




Understanding the Difference Between Autism and the Autistic Spectrum: A Focus on the South African Context

Ntombophelo Sithole-Tetani^a

a. Psychology/Faculty of Law,
Humanities and Social Sciences, Walter
Sisulu University, Mthatha, South Africa.

Email: nsithole@wsu.ac.za

 10.46303/ressat.2024.62

Article Info

Received: July 23, 2024

Accepted: September 15, 2024

Published: October 21, 2024

How to cite

Sithole-Tetani, N. (2024). Understanding the Difference Between Autism and the Autistic Spectrum: A Focus on the South African Context. *Research in Social Sciences and Technology*, 9(3), 327-339. <https://doi.org/10.46303/ressat.2024.62>

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ABSTRACT

Autism is a group of severe developmental disorders with impairments beginning before 30 months of age and characterized by a qualitative disturbance of social development and of language for communication, a stereotyped behaviour, and a lack of a broad set of interests. The expression of autism varies from one individual to the next. It is a communicative disorder and is not due to poor reception. The researchers drew their literature from reputable journal articles, book chapters from established publishers, and informal community conversations amid the researchers' experiential intuition. Currently, South African children with autism spectrum disorder (ASD) lack government support structures and rely primarily on families for assistance with education and therapy. An additional challenge is that in some South African black communities, autism is not recognized as a disorder. A study exploring differences in the nature, application, experience, and examination of social awareness and understanding of selected educators about new terminology in their environment found that local black teachers had less exposure to autism knowledge, diagnosis, treatment, and prognosis in their communities, and little understanding, awareness, or acceptance of this condition. This article underscores the crucial role of social service professionals, such as psychologists, registered counsellors, social workers, etc, in these communities. Their presence and active involvement provide hope in these challenging times. It recommends that they conduct psychotherapeutic education, which could involve awareness campaigns and counselling about psychotherapeutic education. Their role would be to provide support, guidance, and education to the community members, helping them to build their resilience to fight the coronavirus.

KEYWORDS

Autism; Autistic spectrum; disorder; children; behavior; development.

INTRODUCTION

It is essential to clarify the discussion about the understanding between autism and Autistic Spectrum disorders (ASD) in South Africa. To do this, the researcher has started by recalling the historical perspectives of autism in South Africa and how it had to be edified in the minds of those it affects (Pillay et al., 2022). Then, conclude this article with a clear understanding of what the terms 'autism' and 'ASD' mean and the sensitivity that has to be attached to their usage, such that the emerging understanding of people with Autistic Spectrum Disorder is made at every level of human society (Van Schalkwyk et al., 2021). The discussion attempts to show a clear demarcation between medical and social understanding to facilitate and challenge South African society's attitude in their approach when discussing autism and ASD. In the conclusion, the researcher comments on the current medical understandings within a South African context. Aim to promote a societal language that does not further isolate the marginalized.

Currently, people with ASD and their caregivers are bogged down in terminology that is perceived as complex and challenging. The researcher begins by discussing the historical evolution of autism in South Africa to understand the current context of the terminology used within society (Pillay et al., 2022). In addition, it is important to know and understand the historical evolution of autism in our socio-cultural context before one becomes involved in diagnosing, caring for, and teaching people with ASD (Manono & Clasquin-Johnson, 2023). Not only are the myths that surround the origins and causes of autism important, but also, society's titling of people with ASD has an impact on the way that people with ASD are looked at, handled, and understood. There are many facets to naming autism. The literature has presented names such as Kanners, infantile autism, psychotic disorder, poor psychotic, autistic, developmental disorder, and a multiplicity of titles, including Asperger's syndrome (Pillay et al., 2022).

Background and Rationale

Autism refers to a complex lifelong developmental disorder that appears during the first three years of life and affects the ability to communicate and interact with others. It is defined and diagnosed according to the characteristics and behavior of people with autism. These characteristics and behaviors fall along a continuum of symptom severity (Francis., 2021). People with autism can present with profound impairment in a variety of areas, including receptive and expressive language, the ability to relate socially to others, sensory integration, self-help skills, and even aggressive or self-injurious behaviors. This is why autism has been referred to as autism spectrum disorder (Ekawati & Arofat, 2022).

Inopportunately, in the South African context, insoluble misconceptions have resulted in severe delays in these children receiving the educational and therapeutic services they require (Francis et al., 2021). Teachers in mainstream schools remain uninformed about autism and how to deal with and teach these children. The discipline is poorly dealt with, and ultimately, the progress of these children is affected. Therefore, their successful development within the educational system and independence outside school-going years are compromised because they do not receive the required intervention programs. The inadequate curricular provisions

and the implications for education have created a mostly barren educational desert for autistic children (Bhandari et al., 2020).

