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SYSTEMATIC REVIEW OF LITERATURE ON SOCIETAL PERCEPTIONS OF THE QUALITY OF LIFE OF CHILDREN WITH AUTISM AND THEIR PARENTS

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ABSTRACT

The primary goal of this paper is to discuss how society evaluates the quality of life of children with autism (CWA) and their parents (QoL). Despite widespread beliefs about the universality of autism, there are strong scientific and humanitarian reasons to investigate the condition in non-Western countries like Kenya, as well as among other ethnocultural groups. The majority of reviews in the field of autism have mostly focused on inclusion. As a result, this article focuses on the perspective and/or associated notions of Children with Autism (CWA) and their parents, as well as the Quality of Life (QoL) of CWA and their parents. The systematic literature review included studies on parental perspectives on raising a child with Autism Spectrum Disorder (ASD) as well as cultural views toward their child's autism diagnosis. There were 23 papers found in the systematic review, however only five were assessed since they met the inclusion criteria. CWA behavioral features are the best predictor of cultural conceptions about parenting a CWA, according to a systematic research evaluation,

which has an impact on their quality of life. Finally, cultural views have a negative impact on how CWAs are perceived and how well their parents live. Future research should focus on the impact of parental understanding of their child's CWA diagnosis on QoL.

Keywords: Societal, Perception, Autism, Quality of life.

1. INTRODUCTION

Autism is a neurodevelopmental condition that causes difficulty in speech, communication, social interaction, behavior, sensory disorders, and intellectual capacity, according to Nandini et al. (2015, p3). Autism is a lifelong neurodevelopmental illness that can impede an individual's social, verbal, cognitive, and behavioral development and daily functioning, according to the American Psychiatric Association (APA, 2013). Social communication problems, limited interests, and repetitive behaviors are some of the symptoms (APA, 2013). Researchers and clinicians use the term "Autism Spectrum Diseases" (ASDs) to define a set of neurodevelopmental disorders characterized by qualitative impairments in social-communicative and repetitive behaviors, as well as restricting behavior and interest (Matson & Sturmey, 2011, p 37).

CWA is challenged in several developmental domains that are important in their QoL because of the extensive nature of this neurodevelopmental condition (de Vries & Geurts, 2015 p1). In Models of Best Practice in the Education of Students Preschool and Elementary (2011, p13), the Virginia Department of Education (VDOE) lists social interaction, communication, restricted repetitive stereotyped patterns of behavior, imitation, theory of mind, motor, sensory, and executive functions as characteristics of Autism.

Recently, there has been considerable writing on the subject of quality of life (QoL). The World Health Organization (WHO, 2012, p11) defines QoL as "individuals' assessments of their place in life in relation to their objectives, aspirations, standards, and worries in the context of the culture and value systems in

which they live." It is a comprehensive notion that encompasses a multifaceted view of a person's physical health, physiological state, amount of independence, social interactions, personal views, and linkages to key environmental elements .The WHOQOL Group (1995) defined QoL as "individual's subjective perceptions of both positive and negative dimensions of functioning [functioning itself (example , "are you healthy?"), evaluations of functioning (example , "do you feel well?"), and personalized evaluations of functioning (e.g., "are you stratified with your health?") on multiple domains" (physical, psychological, and social).

It should be highlighted that despite WHOQOL group QoL's acknowledgment of developmental domains, CWA and their parents still experience deviation and are far from realizing their QoL due to societal cultural concepts and beliefs about having a child with autism. "Attempts to address key issues connected to educational services provided to children with autism and other third-world nations are stifled by a lack of policies and enough money, as well as negative cultural attitudes about impairments" (Mutua & Dimitrov, 2001; Obiakor; Maltby, & Ihunnah, 1990).

The basic domains of QoL differ depending on the discipline and researcher. Physical well-being, material well-being, rights, social inclusion, interpersonal relationships, self-determination, personal growth, and emotional well-being are listed as essential categories in the field of intellectual disabilities by Schlock and Alonso (2002) QoL of model. Each of these indicators is made up of indicators that can be used to assess an individual's quality of life. For more than three decades, quality of life indicators have been used to improve outcomes and raise

standards for the administration and implementation of interventions for people with disabilities (Burgess & Gutstein, 2007).

