOEMFONTEIN CAMPUS)

APPLICATION APPROVED

Please ensure that you read the whole document.

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance and research can commence in the following province

- Limpopo (4/2/2)

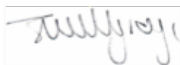
We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

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For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or [email](mailto:EthicsFHS@ufs.ac.za) EthicsFHS@ufs.ac.za Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours faithfully



.....
DR SM LE GRANGE
CHAIRPERSON: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE

20 January 2020

Dear Dr MJ Matlou

ETHICS CLEARANCE: SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA
PRINCIPAL INVESTIGATOR: DR MASEFETSANE J MATLOU
DEPARTMENT: PAEDIATRICS AND CHILD HEALTH (BLOEMFONTEIN CAMPUS)

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance and research can commence in the following province:

- North West (NW201911 004)

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za. Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours faithfully



DR SM LE GRANGE
CHAIRPERSON: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



20 January 2020

Dear Dr MJ Matlou

ETHICS CLEARANCE: SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA
PRINCIPAL INVESTIGATOR: DR MASEFETSANE J MATLOU
DEPARTMENT: PAEDIATRICS AND CHILD HEALTH (BLOEMFONTEIN CAMPUS)

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance and research can commence in the following province:

- Northern Cape (NC201911 002)

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za. Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours faithfully



.....
DR SM LE GRANGE
CHAIRPERSON: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



20 January 2020

Dear Dr MJ Matlou

ETHICS CLEARANCE: SCREENING, DIAGNOSIS AND MANAGEMENT OF AUTISM SPECTRUM DISORDERS AMONGST HEALTHCARE PRACTITIONERS IN SOUTH AFRICA
PRINCIPAL INVESTIGATOR: DR MASEFETSANE J MATLOU
DEPARTMENT: PAEDIATRICS AND CHILD HEALTH (BLOEMFONTEIN CAMPUS)

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance and research can commence in the following province:

- Western Cape (WC201911 013)


We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za. Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours faithfully



.....
DR SM LE GRANGE
CHAIRPERSON: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



The Chair: Health Sciences Research Ethics Committee
Dr SM Le Grange
For Attention: Mrs M Marais
Block D, Room 104,
Francois Retief Building
Po Box 339 (G40)
Nelson Mandela Drive
Faculty of Health Sciences
University of the Free State
Bloemfontein
9300

31 May 2019

Dear Dr SM Le Grange

Dr MJ Matlou (Student number: 2015088665)

Screening, diagnosis and management of autism spectrum disorders amongst healthcare practitioners in South Africa.

I, André Venter, hereby grant Judith Matlou permission to conduct the above mentioned research project. The research will be completed in accordance with myself as Head of Department of Paediatrics and Child Health and Dr David Griessel as supervisor of this study.

Yours faithfully



Prof A Venter

3/6/2019

Date

- Research protocol approved by HSREC



Health Sciences Research Ethics Committee

13-Nov-2020

Dear **Dr Masefetsane Matlou**

Ethics Clearance: **Screening, diagnosis and management of autism spectrum disorders amongst health care practitioners in South Africa**

Principal Investigator: **Dr Masefetsane Matlou**

Department: **Paediatrics and Child Health Department (Bloemfontein Campus)**

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is: **UFS-HSD2019/1336/2411**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. SM Le Grange
Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee

Office of the Dean : Health Sciences

T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za

IRB 00011992; REC 230408-011; IORG 0010096; FWA 00027947

Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa



Protocol

Screening, diagnosis, and management of autism spectrum disorders amongst healthcare practitioners in South Africa.

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6.	Methodology.....
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	• Study population
	• Sample
	• Measurement
	• Methodological and measurement errors
	• Pilot Study
7.	Analysis.....
8.	Time schedule.....
9.	Budget.....
	10. Ethical Aspects

11. References.....

12. Appendices.....

Title:

Screening, diagnosis, and management of autism spectrum disorders amongst healthcare practitioners in South Africa

Researchers:

Dr Matlou MJ MBBCh (Wits)
Paediatrics Registrar at University of the Free State

Supervisor:

Dr DJ Griessel MMed(Ped)
Department of Paediatrics and child health University of the Free State

Introduction and literature review

Autism spectrum disorder (ASD) is defined as a life-long neuro-developmental disorder that presents with difficulties in social communication, restricted interests, and repetitive behaviour.¹ Since first being described in the early nineteenth century there has been an explosion of research, interest, and debate about this disease entity. Africa has not contributed much to research of autism spectrum disorder and the lack of statistics is alarming. The true prevalence of ASD in Africa is unknown and up to date there have been no proper epidemiological studies of ASD in sub Saharan Africa. Furthermore, there are very few studies describing the presentation, features, and management of autism in developing countries.² Although many international guidelines are available little is known on what actually happens in clinical practice.

Developmental surveillance, screening and early recognition of autism spectrum disorder symptoms allow for the benefits of early intervention and should be part of the routine developmental assessment of every child.^{3,4} Previous studies examining the age of presentation with developmental delays, including autism, reflects disparities between socio-economic class and availability of resources with those living on the lower margin of society, being diagnosed later.^{5,6} It is assumed that individuals with ASD in South Africa will follow the same trend but there has been no evaluation of current screening practices in either the public or private sector. The current recommendation by the American Academy of Paediatrics is to screen all

children at 18 and 24 months.⁷ Various autism specific screening tools are available although not all of them are equally sensitive or user friendly.^{3, 8} Validation of screening tools such as the Social communication questionnaire and Modified Checklist for Autism in Toddlers (M-CHAT) for the South African population is under way but results are yet to be published.⁹