Defining Autism and the Autistic Spectrum

Autism Spectrum Disorder (ASD) is a complex developmental disorder that affects approximately 1 in every 54 children in the world. When diagnosing autism, there is no specific laboratory test, and it is currently based on behavioral symptoms and disabilities (Maenner, 2020). ASD is a disorder characterized by delays and disabilities in social, emotional, and communication skills, as well as repetitive behaviors. There is no known cure for autism; only the symptoms can be treated with therapy. The Autism Spectrum refers to a range of developmental conditions characterized by differences in communication, social skills, and behaviors. Many people with autism do not have an intellectual disability. Shaw (2020) states that the complexity of the autistic spectrum in the United States is well understood, so the spectrum is referred to as autism spectrum disorder. However, people with the following developmental conditions are often included within the autism spectrum disorder: Autism, Asperger Syndrome, and High Functioning Autism. These individuals often prefer the term autism spectrum, as opposed to autistic spectrum, as they feel that the term acknowledges their individuality and personhood (Hirota & King, 2023). It is important to recognize that autism is a developmental spectrum that can affect people of all ages, races, and geographical locations, especially as no two people who are affected by autism are the same (Hirota & King, 2023).

In South Africa, the term "Autistic Spectrum" is often used instead of "Autism Spectrum," and "Childhood Autism" is used instead of "Autism" (Tager-Flusberg, 2005, April 15). The medical fraternity sometimes uses these terms, and the two are different. However, the term "Autistic Spectrum" is preferred by the National Advisory Council for Autism in South Africa (NACSA) (Zeidan et al., 2022). It appears that at present, more children are being labeled as having "Pervasive Developmental Disorder" (PDD) not otherwise specified under the autistic spectrum rather than "Autistic Spectrum Disorder." The term autism was introduced in the early 1980s as a clinical diagnosis based on the criteria of the "Diagnostic and Statistical Manual of Mental Disorders (DSM) (Christensen et al., 2016, April 1)." The use of this term led to vast diagnoses and made the identification of the syndrome difficult. This was followed by the use of the term "PDD," which was used to describe several diagnostic entities such as Autism, Asperger Syndrome, and Rett Syndrome. In March 2004, the World Health Organization consensus conference on autism agreed that "Autism" should be used universally as a standardized term (Christensen et al., 2016, April 1).

Epidemiology of Autism in South Africa

Key issues include the timing of significant changes in understanding autism and establishing autism support systems, a relatively recent development in South Africa, similar to many other countries (Pillay et al., 2022). However, by its very nature, the number of pieces of pivotal information, such as the rate (spread, prevalence) of autism and the impact of the environment on the disorder, is lacking, and the high demand for assistance and treatment far outstrips the

available knowledge. Aderinto et al. (2023) There is a globally escalating interest in understanding the occurrence and impact of autism spectrum disorders. Scant information is available in the South African context. The only pertinent local studies are about the numbers of affected individuals, often termed the epidemiology, hospital data, and reviews (Aderinto et al., 2023).

Aim and Objectives

The main aim of the current study is to determine the understanding of the difference Between Autism and the Autistic Spectrum in a South African context, and this will be achieved through the following objectives:

- To establish an updated review of the epidemiology of autism in South Africa.
- To explore challenges and if the South African society understands the difference between Autism and the Autistic spectrum

METHODOLOGY

This discourse-based paper used a scoping-based literature review to discuss the difference Between Autism and the Autistic Spectrum in the South African Context. A narrative literature review is an extensive joining and assimilation of existing research on a specific issue, providing an overview of major discoveries and their interconnectedness. Therefore, the researcher has employed a narrative literature review as a methodology to find and analyse the literature. As elucidated earlier narrative literature review is an extensive consolidation and integration of existing research on a specific issue and for the current study the researcher has consolidate and integrated existing research on autism and autistic spectrum, providing an overview of major discoveries and their interconnections using a narrative structure devoid of structured meta-analysis to delineate the factors contributing to the Autism (Creswell, 2013). When the researcher synthesizes, they organize similar ideas together so readers can understand how they overlap. This process assists in showing where the researcher's voice or ideas are incorporated into existing knowledge (Barton et al., 2018).