2. REVIEW OF LITERATURE

De Varies and Geurts (2015) studied whether IQ, early development, current autistic characteristics, and daily Executive Functions (EFs) are connected with QoL in children aged 8 to 12 years with Autism Spectrum Disorder (ASD). The study's hypothesis was as follows: Do Children with ASD Have a Lack of Cognitive Flexibility? Is There a Difference in Speed Accuracy Tradeoff Between Children with and Without ASD? Is Switch Task Performance Linked to Stereotyped and Repetitive Behavior? This study included 35 children with ASD and 35 typically developing (TD) children who were age, IQ, and gender-matched. Children with ASD were recruited from numerous mental health clinics in the Netherlands, and they all had a clinical diagnosis of an ASD, such as autism or Asperger syndrome, according to the DSM-IV criteria. Children with a psychiatric or developmental problem, those taking psychotropic drugs, or those scoring above the ASD cut-off on the Social Responsiveness Scale (SRS) were excluded from the study. Both groups were also required to be between the ages of 8 and 12 years old, have an IQ score of 80, and be free of seizure problems.

Three children in the ASD group, as well as the age-, IQ-, and gender-matched children in the TD group, were excluded from participation due to an estimated IQ score of less than 80. Individual matching was effective, according to the researchers, because there were no significant group variations in age,

estimated Full-Scale Intelligence Quotient (FSIQ), or male/female ratio. The researchers claim to have discovered that children with ASD who perform poorly (i.e., incorrectly) on a switch task also exhibit more repetitive behavior in everyday life. According to the research, only a fraction of children with ASD have cognitive flexibility problems, and only a subgroup performed slower and was less accurate in the current investigation. Also, when transitioning from emotion to gender trials, children with ASD had larger switch costs in response speed than children without ASD. According to the authors, low QoL was connected to higher levels of autism symptoms and EF deficiencies, and this was attributed to their parents' lack of exposure to CWA due to cultural beliefs and social attitudes about parenting a CWA.

One of the most important contemporary debates in raising CWA is the impact of

culture on CWA's QoL. Rainy, Cuskelly, and Meredith (2016) looked into Indonesian cultural beliefs of autism spectrum disorder. The purpose of this study was to see how Indonesian moms from various backgrounds and without a kid with autism understood autism and how to parent such a child in the best way possible. The study used semi-structured interviews with nine Indonesian mothers to conduct a qualitative investigation. Understanding of autism, views about its causes, potential reactions to having a child with autism, perspectives of parenting a child with autism, and perceptions of parent-child connections were all explored. Their findings reflect traditional cultural ideas on appropriate behavior during pregnancy, karma, and God's purpose, all of which are not widely recorded in Western countries' literature.

In a recent study, Fong et al. (2021) compared Korean immigrant families to Canadian families of CWA to evaluate cross-cultural perspectives on the concept of family QoL. Semi-structured interviews with 13 Korean immigrant parents and 12 Canadian parents of CWA in British Columbia, Canada were used to do thematic analysis. Three themes were discovered by the researchers: family closeness, value orientation, and societal acceptance. Family relationships, support, emotional well-being, individual qualities, and comparisons to other families were all important aspects in defining family quality of life for Canadian families. In the discussion of their findings, the authors observed that cultural values and inequities may translate into various conceptualizations of family QoL, underlining the importance of cross-cultural and diverse viewpoints in the study and construction of future assessment instruments. The authors backed up their claim by referring to a number of previous studies that looked at cross-cultural viewpoints in CWA families.

CWA's and their parents' quality of life is constantly harmed by culture. A review of research on raising an autistic child was published by Enea and Rusu (2020). The researchers wanted to (a) figure out how parenting stress was used as an independent, outcome, moderator, and mediator variable in empirical studies, (b) figure out what predicts parenting stress in parents of children with ASD, (c) figure out how parenting stress relates to mental health, and (d) make recommendations for future research. 45 research met strict inclusion criteria after a thorough search for peer-reviewed articles on parenting stress. Problem behaviors and sensory issues in children are the biggest predictors of parenting stress during a two-year period.

Single young mothers with maladaptive coping mechanisms who have an ASD child with problem behaviors and sensory challenges are the ones who are most likely to have high levels of parenting stress and mental health problems. The researchers concluded that parenting stress has a negative impact on the mental health-related quality of life of parents. Future research should look into socio-cultural aspects that influence parenting stress in different cultures.