Following the release of the DSM 5 with its revised diagnostic criteria for autism spectrum disorder there has been renewed interest in the diagnosis and impact thereof on the prevalence of autism.^{10,11} The recommended practice parameter by the American Academy of child and adolescent psychiatry uses the DSM 5 criteria as the clinical standard to diagnose individuals with autism spectrum disorder.³ Although the criteria are clear it is advised that only practitioners with relevant training and experience in the field should make the diagnosis of autism.⁴ Informed clinical judgement remains the cornerstone of diagnosing autism but various diagnostic instruments are available to improve diagnostic accuracy, especially in doubtful cases. As part of the diagnostic process children with ASD should be referred for multidisciplinary assessment. This includes a medical assessment, genetic and/or neurologic consultation, as well as psychological and communication assessment. Evaluations by occupational and physiotherapy are important to assess for sensory and motor difficulties. Coordinated multidisciplinary assessment ensures that all aspects are fully evaluated and included in the treatment plan.^{3, 12}

The management of autism spectrum disorder is challenging and an individualized treatment plan catering for the patient and the family alike are of utmost importance.¹² Research on comprehensive treatment models is flawed by methodological errors but some behavioural interventions are supported by evidence as cited in Fuentes-Biggi et al (2005).¹³ Interventions can be divided into medical, educational, behavioural, family and complimentary or alternative treatments.³ Research on different treatment modalities in the South African context is sparse but a small study done in the Western Cape showed that in keeping with international data our autism population are frequently using prescription and over the counter drugs.¹⁴ The management of ASD in South Africa is further undermined by the lack of specialized education.¹⁵

As most children with red flags for ASD will be seen by a healthcare practitioner (healthcare practitioner refers to only medical doctor in the study) at some stage in the diagnostic process it is imperative to broaden our understanding of how healthcare practitioners in South Africa screen for, diagnose and manage ASD.

Research question/aims/objectives

- Research question:

How do healthcare practitioners in South Africa screen for, diagnose and manage autism spectrum disorder?

- Research aim:

The aim of this study is to determine how healthcare practitioners in South Africa screen for, diagnose and manage autism spectrum disorder in their respective workplaces

- Research objectives:

The objectives of this study are:

- To determine and document screening practices for autism spectrum disorders by healthcare practitioners in South Africa:
- Calculate percentage of healthcare practitioners that routinely screen for autism
 - Document the age at which they screen patients for autism
 - List the tools that they use to screen for autism
- To document the diagnostic process used by healthcare practitioners when considering the diagnosis of autism spectrum disorder.
- To list the different methods used by healthcare practitioners to diagnose autism.
- To calculate the percentage of healthcare practitioners that uses an autism specific diagnostic tool to diagnose autism.
- To calculate the percentage of healthcare practitioners that use multidisciplinary input to diagnose autism.
 - To list special investigations done when assessing a child for ASD
- To document the management plan for autism spectrum disorders used by health-care practitioners in South Africa:
 - To list the referral pattern of children with autism
- To list the general management of patients with autism and to calculate which treatment modalities are most frequently prescribed.
- To compare practices relating to autism spectrum disorder between the healthcare practitioners in the private and state sector.

Concepts

Autism spectrum disorder:

Autism spectrum disorder (ASD) refers to a constellation of clinical signs that manifests early in life and persists through adulthood. The core features are impairments in social communication as well as repetitive behaviours and restricted interests. For this study, the term ASD refers to the criteria as described in the 5th edition of the Diagnostic and Statistical Manual of Mental disorders.^{1, 3}

Methodology

- Study design

A Cross sectional descriptive analytical study design will be used.

- Study population

All healthcare practitioners registered with the Health Professions Council of South Africa working in paediatric departments in South Africa. Questionnaires will be sent to the health care practitioners via email using the existing departmental mailing lists and site visit. We are aiming for a minimum of 90 healthcare practitioners.

Inclusion criteria:

- Valid registration as a healthcare practitioners with the HPCSA (Health Professions Council of South Africa)
- In current healthcare practice in the department of paediatrics in statehealth facilities

Exclusion criteria:

- Practice in a sub-specialty where it is never required to assess for ASD e.g., neonatology, intensive care
 - Any persons without a valid registration as a healthcare practitioner
- Sample size and study period

All the completed questionnaires will be included in the study sample.

Data will be collected over a period of 4 months from 30/November/2019-28/ March/2020

Measurement

Questionnaire

A questionnaire has been designed after an in-depth literature study. See annexure A for an example of the questionnaire which the researchers plan to use to obtain the information needed to meet the objectives of this study.

Measurement

After consent has been granted by the Ethics Committee and the protocol committee the researcher will obtain a list of registered healthcare practitioners via methods stipulated in under study population. Questionnaires will be distributed electronically to all eligible participants. The questionnaire will be distributed using electronic means. This process can be split into 2 sections, acquisition, and executions.

- Acquisition

Emails will be sent to healthcare practitioners via their departmental mailing lists, who then have access to a website.

A Website will be developed to function as a conduit through which the questionnaire can be accessed

- Execution

Once acquired, a healthcare practitioner can choose from a host of options to answer the questionnaire. Available channels:

-Facebook messenger

-Telegram app

-Web app

-WhatsApp

Completed questionnaires can be submitted electronically after which data will be captured on a google spread sheet for statistical analysis. Communication with departmental heads as well site visit to raise awareness and win buy in of health care professional to participate in the study.

Measurement and Methodology errors?

The limitations of this study will be that of any cross-sectional descriptive research method. Because a self-completed questionnaire will be used data may not be representative as not all healthcare practitioners are equally likely to respond.

Misinterpretation of questions and reporting errors by respondents will decrease the quality of data obtained.