The data was gathered through desktop research using search engines such as Google Scholar, Ebscohost, YouTube, Lib-guides, Research Gate, etc. The researcher also relied on secondary data, which gave rise to heterogeneous sources, including empirical monographs, books, theses, and journal articles. Had informal conversations with colleagues and families in rural areas about their understanding of autism. Data for this study was also solicited from articles found on Google Scholar that were searched through desktop research using a variety of data sources, including books, dissertations, and journal articles. The sources were deemed to be advantageous and provided with reliable information for this discussion paper. Mastrodicasa & Metellus (2013) also commends the use of the information contained in documents as compared to people, given that individuals may forget valuable information, while documents save time and money. It is also important to note that documents might be

more accessible than people, as is the case in this study. Altogether, large data used in this paper is posted on various websites.

Collected data files were analysed through content analysis through the following process: The researcher developed her research questions. Followed by choosing the content she wanted to analyse from the files that were collected. Thirdly the process of Identifying biases followed. Lastly the researcher defined the units and categories of coding, and the text was coded into manageable content categories. This process assisted in ensuring validity and reliability of the current and this study would be repeated many times and give the same results. Data was stored according to file naming schemes that were developed as follows: Autism, Autistic spectrum, disorder, children, behavior, development. This method is also supported by Rao & Ippili (2020) for tracking data that has been collected to answer research questions.

Challenges and Opportunities in Diagnosis and Intervention

In the South African context, where medical services are stretched, it is almost impossible to diagnose high-functioning children early on as the ratios of medical professionals to patients are too high (Mazibuko et al., 2020). This results in children being in schools without the correctly trained educational psychologists or remedial therapists who can cope with any problems such learners may be experiencing. If children are fortunate enough to be diagnosed as high functioning, these skills can be accommodated within the small classroom settings available only in well-funded schools. This leads to inequity in the educational system. As autism conditions are beginning to be better understood, many people with autistic conditions well-suited to certain future occupations are mismanaged in the South African educational systems due to their lack of facilities (Mushambi et al., 2024).

Jagwanth (2021) South Africa has excellent nursery and preschool settings within which to diagnose and treat children with autism. However, once the child reaches school-going age, he/she is forced to go to an inadequate educational system instead of a therapeutic system (Mushambi et al., 2024). There is also no funding model within the health, nursing, or educational systems to cope with high-functioning children. Teachers or caregivers are not given the appropriate coping skills to deal with these children, and they frequently become frustrated. This impairs the child's learning process. Not all adults medically or educationally qualified to handle children can cope with teaching autistic and high-functioning children. Furthermore, parents are not treated by sufficient support groups or information (Pillay et al., 2022).

Cultural Considerations in Understanding Autism in South Africa

At the time of the start of this study, there was very little in the academic literature documenting the way that autism was conceptualized and understood in South African communities. Even when coursebooks and other instructional materials are considered, disability generally receives little attention in research and teaching (Bulut & Arıkan, 2015). There is an extensive literature on culture and autism, but this has been predominantly conducted in Western Indigenous contexts (Mokoena & Kern, 2022). Only one study, at the time of conception of this project, had taken a systematic approach to considering indigenous people's perspectives in conceptualizing

autism in Africa. This was a small-scale study of people with intellectual disabilities of different cultural backgrounds (Shilubane & Mazibuko, 2020). It reported that significant differences existed in how parents and families of African background perceived and experienced their child's intellectual disability and the stereotypes they faced. Smit points to the significant ways the concept of disability holds different meanings for different social and cultural contexts and shows how this affects the subjectivities of both the individual and the family surrounding them (Manono & Clasquin-Johnson, 2023). Autism is primarily understood and diagnosed using methods and drawings predominantly drawn from white male children from Western cultures (Shilubane & Mazibuko, 2020). It is a no-brainer that questions of validity may be pertinent in an African context, considering differences in lived experiences and cultural values. However, among other scholars, most hosts of community-based projects consider the views of locals unimportant (Manono & Clasquin-Johnson, 2023).

Misconceptions

In the South African context, the understanding and acceptance of autism spectrum disorder has been evolving, but significant gaps and misconceptions persist. Pediatricians and other healthcare professionals play a vital role in early identification, referral for specialist assessment, and the coordination of multidisciplinary teams to address the complex needs of individuals with autism spectrum disorder and their families (Filipek et al., 2000).

Ravet (2011) The focus on inclusive education over the past decade has also meant that many children on the autism spectrum are now being taught in mainstream classrooms rather than in specialized units or schools. This shift has brought new challenges for teachers and schools as they strive to create environments that are accessible and supportive for students with diverse needs. Ravet (2011) Ultimately, the heterogeneity of autism spectrum disorder, combined with the unique cultural and socioeconomic contexts of South Africa, highlights the need for a nuanced and comprehensive approach to understanding and supporting individuals on the spectrum.

