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CONCEPTUALIZING, DEFINING CHILDREN WITH AUTISM IN KENYA: STAKEHOLDER PERSPECTIVES INVESTIGATING STRATEGIES TO PROMOTE AND SUPPORT CHILDREN WITH AUTISM BETWEEN 0-3 YEARS

Sharon Onditi

Lecturer, Department of Education, Psychology and Science

Email Address: shahanyango@yahoo.com

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ABSTRACT

Purpose: This study developed a conceptual framework addressing the gap in autism research in low- and middle-income countries, particularly Kenya.

Statement of the Problem: In Kenya, autism research faced significant challenges as research was heavily concentrated in wealthy Western nations, while these regions lacked culturally appropriate screening and diagnostic tools for autism.

Research Methodology: The study employed a multidisciplinary review approach combining analysis of autism research literature with works on mental health, cultural psychiatry, cross-cultural psychology, and intellectual disability research.

Findings: The framework took into account four interconnected levels: expression, recognition, interpretation, and reporting of autism symptoms, describing cultural and contextual factors associated with each level.

Conclusion: The framework aided development of culturally appropriate autism screening tools and cross-cultural research directions by outlining cultural factors affecting ASD identification and diagnosis.

Recommendations: The concept is pertinent to Kenyan physicians and decision-makers seeking to enhance support for marginalized autism populations through culturally informed approaches.

Keywords: *Conceptualizing, Defining Children, Autism, Stakeholder Perspectives, Strategies, Promote and Support Children, 0-3 Years*

INTRODUCTION

Autism research is significantly biased in favor of Western, wealthy nations (Abubakar, Ssewanyana, de Vries, & Newton, 2016; de Vries, P.J., 2016; Durkin et al., 2015; Elsabbagh et al., 2012; Hahler & Elsabbagh, 2014). These high-income nations only account for less than 20% of the world's population (Durkin et al., 2015; World Bank, 2015), but they are the focus of practically all studies on autism (de Vries, 2016; Durkin et al., 2015). Additionally, ethnic minorities are underrepresented in autism research even in high-income countries (West et al., 2016). Our understanding of the symptom expression of Autism Spectrum Disorders (ASD), the screening and diagnostic tools used to aid ASD identification and referral, and the interventions created to support people with ASD are likely to be biased in terms of culture and context as a result of this global imbalance (Durkin et al., 2015; Freeth, Sheppard, Ramachandran, & Milne, 2013). The demand for a broader global view on ASD has just recently gained significant traction (de Vries, 2016; Durkin et al., 2015; Munir et al., 2016; Rice & Lee, 2017; World Health Organization, 2013).

Given that the vast majority of the world's autistic population is now severely ignored and neglected, the Kenyan on ASD is of vital relevance (de Vries, 2016; Durkin et al., 2015). Most people with ASD are still undiagnosed in low- and middle-income countries (LMIC), and the great majority do not have access to evidence-based care or education (Kieling et al., 2011). The World Health Organization supports an approach that involves enhancing developmental surveillance systems and monitoring developmental progress to identify developmental challenges early (WHO, 2012). The creation of culturally appropriate monitoring, screening, and diagnostic methods is essential for keeping track of developmental issues, or more precisely for screening for autism.

According to several studies (Bakare & Munir, 2011; Bello-Mojeed, Omigbodun, Bakare, & Adewuya, 2017; Montiel-Nava, Chacn, & González-vila, 2017; Ruparelia et al., 2016), individuals with ASD who receive a late or nonexistent diagnosis are at a disadvantage in their respective cultural or socioeconomic contexts. Furthermore, little is known about the contextual and cultural adjustments necessary to make treatments possible, palatable, and successful in low-resource contexts (Al Maskari, Melville, & Willis, 2018; Franz, Chambers, von Isenburg, & de Vries, 2017; Guler, de Vries, Seris, Shabalala, & Franz, 2017). A greater comprehension of the cultural and contextual aspects of ASD may help to better support underprivileged communities in high-income nations in addition to helping populations from LMIC.