Pilot study

A Pilot study will be conducted. Five local healthcare practitioners in the five districts in Free State will be asked to complete the questionnaire electronically to evaluate the quality and effectiveness of the questions asked.

The Chatbot digital method would allow basic comparisons between each channel. From the website (landing page) it will be able to determine by click through which of the methods the healthcare practitioner finds to be the most appealing. Inferences could then be made by comparing the click through rate to the completion rate of the questionnaire across each channel. The digital solution is monitored for uptime and should there be any problem the team would be notified and would be able to remedy it.

Analysis

Descriptive statistics namely means and standard deviations or medians and percentiles for numerical data and frequency and percentages for categorical data will be calculated per group. 95% Confidence intervals will be calculated for the main outcome. The Biostatistics department of the University of the Free State do the analysis.

Data will be collected via the means provided on questionnaire distribution, this data will be collected in real time and presented in the form of google sheet with live data being added as questions are answered. This means that should the healthcare practitioner abandon the questionnaire and fail to complete it to the end whatever data they had entered so far would be captured and retained. The google sheet would be the location for raw data that can then be exported, manipulated, and analysed

Budget

This study will be funded by the Department of Paediatrics at the University of Free State Research funds, the principal investigator, and the main supervisor.

ITEM	COST (R)
Web based questionnaire	5000.00
Communication	1000.00
Transport	3000.00
Printing and copying	150.00
TOTAL	9150.00

Ethical aspects

The protocol will be presented to the Health Sciences Research Ethics Committee, University of the Free State. Completion and returning of the questionnaire will be voluntary and subject to the terms and conditions as stipulated in the information document.

To ensure confidentiality correspondents can return the questionnaire anonymously by using the website and Chatbot Company will keep the information confidential. See annexure B.

All responses will be confidential and identifying information such as your name, email address or IP address will not be collected.

All data is stored in a password protected electronic format on a research laptop accessible only to the principal investigator and the supervisor. The data will be stored for 5 years and results used for scholarly purposes only after will it be permanently deleted.

There are no anticipated risks for the study population in this project. Participation is voluntarily and anonymous. Participants will not receive any remuneration.

This project does not hold direct benefit to the participants; however, it does contribute to knowledge and management in the field.

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15. Bateman, C. (2013). Autism-mitigating a global epidemic. *SAMJ: South African Medical Journal*, 103(5), 276-278.

Topic: Screening, diagnosis, and management of Autism spectrum disorder by health care professionals in South Africa.

Consent:

NB: Please note that if you choose to complete and return this questionnaire, you are providing implicit consent to participate in the study. Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw from participating at any time, you will not be penalized. There will be no remuneration or reward upon completion of the questionnaire

Questionnaire: General/demographic:

1. What is your highest qualification obtained?
2. Year obtained:
3. Where was the qualification obtained:
4. Where do you practice?
 - a. Private
 - b. Government
 - c. Both
5. In which town/city do you practice?
6. Have you attended any courses/workshops on autism spectrum disorder? (circle what applies)
 - a. Yes:
 - b. NoIf yes, when was the last course you attended?
7. Are you a PANDA (Paediatric Neurology and development association member)?
8. How often do you encounter suspected/confirmed ASD in your practice?
 - a. Daily
 - b. Weekly
 - c. Monthly
 - d. Never
9. How many children have you diagnosed with autism in the last year?
 - a. None
 - b. <10
 - c. 10-20
 - d. >20
10. On a scale of 1 to 10 how confident are you in the diagnosis and management of ASD? (1 being having no confidence and 10 being extremely confident)
11. Do you feel that you had adequate pre-graduate training in ASD:
 - a. Yes
 - b. No
12. Do you feel that you had adequate post – graduate training in ASD:
 - a. Yes
 - b. No

Screening:

1. Do you routinely screen for autism?
 - a. Yes
 - b. no
2. If you do not routinely screen for autism please indicate if one or more of the following statements apply:
 - a. There are no adequate screening tools for preschoolers

- b. A great deal of training is needed to administer screening correctly
- c. Screening takes a lot of time
- d. Tools that incorporate information from the parents are not valid

3. When do you screen for autism? (circle all that apply)

- a. at every well child visit
- b. at 9 months
- c. at 18 months
- d. at 24 months
- e. at school age
- f. only when parents/other health care worker are concerned

4. What do you use to screen for ASD:

	Never	Sometimes	Always
History of general developmental milestones			
General developmental screening tool			
Autism specific tool			
Checklist for autism in toddlers (CHAT)			
Early screening for autistic traits (ESAT)			
Modified checklist for autism in toddlers (M-CHAT)			
Infant toddler checklist			
Quantitative checklist for autism in toddlers (Q-CHAT)			
Screening tool for autism in children aged 2 years (STAT)			
Social communication questionnaire (SCQ)			
Other:			

Diagnosis:

1. Which of the following do you use to make the diagnosis of ASD?

	Never	Sometimes	Always
Parental concern			
Developmental history			

Medical examination			
Unstructured behavioural observation			
DSM V			
ICD10			
childhood autism rating scale (CARS)			
The autism diagnostic interview-revised (ADI-R)			
The autism diagnostic observation schedule (ADOS)			
The diagnostic interview for social and communication disorders (DISCO)			
The developmental, dimensional, and diagnostic interview (3DI)			
Other:			

2. How long does it usually take you to make the diagnosis of ASD?

- a. less than 30 minutes
- b. 30 minutes to one hour
- c. more than one hour

3. Which of the following investigations do you do when evaluating a child with possible ASD?

	Never	Sometimes	Always
CT/MRI			
EEG			
Karyotype			
Micro array			
Fragile X			
Hearing screen			
Wood's lamp evaluation			