Awareness

The prevalence of autism spectrum disorder appears to be rising globally, with estimates suggesting that approximately 1 in 88 individuals are affected (Christensen et al., 2016). This increase may be attributed to various factors, including improved public awareness leading to earlier identification, refinements in diagnostic criteria that have broadened the spectrum, and advancements in our scientific understanding of the underlying neurobiological mechanisms of the disorder. Remarkably, the outlook for many individuals with autism spectrum disorder today is brighter than it was 50 years ago. (Eapen et al., 2014) More people with the condition can now speak, read, and live in the community rather than in institutions, and some may even be largely free from symptoms by adulthood. However, it is crucial to recognize that the term "autism spectrum disorder" encompasses a wide range of functional abilities and challenges. While some individuals may thrive and live independently, others will continue to require significant support throughout their lives. Genetics and neuroscience have uncovered intriguing

risk patterns, but their practical benefits for treatment and understanding the heterogeneity of the disorder remain limited. Parenting children with autism spectrum disorder can also be emotionally, socially, financially, and physically challenging, underscoring the importance of comprehensive support systems for families (Eapen et al., 2014).

DISCUSSION

Practical implementation of Ideas in Diagnoses

How do you know if you're on the right track to identifying autism in your child? Although some signs will be more obvious than others, diagnosis of autism is usually carried out by a team of medical experts. They may speak to the parent and the child and observe child's behavior. A paediatrician, developmental pediatrician, or a medical specialist usually helps to determine if delay is related to autism or another cause.

The diagnosis of Autism Spectrum Disorder according to DSM-5 criteria is characterized by the manifestation of each of the following criteria, and the severity levels for each are defined on the basis of the range of impairment they cause. For example, with regard to the first domain, deficits in social-emotional reciprocity which are evidenced by: 1) failure of development of normal back-and-forth conversation; 2) reduced sharing of interests, emotions, or affect; or 3) failure to initiate or respond to social interactions. For each of these symptom indicators, a child may display underlying features that range from low to high severity (Rice et al., 2022).

In addition to traditional ways of diagnosis an innovative way can also be employed in diagnosing Autism. However, there are barriers and challenges that comes with these ways. One from many barriers to this innovation include the lack of normal data and the fact that structural brain development of autistic children does not follow the typical timetable. A solution may be to use artificial neural networks to train classifiers that can identify those brain regions that are responsible for autism spectrum disorders. This has been done for typical brain growth: greyscale statistical parametric maps were extracted from a growth database, and this information was used to train classifiers that identified the age of children from their spatial grey level patterns (Mergel, 2021).

An alternative is to use morphometry to extract a small set of features of each child's MRI and use these summaries to estimate the occurrence of autism spectrum disorders. Recently, there has been interest in using MRI techniques to determine whether there are differences in the large-scale structure of the brains of neurotypical individuals and individuals showing ASD (Guldmann & Huulgaard, 2020). These studies have found significant differences, mainly in the anatomical structures related to social behavior regions of the brain. Nonetheless, no statistical method has been provided to learn prototypes representative molecular methylation profiles associated with autism. The lack of ground truth understanding of a coarse-grained principal force may be induced by the possibly associated risk factors, for example, environment, genetic, epigenetic, and sex-related factors (Gupta et al., 2020).

Cultural perceptions of autism

In the South African context, autism is often treated as an illness that needs to be "cured" rather than accepted. Autism within the African context is based more on a traditional or cultural perspective, not just a medical one. The occurrence of things such as different stimming behavior in someone with autism is often seen as demonic possession in other African cultures, and an autistic individual is more likely to be seen within the village and not be a part of the family (Mazibuko et al., 2020).

In many rural and peri-urban communities of South Africa, autism is not recognized and accepted as a disorder of brain dysfunction, but rather, it is perceived as a result of wrongdoing. Traditional beliefs and a range of community-based concepts also shape perceptions and acceptance, or lack thereof, of the individual with autism and intellectual disability in these communities, to a large extent. The social and genetic inheritance of this condition is rarely acknowledged, ascribed, or indeed, reported in these early kingdoms. Autism is often attributed to witchcraft, theft, or toxic intake by somebody in the family for their own benefit. Such a belief, especially when based on community accusations, results in rejection and stigma (Nyoni, 2022).

Individuals may withdraw or become isolated from their own family and community. It is the process of this secluded rejection that can lead to a lack of identification of autistic symptomatology and academic knowledge that may well still be viewed with skepticism or disdain. A large burden of non-diagnosis and rejection by society exists in much of South Africa for individuals with neurodevelopmental disorders (Mazibuko et al., 2020).