Several initiatives to create or modify screening tools for use in other cultural or socioeconomic contexts have been made in recent years in response to the request for more Kenyan representation in ASD research, though not always with the desired results. For example, screening tools used in Sri Lanka (Perera, Wijewardena, & Aluthwelage, 2009), Japan (Kamio et al., 2014), Uganda (Kakooza-Mwesige et al., 2014), and Japan (Kamio et al., 2014) reported low sensitivity. Studies using the Modified Checklist for Autism in Toddlers (MCHAT) in low socioeconomic or ethnically diverse settings in the USA reported high false positive rates in children of color and children from lower-income households (Khowaja, Hazzard, & Robins, 2015; Scarpa et al., 2013), as well as low specificity and low positive predictive values (Guthrie et al., 2019).

The process of cultural adaptation and the psychometric characteristics of ASD screening tools have been examined in several prior reviews (Al Maskari et al., 2018; Marlow, Servili, & Tomlinson, 2019; Soto et al., 2015; Stewart & Lee, 2017). This research, however, mostly concentrated on the technical adaptation of the instruments, giving little thought to the underlying cultural or socioeconomic issues that may have required the modification (Al Maskari et al., 2018). There is currently a lack of an organized overview of the cultural and contextual variables that may have an international impact on the recognition and diagnosis of autism. The purpose of this research is to explore potential cultural and contextual influences that can affect the recognition, request for assistance, and diagnosis of ASD as well as to provide a conceptual framework that depicts these influences. This conceptual framework is intended to support future cross-cultural research on autism and serve as a roadmap for the creation or modification of culturally and contextually appropriate autism screening and diagnostic tools.

METHODOLOGY

This review study's methodology is interdisciplinary because international, cross-cultural research on autism is still in its infancy. Instead of focusing simply on autism studies, the researcher drew from sociocultural research studies that looked at a variety of mental health issues as well as typical and atypical child development and that may be instructive for the overall field of autism research. We gathered studies on cultural and socioeconomic aspects that might influence the detection and diagnosis of ASD from the domains of ASD, intellectual impairment, cultural psychiatry, cross-cultural psychology, and global mental health research.

To develop the conceptual framework, the researcher also took into account conceptual and systematic review papers on the topic of help-seeking for mental health issues (Jacobs, Ir, Bigdeli, Annear, & Van Damme, 2012; Reardon et al., 2017) as well as cultural and contextual influences on psychiatric diagnoses (Rogler, 1993) and help-seeking (Cauce et al., 2002). This strategy could draw attention to factors that are potentially important but have not yet received enough attention in the field of autism research. Instead of reviewing data from earlier autism research on what are previously known to be significant characteristics, the goal of this study was to map out what cultural and contextual factors could be of potential value in identifying and diagnosing ASD. The main focus is on autism in children rather than adults because the overall goal is to promote early diagnosis globally. The crucial role parents can play as their children's champions is also taken into consideration. The path of identification, help-seeking, and diagnosis from the perspective of the individual and their family was the main focus throughout the framework's development.

A narrative method was employed since the transdisciplinary literature that may be relevant to this topic is too diverse and large to be approached systematically. Nevertheless, a search was done in the databases Medline (Pubmed), PsycInfo and the Cochrane Library to acquire an idea of the material that has been published to date in the area of cross-cultural ASD research. On August 28, 2019, the final comprehensive search was carried out. MesH search phrases for ASD (Autism, Autism Spectrum Disorder, Asperger Syndrome, Pervasive Development Disorder) and culture ('culture', 'ethnology') were used. Search results returned 800 articles. 167 pertinent publications were found and reviewed after these papers underwent title and abstract screening and articles that had no connection to ASD or culture were disregarded. This collection of research was then merged with the authors' databases of a wider body of literature beyond autism research, encompassing major texts in international research on global mental health, cross-cultural psychiatry, cross-cultural psychology, and intellectual impairment.

Using the snowballing method (Greenhalgh & Peacock, 2005), citations and reference lists of the discovered papers were manually examined. More than 550 papers were included in the extensive search of the literature on autism and other fields, which influenced the creation of our conceptual framework. There were no limitations placed on the year of publication. There were no restrictions placed on the research's design; both qualitative and quantitative studies were included.

RESULTS

The expression, recognition, interpretation, and reporting of autism symptoms are the four interrelated levels that make up the framework. Each level examines a particular issue before outlining any potential cultural or contextual influences that may be present that were found in our literature review. The framework's levels and the variables pertinent to each level will be covered one at a time.

Level One: Expression of Symptoms

How uniformly do ASD symptoms manifest across cultural boundaries, according to the DSM-5 (American Psychiatric Association, 2013) and the new ICD-11 (WHO, 2018) definitions? This is the initial level of the conceptual framework.