Testing of cognitive ability and adaptive function			
--	--	--	--

5. Do you refer a child with suspected ASD for **assessment** to?

	Never	Sometimes	Always
Occupational therapist			
Speech therapist			
Physiotherapist			
Psychologist			
Psychiatrist			
Education service			
Neurologist/developmental specialist			

Other

6. What information do you give to the caregiver/family once you have made the diagnosis of ASD? (circle all that apply)

- a. Information booklet or brochure
- b. Book references/ recommendations
- c. Recommended internet sites
- d. Support groups in area

Management

1. Do you refer a child with suspected ASD for **treatment** to?

	Never	Sometimes	Always
Occupational therapist			
Speech therapist			
Physio therapist			
Psychologist			
Psychiatrist			
Education service			
Neurologist/developmental specialist			

2. Which of the following interventions do you recommend?

	Never	Sometimes	Always
Early Intensive Behavioral Intervention (Applied Behavioral Analysis)			

Communication intervention			
Pragmatic language skills training			
Early start Denver Model intervention			
TEACCH (treatment and education of autism and related communication handicapped children program)			
Cognitive behavioural therapy			
Developmental individual difference relationship based/floor time			
Social communication emotional regulation and transactional support			
Play and language for autistic youths			

3. What percentage of your patients with ASD is on medication?

- a. <25%
- b. 25 – 49%
- c. 50 – 75%
- d. >75%

4. How often do you prescribe any of the following for your ASD patients?

	never	seldom	often	always
Clonidine				
Haloperidol				
Olanzapine				
Risperidone				
Valproic acid				
Lamotrigine				
Levitiracetam				
Atomoxetine				
Citalopram				
Fluoxetine				
Clomipramine				
Methylphenidate				

5. Which of the following alternative/complimentary treatments do your patients use? (circle all that apply)

- a. Multi vitamin supplements
- b. Omega acids supplements
- c. Gluten free, casein free diet
- d. Hyperbaric oxygen therapy
- e. Miracle mineral solution
- f. Gut therapy
- g. Oral human immunoglobulin
- h. Vitamin B 6
- i. Magnesium
- j. Chelation therapy
- k. Other : please specify

6. Which of the following alternative/complimentary treatments do you recommend?

- a. Multi vitamin supplements
- b. Omega acids supplements
- c. Gluten free, casein free diet
- d. Hyperbaric oxygen therapy
- e. Miracle mineral solution
- f. Gut therapy
- g. Oral human immunoglobulin
- h. Vitamin B 6
- i. Magnesium
- j. Chelation therapy
- k. Other: please specify

7. In your experience, what are the most common barriers to diagnosing and managing ASD: (circle all that apply)

- a. Time
- b. Experience
- c. Lack of specialists in the field
- d. Lack or referral centre
- e. Lack of educational resources
- f. Lack of therapists (speech/OT/Physio)
- g. Lack of family support
- h. Parental denial

- **Copy of the questionnaire completed electronically**

See ChatBot link attached for electronic questionnaire <https://asdquestions.co.za/chat>

General/demographic:

Which Province do you work in? Option to choose amongst the provinces

- Which year did you complete your medical degree?Free text

- What is your highest qualification?
- Medical degree
- Diploma
- Specialisation
- Where do you practice?
- Government
- Private
- Both
- I do not practice
- Which town/city do you

practice in?Free text

- When last did you attend a course/workshop on Autism Spectrum Disorders?
 - 1 year
 - <1 year
 - Never
- How often do you encounter ASD in clinical practice?
 - Weekly
 - Monthly
 - Yearly
 - Never
- How many children have you diagnosed with autism in the last year?
 - a. None
 - b. 1-5
 - c. 6-10
 - d. >11
- How confident are you with the diagnosis and management of ASD?
 - Very confident
 - Moderately confident
 - Not confident
 - Do you feel that you had adequate undergraduate training in ASD?
 - Yes
 - No
 - What about postgraduate training, Was your postgraduate training in ASD adequate?

Screening

- Do you routinely screen for ASD?
 - Yes
 - No
- Do you screen for ASD every visit?
 - Yes
 - No
- Would you say that too much training is needed to screen properly?
 - Yes
 - No
- Would you say that screening takes too long?
 - Yes
 - No
- Would you say you feel the tools to collect collateral information from parents are invalid?
 - Yes
 - No
- Would you say that there are no good screening tools for preschoolers?
 - There are good tools
 - No good tools
 - I have never used one
- There are many tools for screening Autism like the Checklist for autism in toddlers or early screening for autistic traits tool. do you make use of any of them?
 - Yes
 - No

Let us take a closer look at the tools you use for screening. Question 8 – 15 (excluding question 9) options are:

- Always
 - Sometimes
 - Never
 - I do not know this tool
-
- Do you use the history of the child's milestone development to screen?
 - Do you do a general development screen as a way of checking for autism?
 - Always
 - Sometimes
 - Never
 - Let us talk about Autism specific tools.

- How often do you use the CHAT - Checklist for Autism in Toddlers?
- How often do you use the ESAT - Early screening for Autistic traits?
- How often do you use the M-CHAT - Modified checklist for Autism in toddlers?
- How often do you use the infant toddler checklist?
- How often do you use the Q-CHAT - Quantitative checklist for Autism in toddlers?
- How often do you use the STAT - Screening tool for autism in children aged 2 years?
- How often do you use the SCQ - Social communication questionnaire?

Diagnosis

Have you ever made the diagnosis of an ASD?

Yes or No

- If response is NO the ChatBot will skip Question 1-20

How long does it usually take you to make the diagnosis of ASD?