The cultural notion dominates the examination of CWA QoL. Super and Harknes (2020) studied culture and the perceptual organization of baby behavior in Kenya and the United States. To judge the "similarity" of behavioral items in the Neonatal Behavioral Assessment Scale, the researchers enlisted individuals of diverse cultural groups (total n = 100). (NBAS). NBAS experts, moms, and undergraduates in Massachusetts, as well as mothers and high-school students in rural Kenya, provided data. Data was collected using the Neonatal Behavioral Assessment Scale (NBAS). NBAS specialists were especially attentive to a dimension of State Control, as the scale underlines, according to the multidimensional scaling of their judgments. Kenyan mothers concentrated on a dimension of motor responsiveness in accordance with their concerns and practices involving motor development, whereas Massachusetts women grouped their judgments around cognitive competence abilities stressed in contemporary early development discourses.

A lot of material has recently sprung up on the topic of cultural perceptions about raising a child with a disability. Seo (1992) investigated how CWA's behavior tendencies are influenced by culture. She compared three CWA groups: a) 25 South Koreans,

b) 25 Korean Americans, and c) 25 children from the United States. Between the group of South Korean children and the group of American children, Seo discovered variations in social impairments and developmental disorders. She supported her findings by stating that the disparities were due to changes in symptoms rather than parental perception.

In Kenya and the United States, Wambui (2005) looked at the impact of culture on autistic behavioral symptoms. The Autism Behavior Checklist (ABC) and the Gilliam Autism Rating Scale (GARS) were employed. A Developmental History Questionnaire (DHQ) was also developed specifically for this research. Eighty people were matched for age and gender (40 African Americans and 40 Kenyans). A comparison sample of 20 typically developing youngsters, 10 from each culture, was used to adjust for perceptual differences between African American and Kenyan raters. For 80 people, gender and age were matched (40 African Americans and 40 Kenyans). Between Kenyans and African Americans with autism, multivariate analysis and independent t-tests indicated substantial differences in social interactions, communication, stereotyped behaviors, developmental abnormalities, and overall behavior disorders.

Kenyans with autism exhibited a definite trend of having more issues with all behavioral indicators of autism than their American counterparts. The autistic people were grouped into four age groups. Kenyans with autism had fewer difficulties on the sensory subscale of the ABC when they were 3–7 years old. Kenyans aged 8–12 had fewer issues with the GARS' social engagement. According to the researchers, there was no significant difference in symptoms between normal Kenyans

and those in the United States. The only difference between Kenya and the US was due to true differences in autistic behavioral symptoms, not to rater perception. An interesting finding was that at age 13–17, behavioral symptoms were fewer for both groups but increased at age 18–21 for both groups. Overall, the behavioral symptoms of autism increased by age for the Kenyans group and decreased with age for African Americans.

3. RESEARCH METHODOLOGY

Google Scholar, ERIC, EBSCO, Academia, and ResearchGate databases were utilized to search for papers on culture, autism, and quality of life for this systematic literature review study. Quantitative, qualitative, and mixed-method papers relevant to culture and QoL for CWA were included to acquire a thorough understanding of societal attitudes and QoL for CWA (Miles et.al. 2014). We followed the Preferred Items for Systematic Reviews and Meta Analysis (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009) to ensure that our review was systematic, and we completed the following steps: (1) defining relevant studies and establishing inclusion/exclusion criteria; (2) developing the search strategy; (3) identifying potential studies through searching and screening; (4) describing and appraising included studies; and (5) analyzing included studies These procedures are explained below.

3.1 Identification of Relevant Literature Material

The search took place from 25th August 2021 to 25th November 2021 (Google Scholar and ERIC 25th Aug-25th Sept), EBSCO and PubMed (25th Sept- 25th Oct), and

ResearchGate (25th Oct- 25th Nov). There were no limitations on the year in which the book might be published.

3.2 Inclusion and Exclusion

Reviews of autism spectrum disorder, quality of life, and cultural perceptions of having a child with ASD were among the articles considered in this systematic literature review. Furthermore, the diagnostic criteria for CWA that were mentioned in the articles were not included in this study. Articles were included if they mentioned and further related to the key terms used during the search for the purpose of evaluating the influence of cultural conceptions on QoL of CWA and their parents in the context of educational services in Kenya. Articles largely focused on the following subjects were also excluded: teaching methodologies for CWA and the impact of CWA.