The Global Nomenclature of ASD

According to the DSM-5 diagnostic criteria for ASD, there are three levels at which the behavioral aspects of ASD could vary cross-culturally: the broad domains (e.g., "persistent deficits in social communication and social interaction" and "restricted repetitive patterns of behavior, interests, or activities"); the subdomains (e.g., "deficits in social-emotional reciprocity"; "hyper- or hypo reactivity to sensory input"); or the more narrowly (American Psychiatric Association, 2013). The ICD-11's ASD criteria (WHO, 2018) adhere to the same two-domain framework but are less stringent in identifying specific subdomains and behavioral models (in line with the ICD classification system overall).

Globally and across several ethnic groups, the broad domains that define ASD are present (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2014; Zager, Cihak, & Stone-MacDonald, 2016). The specific presentations of autism symptoms may, however, fluctuate slightly depending on the subdomain or behavioral exemplar level. Qualitative differences, quantitative differences, differences in the degree to which symptoms cause clinical impairment in daily functioning, and differences in the way these symptoms cluster together in broad areas are all possible at various levels. Two difficulties should be kept in mind when examining how the nosology of ASD may differ across cultures: the categorical fallacy that could influence cross-cultural research in psychiatry (Kleinman, 1987), and the interconnectedness of the nosology of autism with its etiology and developmental pathway (Lai et al., 2015).

Level Two: Recognition

At this level of the conceptual framework, the goal is to make the recognition process more understandable. At this level, the key concern is: What are the underlying socioeconomic and cross-cultural variables that affect whether or not aberrant behavior or characteristics associated with ASD are recognized?

Global Variations in The First Parental Concern's Age

According to research done in high-income western countries, parents typically get concerned when their child is between the ages of 14 and 19 months (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Chawarska et al., 2006; Kishore & Basu, 2011; Matheis et al., 2017; Rosenberg, Landa, Law, Stuart, & Law, 2011). The stated age of the first parental concerns, however, tends to be higher in nations with differing culturally or socioeconomic backgrounds. The average age of the first parental concern was reported to be 24 to 26 months in India (Daley, 2004; Srinath, Seshadri, Girimaji, & Kommu, 2017), 29 months in Latin America (Irarrazaval et al., 2017), and 31 months in Hong Kong Chinese (Tait, Fung, Hu, Sweller, & Wang, 2016). The following discussion will look at some potential cultural and contextual causes for this discrepancy, even though these studies used somewhat different approaches that may potentially account for some of the disparities seen.

Cultural Standards of Acceptable Behavior

Almost all milestones, except those relating to self-help skills, are similarly attained in the first three years of life, according to a large study of typically developing children from four culturally and linguistically diverse countries (Argentina, India, South Africa, and Turkey) (Ertem et al., 2018). While there isn't much evidence in this study to suggest that children from different cultures complete developmental milestones at different rates, parents' degrees of attention to particular behaviors may vary between cultures. Cultural variations in what is regarded as typical behavior may have an impact on the recognition of autistic symptoms. Other cultural contexts would not consider a behavior to be out of the ordinary even though it might be in a Western sociocultural context. They might not deviate from both because the behavior is intertwined with the cultural norm and therefore tends to go unnoticed in this culture (Norbury & Sparks, 2013; Donohue, Childs, Richards, & Robins, 2017; Harrison, Long, Tommet, & Jones, 2017; Kirmayer & Swartz, 2014; Mandell & Novak, 2005) or because it is not salient in this culture.

Similar cultural variance may be related to autistic traits in rural India, according to a qualitative study (Daley, 2004). According to a psychiatrist featured in this report, "Our rural mass may have a tendency to accept and endure some degree of aberration as normal." Therefore, whether or not signs of autism are considered abnormal may depend on cultural or contextual (urban vs. rural) variances in tolerance and acceptance of deviating from the norm.

Caregivers' Awareness of their Child's Developmental State and Mental Health

Depending on the culture or socioeconomic environment, different children may receive different levels of attention. Atypical behavior may be detected more readily and earlier if a child's cognitive, behavioral, and (mental) health development are given more attention. Parental awareness of their child's development may be influenced by cultural differences in parenting and other demands on the caregiver's time.