- > 60min
- 30-60min
- <30min

Does parental concern ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does developmental history ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does medical examination ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does unstructured behaviour observation ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does the DSM 5 ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does ICD10 ever play a role in your diagnosis?

- Always
- Sometimes

- Never

Does the Childhood Autism ratings scale (CARS) ever play a role in your diagnosis?

Options below apply for Question 8-11

- Always
- Sometimes
- Never
- I do not know this tool

Does the revised autism diagnostic interview (ADI-R) ever play a role in your diagnosis?

Does the diagnostic interview for social and communication disorders (DISCO) ever play a role in your diagnosis?

Does The developmental, dimensional, and diagnostic interview (3DI) ever play a role in your diagnosis?

Do you ever use investigations when evaluating a child with possible ASD? If response is NO the ChatBot will skip Question 13-20

If response is YES, the options to Question 13-20 are:

- Always
- Sometimes
- Never

Do you use CT/MRI as an investigation for ASD?

Do you use EEG as an investigation for ASD?

Do you use Karyotyping as an investigation for ASD?

Do you use a micro-array as an investigation for ASD?

Do you routinely test for Fragile X in Male children as part of ASD investigation?

Do you use a Hearing Screen as an investigation for ASD?

Do you use a Wood's lamp evaluation as an investigation for ASD?

Do you use the testing of cognitive ability and adaptive function as an investigation for ASD?

- Have you ever made the diagnosis of an ASD?

Yes or No

- If response is NO the ChatBot will skip Question 1-20

How long does it usually take you to make the diagnosis of ASD?

- > 60min
- 30-60min
- <30min

Does parental concern ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does developmental history ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does medical examination ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does unstructured behaviour observation ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does the DSM 5 ever play a role in your diagnosis?

- Always
- Sometimes

- Never

Does ICD10 ever play a role in your diagnosis?

- Always
- Sometimes
- Never

Does the Childhood Autism ratings scale (CARS) ever play a role in your diagnosis?

Options below apply for Question 8-11

- Always
- Sometimes
- Never
- I do not know this tool

Does the revised autism diagnostic interview (ADI-R) ever play a role in your diagnosis?

• Does the diagnostic interview for social and communication disorders (DISCO) ever play a role in your diagnosis?

• Does The developmental, dimensional, and diagnostic interview (3DI) ever play arole in your diagnosis?

• Do you ever use investigations when evaluating a child with possible ASD? If response is NO the ChatBot will skip Question 13-20

If response is YES, the options to Question 13-20 are:

- Always
- Sometimes
- Never

Do you use CT/MRI as an investigation for ASD?

Do you use EEG as an investigation for ASD?

Do you use Karyotyping as an investigation for ASD?

Do you use a micro-array as an investigation for ASD?

Do you routinely test for Fragile X in Male children as part of ASD investigation?

Do you use a Hearing Screen as an investigation for ASD?

Do you use a Wood's lamp evaluation as an investigation for ASD?

Do you use the testing of cognitive ability and adaptive function as an investi-gation for ASD?

Have you ever referred a child with suspected ASD to another Doctor or AlliedHealthcare worker?

- Yes
- No

If response is NO the ChatBot will skip Question 22-27

If response is YES, the options to Question 22-27 are:

- Always
- Sometimes
- Never

Please help us to figure out who you refer to.

Do you ever refer to anOccupational Therapist?

Do you ever refer to speech therapy?

- Do you ever refer to a Psychologist?
- Do you ever refer to a Psychiatrist?
- Do you ever refer to an Educational Service?
- Do you ever refer to a Neurologist/Developmental Specialist?
- Do you give the caregiver or family any information once you have madean

ASD diagnosis?

- Yes
- No
- Do you give the caregiver or family any information booklets or brochures once you have made an ASD diagnosis?
- Yes
- No
- Do you give the caregiver or family any book references/recommendations after you have made an ASD diagnosis?
- Yes
- No
- Do you recommend any internet sites to the caregiver or family after you have made an ASD diagnosis?
- Yes
- No
- Do you recommend any support groups in the area to the caregiver or family after you have made an ASD diagnosis?
- Yes
- No

Management

Have you ever managed a child with a **Suspected or Proven Autism Spectrum Disorder**?

- Yes
- No

If response is NO the ChatBot will skip Question 2-41

If response is YES, the options to Question 2-8 are:

- Always
- Sometimes
- Never
- Do you refer a child with suspected ASD for treatment to an occupational therapist?
- Do you refer a child with suspected ASD for treatment to a speech therapist?
- Do you refer a child with suspected ASD for treatment to a physio therapist?
- Do you refer a child with suspected ASD for treatment to a psychologist?
- Do you refer a child with suspected ASD for treatment to a psychiatrist?
- Do you refer a child with suspected ASD for treatment to an education service?

Do you refer a child with suspected ASD for treatment to a neurologist/developmental specialist?

How often do you recommend early Intensive behavioral intervention (Applied Behavioral Analysis)? Options for Question 9-17 are:

- Always
- Sometimes
- Never
- I do not know this intervention
- How often do you recommend Communication intervention?
- How often do you recommend Pragmatic language skills training?
- How often do you recommend early start Denver intervention or another natural developmental intervention?
- How often do you recommend TEACCH (treatment and education of autism and related communication handicapped children program)?
- How often do you recommend Cognitive behavioural therapy?
- How often do you recommend Developmental individual difference relationship based/floor time?