Misconceptions about Autism in South African Rural Areas

Filipek et al. (2000) Misconceptions or beliefs about autism exist globally, and South Africa is no exception. Much of the research dedicated to the perspectives of rural South African families residing in villages and townships has identified common beliefs about autism that are not supported by scientific research. For example, a commonly held belief is that autism is contagious, due to a widespread misbelief in the role of westernized or modern food, environmental pollution, or that vaccinations may have caused "mysterious ailments" (Abebe, 2020). Furthermore, intellectual disability and mental illness are often conflated with autism by village families. The association of neurological differences like autism with spirit possession serves to further isolate families of autistic children in South African rural areas. Some families are suspected of wrongdoing and can become social outcasts due to the widely held belief that there is a causal relationship between shame and the birth of disabled children, seen as a divine punishment for earlier actions of the parents or other relatives, such as secret abortion decisions, theft, or substance abuse. Often boys with autism are suspected to have been born out of wedlock, illegitimately perceived as disabled as a result of parental sin (Matshabane et al., 2021).

Furthermore, In South African rural areas, persons with autism and their family members continuously face the challenges related to people's misconceptions and misunderstandings about autism, as people have come to generally accept everything that has been said about

autism as "gospel truth." Autism is also often not considered a medical (neuro-developmental impairment) and neurological condition, as people are quick to throw insults around like "umuntu onjalo" (Xhosa phrase), meaning he or she is acting strange (Ravet, 2011). The autism misinformation almost always gets communicated to the immediate family, other family members and community members and local places of worship. The grandparents tend to put their foot down and serve as gatekeepers to stop health promoters and researchers from spreading the word and encouraging the youth to donate DNA samples. It also becomes quite a culture shock if practitioners try to discuss "autism" as the mere thought of using the concept of "autism" to explain the neurological symptom manifestation usually makes people hit the roof. Family members tend to listen only to traditional health practitioners' explanations and courses of action as to how to manage "autism" (van Schalkwyk, 2021).

Education and Awareness

Malahlela (2023) is of the view that to address some of the aforementioned misconceptions about autism within the context of the rural South African setting, knowledge transfer strategies and approaches are needed. This would be achieved more effectively by educating and raising awareness for various stakeholders. It is critically important to provide accurate and relevant information to the caregivers or stakeholders of people with autism in the context of their own culture and traditions, beliefs, and practices.

In South Africa, there has been a significant shift legislated to include people with disabilities as full participants in all aspects of community life. Their central focus is entrenched in development and includes access to all developmental benefits. An important part of this shift is the understanding that society as a whole is ill-informed about the subject of disability, and this then impacts on the interpretation of discriminatory policies and practices (Malahlela, 2023).

Workshops that are attended by large sectors or communities of people and are seen as integrated activities do not always confront specific stigma-related misconceptions. Educated urban stakeholders are more likely to advocate, understand, and accept community-based services for people with mental and physical disabilities. Parents are key stakeholders in the lives of people with disabilities but unfortunately tend to seek solutions within their own families, seek cures or interventions at the individualizing level rather than assist communities to develop community-based services (Jost et al., 2022).

In the South African rural context, the challenge then is to find a mechanism to educate parents, teachers, health workers, and service providers. Each of these groups of people has a role to play in reducing the stigma of disability. The relationship between them needs to grow around shared interests in a project that is broader than disability when it comes to transcending the social morbidity of growing up in a society with an inherent bias towards able-bodiedness (Jost et al., 2022).

CONCLUSION AND FUTURE DIRECTIONS

Over the past two decades, variations have been reported in the prevalence of autism and how symptoms, causes, and appropriate treatments should be understood, affecting policymakers' attempts at service provision. Despite these complexities and the numerous attempts to understand the evolution of autism as a construct, biologically as a disease, or as a genetic variation, an understanding of the disorder as a developmental misfit on a continuum with evolutionary consequences remains prevalent. However, there is consensus that the search for the genes associated with aspects of autism is important and will clarify the architecture of the disorder, although it is also recognized that they will only be able to account for a small proportion of the variance.

The focus in international medical research on identifying the genetic causes of autism has begun to focus on environmental influences that can modulate the autism phenotype. Most of this literature manages to associate autistic traits with genetic, environmental, and gene-environment interaction without providing a full explanation of the relationship between these and autism. While it is true that genetic explanations for autism, in common with other conditions, function both to explain and manage the fear and judgment associated with it, it can also be argued that calculations of heritability do not tell us whether a condition is genetic or how other factors are contributing to its cause. Genetic claims about autism are thus likely to be overestimated, particularly because they fail to appreciate the dynamic nature of genes and the processes that shape them across time and space. Similarly, the nature-nurture dichotomy inherent in many genetic association studies is problematic.

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