Level Three: Interpretation

The process of interpretation is the focus at this level of the conceptual framework. What explanations might be offered for the abnormal behavior (as seen and acknowledged at the second level of the conceptual framework) and how might cultural and environmental factors influence this interpretation?

Models for Explaining Recognized Abnormal Behavior

Explanatory models, which can be influenced by culture, are a person's viewpoints on the nature, causes, course, diagnosis, and treatment of sickness (Kleinman, 1978). Most cases of autism are idiopathic, and this uncertainty may add to the multiplicity of perceived reasons described by parents of children with ASD. The causes of autism are complicated and multi-factorial (Lai et al., 2013). Examples of biological or medical explanations for ASD include hereditary factors (Gona et al., 2015; Heys et al., 2017); infectious diseases (Gona et al., 2015; Tilahun et al., 2016); accidents (Al-Dababneh, Al-Zboon, & Baibers, 2016; Minhas et al., 2015; Shaked & Bilu, 2006;

Tilahun (Gona et al., 2015; Heys et al., 2017). In the USA, genetics/heritability and environmental risk factors, such as heavy metals, diet, pesticides, pollution, and other exposures, are the most frequently cited perceived causes by parents (Chaidez et al., 2018; Zuckerman, Lindly, & Sinche, 2016). Even though there is no conclusive scientific evidence linking childhood vaccinations to autism, this explanation is frequently put forth, particularly in North America (Bazzano, Zeldin, Schuster, Barrett, & Lehrer, 2012; Buehning & Peddecord, 2017; Decoteau, 2017; GoinKochel et al., 2016; Wolff & Madlon-Kay, 2014). (Eggertson, 2010; Smeeth et al., 2004).

The acceptance of particular explanations may be influenced by cultural and contextual factors. For instance, while the idea that vaccines can cause autism is significantly more common in North America than in sub-Saharan Africa, it seems to be especially widespread in Somali communities in the United States (Wolff & Madlon-Kay, 2014). Furthermore, because many do not think autism exists in Somalia, the Somali community in North America frequently views autism as "the western disease." One of their hypotheses is that Somali Americans have high incidence of autism because of exposures to the American cuisine and environment, including the use of antibiotics in food production (Decoteau, 2017).

What kind of support is sought and when this support is sought depends on the causal explanations for a child's condition (Mandell & Novak, 2005; Yeh, Hough, McCabe, Lau, & Garland, 2004). If caregivers exclusively attribute the abnormal behavior of their kid to supernatural or traditional reasons, or biological explanations that are not supported by mainstream evidence-based medicine, there may be a delay or resistance to seek help in a mainstream medical context. According to a study of parents of autistic children in California, families who support causal views about vaccinations or environmental risk exposures are more likely to seek treatment from complementary or alternative medicine than those who do not (Chaidez et al., 2018). In addition to apparent causal beliefs, there are other variables that could affect this process of interpretation and subsequent help-seeking include stigma and mental health literacy.

Level Four: Reporting

The procedure of reporting symptoms to a health worker or clinical professional is the subject of the fourth level of the conceptual framework. At this level, it is possible to discern between two underlying processes: obstacles to seeking assistance and, after assistance is sought, the variables affecting the quantity and quality of clinical data that the clinician receives.

Barriers in Help-Seeking Behaviour

Reardon et al., 2017; Saxena, Thornicroft, Knapp, & Whiteford, 2007) or assistance for people with ASD (Abubakar, Ssewanyana, de Vries, et al., 2016; de Vries, 2016; Durkin et al., 2015; Masri, Al Suluh, & Nasir, 2013) across the world have taken into consideration the difficulties in obtaining support for mental health issues Four hurdles to obtaining help can be identified in addition to the elements described under the conceptual framework's earlier levels: affordability, availability, geographical accessibility, and acceptance (Jacobs et al., 2012; Peters et al., 2008).

DISCUSSION

The researcher put up a four-level conceptual framework in this publication, outlining potential cultural and contextual elements that can influence the recognition and diagnosis of ASD. This is the first attempt, as far as we are aware, to present a comprehensive overview of the cultural and environmental aspects that influence the identification, help-seeking, and diagnosis of ASD on a worldwide scale, drawing on literature from several disciplines. We recommend future research directions based on this framework in order to enhance the urgently required capacity for ASD research and services globally, highlighting both fundamental research topics and applied research to guide the creation and application of therapies. Making sure that the cultural group under consideration is represented in the research team conducting the work, ensuring that the research uses culturally and contextually appropriate research methods, and ensuring that findings are interpreted with appreciation of the local context are all important general guidelines for all of the future cross-cultural research strands suggested in this work (Hoekstra, Girma, Tekola, & Yenus, 2018).