- How often do you recommend Social communication emotional regulation and transactional support?
- How often do you recommend play as an intervention?
- You are doing great so far, what percentage of your patients with ASD are on medication?
 - a. <25%
 - b. 25-49%
 - c. 50-75%
 - d. >75%

Options for Question 19-30 are:

- Always
- Often
- Seldom
- Never
- How often do you prescribe Clonidine for your ASD patients?
- How often do you prescribe Haloperidol for your ASD patients?
- How often do you prescribe Olanzapine for your ASD patients?
- How often do you prescribe Risperidone for your ASD patients?
- How often do you prescribe Sodium Valproate for your ASD patients?
- How often do you prescribe Lamotrigine for your ASD patients?
- How often do you prescribe Levetiracetam for your ASD patients?
- How often do you prescribe Atomoxetine for your ASD

patients?

- How often do you prescribe Citalopram for your ASD patients?
- How often do you prescribe Fluoxetine for your ASD patients?
- How often do you prescribe Clomipramine for your ASD

patients?

- How often do you prescribe Methlyphenidate for your ASD

patients?

- Do your patients use Multi vitamin supplements as an alternative/complementary treatment?

Options for Question 31-41 are:

- Yes
- No

31 Do your patients use Omega acids supplements as an alternative/complementary treatment?

32 Do your patients use Gluten free, casein free diet as an alternative/complementary treatment?

33 Do your patients use Hyperbaric oxygen therapy as an alternative/complementary treatment?

34 Do your patients use Miracle mineral solution as an alternative/complementary treatment?

35 Do your patients use Gut therapy as an alternative/complementary treatment?

36 Do your patients use Oral human immunoglobulin as an alternative/complementary treatment?

37 Do your patients use Vitamin B 6 as an alternative/complementary treatment?

38 Do your patients use Magnesium as an alternative/complementary treatment?

39 Do your patients use Chelation therapy as an alternative/complementary treatment?

40 Do your patients use any other alternative/complementary treatments?

41 Please list the names of any alternative/complementary treatments you have seen your patients use?

Free text

42 Let us talk about barriers to managing and diagnosing Autism Spectrum Disorders. In your experience is TIME a barrier to diagnosing/managing ASD? Options for Question 43-51 are:

- Yes
- No

43 Do you think lack of experience is a barrier to diagnosing/managing ASD?

44 Do you think a lack of specialists in the field is a barrier to diagnosing/managing ASD?

45 Do you think a lack of Referral Centres is a barrier to diagnosing/managing ASD?

46 Do you think a lack of educational resources is a barrier to diagnosing/managing ASD?

47 What about a lack of therapists (Speech/Occupational/Physio), do you think that may be a barrier to diagnosing/managing ASD?

48 Is the lack of family support a barrier to diagnosing/managing ASD?

49 Lastly, do you think parental denial is a barrier to diagnosing/managing ASD?

50 You have done incredibly well, thank you for your time and participating in this novel method of conducting a questionnaire.

- **Dekode IT Company indemnity letter**



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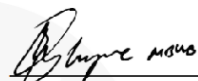
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Dr EK Okyere-Dede
Co-founder Dekode (Pty) Ltd

Signed by and on behalf of client

Date



Signed by and on behalf of Dekode

17 September 2019

Date

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Submitted manuscripts that are not in the correct format specified in these guidelines will be returned to the author(s) for correction prior to being sent for review, which will delay publication.

General:

- Manuscripts must be written in UK English (this includes spelling).
- The manuscript must be in Microsoft Word or RTF document format. Text must be 1.5 line spaced, in 12-point Times New Roman font, and contain no unnecessary formatting (such as text in boxes). Pages and lines should be numbered consecutively.
- Please make your article concise, even if it is below the word limit.
- Qualifications, **full** affiliation (department, school/faculty, institution, city, country) and contact details of ALL authors must be provided in the manuscript and in the online submission process.
- Abbreviations should be spelt out when first used and thereafter used consistently, e.g. 'intravenous (IV)' or 'Department of Health (DoH)'.

- Scientific measurements must be expressed in SI units except: blood pressure (mmHg) and haemoglobin (g/dL).
 - Litres is denoted with an uppercase L e.g. 'mL' for millilitres).
 - Units should be preceded by a space (except for % and °C), e.g. '40 kg' and '20 cm' but '50%' and '19°C'.
- Please be sure to insert proper symbols e.g. μ not u for micro, α not a for alpha, β not B for beta, etc.
 - Numbers should be written as grouped per thousand-units, i.e. 4 000, 22 160.
 - Quotes should be placed in single quotation marks: i.e. The respondent stated: '...'
 - Round brackets (parentheses) should be used, as opposed to square brackets, which are reserved for denoting concentrations or insertions in direct quotes.

If you wish material to be in a box, simply indicate this in the text. You may use the table format –this is the *only* exception. Please DO NOT use fill, format lines and so on.

SAJCH is a Journal on child health, therefore for articles involving genetics, it is the responsibility of authors to apply the following:

- Please ensure that all genes are in italics, and proteins/enzymes/hormones are not.
- Ensure that all genes are presented in the correct case e.g. TP53 not Tp53.
- ** NB: Copyeditors cannot be expected to pick up and correct errors wrt the above, although they will raise queries where concerned.
- Define all genes, proteins and related shorthand terms at first mention, e.g. '188del11' can be glossed as 'an 11 bp deletion at nucleotide 188.'
- Use the latest approved gene or protein symbol as appropriate:
 - Human Gene Mapping Workshop (HGMW): genetic notations and symbols
 - HUGO Gene Nomenclature Committee: approved gene symbols and nomenclature
 - OMIM: Online Mendelian Inheritance in Man (MIM) nomenclature and instructions
 - Bennet et al. Standardized human pedigree nomenclature: Update and assessment of the recommendations of the National Society of Genetic Counselors. *J Genet Counsel* 2008;17:424-433: standard human pedigree nomenclature.

Preparation notes by article type

Research

Guideline word limit: 3 000 words (excluding abstract and bibliography)

Research articles describe the background, methods, results and conclusions of an original research study. The article should contain the following sections: introduction, methods, results, discussion and conclusion, and should include a structured abstract (see below). The introduction should be concise – no more than three paragraphs – on the background to the research question, and must include references to other relevant published studies that clearly lay out the rationale for conducting the study. Some common reasons for conducting a study are: to fill a gap in the literature, a logical extension of previous work, or to answer an important clinical question. If other papers related to the same study have been published previously, please make sure to refer to them specifically. Describe the study methods in as much detail as possible so that others would be able to replicate the study should they need to. Where appropriate, sample size calculations should be included to demonstrate that the study is not underpowered. Results should describe the study sample as well as the findings from the study itself, but all

interpretation of findings must be kept in the discussion section, which should consider primary outcomes first before any secondary or tertiary findings or post-hoc analyses. The conclusion should briefly summarise the main message of the paper and provide recommendations for further study.

- May include up to 6 illustrations or tables.
- A max of 20 - 25 references

Structured abstract

This should be no more than 250 words, with the following recommended headings:

Background: why the study is being done and how it relates to other published work.

Objectives: what the study intends to find out

Methods: must include study design, number of participants, description of the intervention, primary and secondary outcomes, any specific analyses that were done on the data.

Results: first sentence must be brief population and sample description; outline the results according to the methods described. Primary outcomes must be described first, even if they are not the most significant findings of the study.

Conclusion: must be supported by the data, include recommendations for further study/actions.

- Please ensure that the structured abstract is complete, accurate and clear and has been approved by all authors. It should be able to be intelligible to the reader without referral to the main body of the article.
- Do not include any references in the abstracts.

Here is an example of a good abstract.

Scientific letters/short reports

These include case reports, side effects of drugs and brief or negative research findings.

Guideline word limit: 1500 words

- Abstract: unstructured, of about 100-150 words
- May include only one illustration or table
- A maximum of 6 references

Editorials

Guideline word limit: 1 000 words

These opinion or comment articles are usually commissioned but we are happy to consider and peer review unsolicited editorials. Editorials should be accessible and interesting to readers without specialist knowledge of the subject under discussion and should have an element of topicality (why is a comment on this issue relevant now?) There should be a clear message to the piece, supported by evidence.

Please make clear the type of evidence that supports each key statement, e.g.:

- expert opinion
- personal clinical experience
- observational studies
- trials
- systematic reviews.

Review articles

Review articles should always be discussed with the Editor prior to submission.

Guideline word limit: 4 000 words

These are welcome, but should be either commissioned or discussed with the Editor before submission. A review article should provide a clear, up-to-date account of the topic and be aimed at non-specialist hospital doctors and general practitioners. They should be aligned to practice in South and/or sub-Saharan Africa and not a precis of reviews published in the international literature

Please ensure that your article includes:

- Abstract: unstructured, of about 100-150 words, explaining the review and why it is important
- Methods: Outline the sources and selection methods, including search strategy and keywords used for identifying references from online bibliographic databases. Discuss the quality of evidence.
- When writing: clarify the evidence you used for key statements and the strength of the evidence. Do not present statements or opinions without such evidence, or if you have to, say that there is little or no evidence and that this is opinion. Avoid specialist jargon and abbreviations, and provide advice specific to southern Africa.
- Personal details: Please supply your qualifications, position and affiliations and MP number (used for CPD points); address, telephone number and fax number, and your e-mail address; and a short personal profile (50 words) and a few words about your current fields of interest.

Correspondence (Letters to the Editor)

Guideline word limit: 400 words

Letters to the editor should relate either to a paper or article published by the SAJCH or to a topical issue of particular relevance to the journal's readership

Do not: use separate columns for *n* and %:

Rather:

Combine into one column, *n* (%):

Do not: have overlapping categories, e.g.:

Rather:

Use <> symbols or numbers that don't overlap:

References

NB: Only complete, correctly formatted reference lists in Vancouver style will be accepted. If reference manager software is used, the reference list and citations in text are to be unformatted to plain text before submitting..

- Authors must verify references from original sources.
- Citations should be inserted in the text as superscript numbers between square brackets, e.g. These regulations are endorsed by the World Health Organization,^[2] and others.^[3,4-6]
- All references should be listed at the end of the article in numerical order of appearance in the Vancouver style (not alphabetical order).
- Approved abbreviations of journal titles must be used; see the List of Journals in Index Medicus.
- Names and initials of all authors should be given; if there are more than six authors, the first three names should be given followed by et al.
 - Volume and issue numbers should be given.
 - First and last page, in full, should be given e.g.: 1215-1217 **not** 1215-17.
 - Wherever possible, references must be accompanied by a digital object identifier (DOI) link. Authors are encouraged to use the DOI lookup service offered by CrossRef:
- On the Crossref homepage, paste the article title into the 'Metadata search' box.
 - Look for the correct, matching article in the list of results.
 - Click Actions > Cite
 - Alongside 'url =' copy the URL between { }.
 - Provide as follows, e.g.: <https://doi.org/10.7196/07294.937.98x>

Some examples:

- *Journal references:* Price NC, Jacobs NN, Roberts DA, et al. Importance of asking about glaucoma. *Stat Med* 1998;289(1):350-355. <http://dx.doi.org/10.1000/hgjr.182>
- *Book references:* Jeffcoate N. Principles of Gynaecology. 4th ed. London: Butterworth, 1975:96-101.
- *Chapter/section in a book:* Weinstein L, Swartz MN. Pathogenic Properties of Invading Microorganisms. In: Sodeman WA, Sodeman WA, eds. Pathologic Physiology: Mechanisms of Disease. Philadelphia: WB Saunders, 1974:457-472.
- *Internet references:* World Health Organization. The World Health Report 2002 - Reducing Risks, Promoting Healthy Life. Geneva: WHO, 2002. <http://www.who.int/whr/2002> (accessed 16 January 2010).
 - Legal references
 - Government Gazettes:

National Department of Health, South Africa. National Policy for Health Act, 1990 (Act No. 116 of 1990). Free primary health care services. Government Gazette No. 17507:1514. 1996.