The framework is probably relevant to a large audience, including researchers working on studies on the epidemiology, screening, and diagnosis of autism or designing and evaluating interventions, as well as practitioners looking to expand their understanding of potential cultural factors influencing interactions with their clients. The framework might also be useful for mental health service policy makers who want to increase assistance for people with ASD even worldwide.

Although the conceptual framework was created primarily for use in LMIC, it will also be applicable in high-income nations with diverse cultures. To give an example, a study conducted among Somalis living in the UK (Fox, Aabe, Turner, Redwood, & Rai, 2016) found similar results to those of studies conducted among populations living in the horn or east of Africa (Gona et al., 2016; Tekola et al., 2016; Tilahun et al., 2016) regarding perceptions of autism, experiences of stigma, and unmet needs. According to several studies (Decoteau, 2017; Kawa et al., 2016; Sandy Magaa & Vanegas, 2017), ethnic minority groups in high-income nations are frequently underdiagnosed for ASD and underrepresented in autism research populations. Therefore, measures to improve ethnic minority communities' identification, diagnosis, and access to services in high-income nations may be informed by improvements in our understanding of the cultural components of autism (La Roche, Bush, & D'Angelo, 2018).

The conceptual framework indicated factors' capacity to influence is a significant study restriction. This study didn't make the assertion that each element would be relevant in every cultural context; rather, it sought to outline which factors would affect the identification and diagnosis process. Future research is necessary to determine how significant each of these issues is globally. Cultural and socioeconomic elements can be neatly entwined when analyzing cross-cultural disparities around the world. Because of this, this work has not attempted to separate the two sorts of influences. It is crucial to understand that "culture" is not bound by national boundaries; significant cultural distinctions may be found within nations, and cultural similarities between neighbors may be less than those between diaspora groups residing on other continents. Furthermore, "culture" is not static and may vary through time in terms of both similarities and distinctions (Kirmayer & Swartz, 2014). For instance, Kang-Yi et al. (2018) highlight the diversity of attitudes found within the Korean community in New York City, with some community members openly discussing autism and treating families with a child with autism as they would treat any other family, while others are hesitant to talk about autism and are more likely to hide it (Kang-Yi et al., 2018). According to the study's informants, generational differences account for this variation, with the younger generation of Korean immigrants being more "open minded" towards autism than the more senior population. As a result, every particular population's perception of the importance of the components listed in our conceptual framework is likely to evolve throughout time.

This framework was created with a focus on the cultural and environmental elements that may have an impact on the family's path of child identification, help-seeking, and diagnosis. In contrast to focusing on the health system, which would have likely revealed additional clinician viewpoints and systemic or macro elements not included in our framework, this method naturally emphasizes individual and family-level aspects. The study, which makes use of a multidisciplinary approach, lays out a conceptual framework covering aspects that are known to have an impact on autism in terms of context and culture as well as those that may have an impact based on sociocultural research undertaken in other fields. It is envisaged that the framework and related research recommendations would serve as a starting point for the creation of screening, diagnostic, and intervention tools that are suitable for underprivileged people worldwide and that are also culturally and contextually sensitive.

RECOMMENDATIONS

This study made the following recommendations:

i. Expanding access to high-quality early intervention programs, including early intensive behavioral intervention
ii. Creating inclusive classroom environments and providing teacher training on evidence-based practices.
iii. Conducting public awareness campaigns to reduce stigma and promote understanding.
iv. Providing support groups, counseling services, and respite care for families of children with autism.
v. Lobbying for policies that support the rights and needs of individuals with autism.

CONCLUSION

Conceptualizing and defining children with autism in Kenya requires a multifaceted approach that considers the diverse perspectives of stakeholders, including parents, healthcare professionals, educators, and community members. While significant progress has been made in understanding and supporting individuals with autism, challenges such as limited awareness, diagnostic challenges, and resource constraints persist. To effectively promote and support children with autism between the ages of 0-3 years, a comprehensive strategy is essential. This strategy should prioritize early intervention, inclusive education, and community support. Raising awareness, building capacity, and advocating for policy changes, Kenya can improve the lives of children with autism and their families.

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