In this example, 17507 is the Gazette Number. This is followed by :1514 - this is the notice number in this Gazette.

- Provincial Gazettes:

Gauteng Province, South Africa; Department of Agriculture, Conservation, Environment and Land Affairs. Publication of the Gauteng health care waste management draft regulations. Gauteng Provincial Gazette No. 373:3003, 2003.

- Acts:

South Africa. National Health Act No. 61 of 2003.

- Regulations to an Act:

South Africa. National Health Act of 2003. Regulations: Rendering of clinical forensic medicine services. Government Gazette No. 35099, 2012. (Published under Government Notice R176).

- Bills:

South Africa. Traditional Health Practitioners Bill, No. B66B-2003, 2006.

- Green/white papers:

South Africa. Department of Health Green Paper: National Health Insurance in South Africa. 2011.

- Case law:

Rex v Jopp and Another 1949 (4) SA 11 (N)

Rex v Jopp and Another: Name of the parties concerned 1949: Date of decision (or when the case was heard) (4): Volume number

SA: SA Law Reports

11: Page or section number

(N): In this case Natal - where the case was heard. Similarly, (C) would indicate Cape, (G) Gauteng, and so on.

NOTE: no . after the v

- *Other references (e.g. reports) should follow the same format: Author(s). Title. Publisher place: Publisher name, year; pages.*
- Cited manuscripts that have been accepted but not yet published can be included as references followed by '(in press)'.
- Unpublished observations and personal communications in the text must **not** appear in the reference list. The full name of the source person must be provided for personal communications e.g. '...(Prof. Michael Jones, personal communication)'.

From submission to acceptance

Submission and peer-review

To submit an article:

- Please ensure that you have prepared your manuscript in line with the *SAJCH* requirements.

- All submissions should be submitted via Editorial Manager
- The following are required for your submission to be complete:
- Anonymous manuscript (unless otherwise stated)
- Author Agreement form [forthcoming]
- Manuscript
- Any supplementary files: figures, datasets, patient consent form, permissions for published images, etc.
- Once the submission has been successfully processed on Editorial Manager, it

will undergo a technical check by the Editorial Office before it will be assigned to an editor who will handle the review process. If the author guidelines have not been appropriately followed, the manuscript may be sent back to the author for correcting.

Peer Review Process

All manuscripts are reviewed initially by the Editor-in-Chief and only those that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for external peer review. Each manuscript is reviewed by either one or two reviewers selected on the basis of their expertise in the field. A double blind review process is followed at SAJCH.

Authors are expected to receive feedback from reviewers and an editorial decision within approximately 6 weeks of submission. The time period of the entire review process may vary however depending upon the quality of the manuscript submitted, reviewers' responses and the time taken by the authors to submit the revised manuscript.

Manuscripts from review may be accepted, rejected or returned to the author for revision or resubmission for review. Authors will be directed to submit revised manuscripts within two months of receiving the editor's decision, and are requested to submit a point by point response to the reviewers' comments. Manuscripts which authors are requested to revise and resubmit will be sent for a second round of peer review, often to the original set of reviewers. All final decisions on a manuscript are at the Editor's discretion.

Production process

- An accepted manuscript is passed to a Managing Editor to assign to a copyeditor (CE).
- The CE copyedits in Word, working on house style, format, spelling/grammar/punctuation, sense and consistency, and preparation for typesetting.
- If the CE has an author queries, he/she will contact the corresponding author and send them the copyedited Word doc, asking them to solve the queries by means of track changes or comment boxes.
- The authors are typically asked to respond within 1-3 days. Any comments/changes must be clearly indicated e.g. by means of track changes. Do not work in the original manuscript - work in the copyedited file sent to you and make your changes clear.
- The CE will finalise the article and then it will be typeset.

Once typeset, the CE will send a PDF of the file to the authors to complete their finalcheck, while simultaneously sending to the 2nd-eye proofreader.

- The authors are typically asked to complete their final check and sign-off within 1-2 days. No major additional changes can be accommodated at this point.
- The CE implements the authors' and proofreader's mark-ups, finalises the file, and prepares it for the upcoming issue.

Changing contact details or authorship

Please notify the Editorial Department of any contact detail changes, including email, to facilitate communication.

Errata and retractions

Errata

Should you become aware of an error or inaccuracy in yours or someone else's contribution after it has been published, please inform us as soon as possible via an email to publishing@hmpg.co.za, including the following details:

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- Article title and authors
- Description of error and details of where it appears in the published article
- Full detail of proposed correction and rationale

We will investigate the issue and provide feedback. If appropriate, we will correct the web version immediately, and will publish an erratum in the next issue. All investigations will be conducted in accordance with guidelines provided by the Committee on Publication Ethics (COPE).

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- Article title and authors
- Description of reason for withdrawal/retraction.

We will make a decision on a case-by-case basis upon review by the editorial committee in line with international best practices. Comprehensive feedback will be communicated with the authors with regard to the process. In case where there is any suspected fraud or professional

misconduct, we will follow due process as recommended by the Committee on Publication Ethics (COPE), and in liaison with any relevant institutions.

When a retraction is published, it will be linked to the original article.

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