4. RESULTS

Figure 1 shows the 23 papers found using the search approach, which was published between 2000 and 2021. A total of 23 items were identified at the initial round of inclusion and exclusion. The number of articles was reduced to thirteen in the second step (screening), and five of them were eliminated in the third round (eligibility). In the systematic review literature search, this resulted in a final set of five papers being included.

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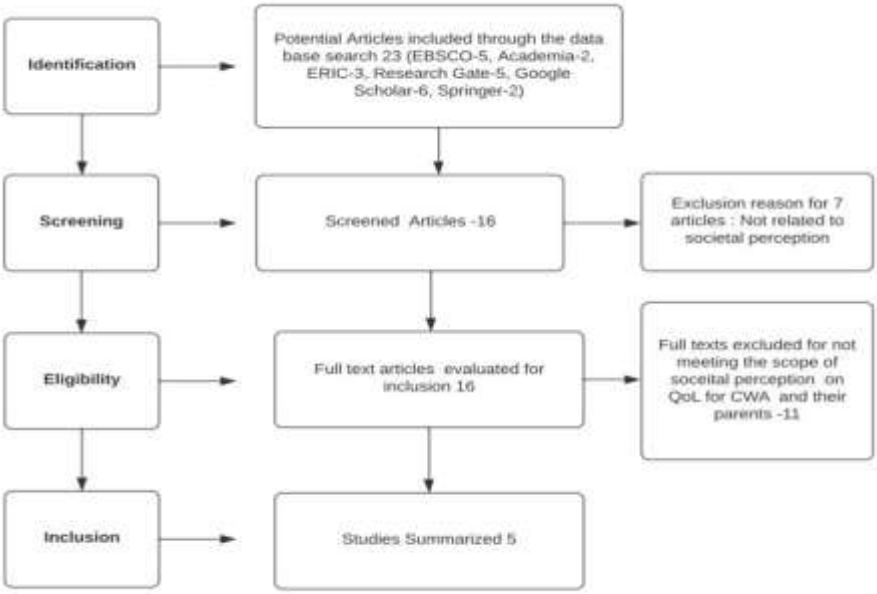

Figure 3. Result of literature search

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Table 1. A Summary Table of Coherent and Contradictory Indications of Societal Perception on QoL of CWA and their parents

Author	Year	Search Word	Participants	Significant Findings	Search database
De Vries, M., & Geurts, H. M.	2015	Perception and Parental QoL	CWA aged 8-12	Low QoL was linked to higher levels of autism characteristics and EF deficiencies, according to the authors, and this was attributable to their parents' lack of exposure to CWA due to cultural beliefs and social perceptions about parenting a CWA.	Research Gate
Rainy, Y.E., Cusekelly, C.,& Meredith, P.	2016	Perception and Parental QoL	Nine parents of CWA	Traditional cultural views regarding appropriate behavior during pregnancy, karma, and God's plan, all of which are not commonly recorded in the literature of Western countries	ERIC
Enea V., & Rusu, D.M	2002	Perception and CWA QoL	Systematic review 45 Articles were selected	Single young moms with maladaptive coping methods who have an ASD kid with problem behaviors and sensory processing problems are most at risk for high levels of parenting stress and poor mental health.	Google Scholar

Seo	1992	Perception and CWA QoL	75 participants	There were variations in social impairments and developmental disorders. The disparities were due to changes in symptoms rather than parental perception.	ERIC
Wambui respondents	2005		80 including 40 African Americans and40 Kenyans	There was a significant differencein symptoms between Kenya and the UnitedStates. The differencewas due to genuine differences in autismbehavioral symptoms, not to changes in later perception.	Google Scholar

4.1 Tools used to Measure the Quality of Life in Children with Autism

Five tools were used to assess the QoL of CWA. The psychometric properties of the tools and the population in which the tools were used are described below. The Autism Behavior Checklist (ABC) and the Gilliam Autism Rating Scale (GARS), Full-Scale Intelligence Quotient (FSIQ), Neonatal Behavioral Assessment Scale (NBAS), and Social Responsiveness Scale (SRS).

4.1.1 The Autism Behavior Checklist (ABC)

The Autism Behavior Checklist is a self-administered, norm-referenced test designed to help diagnose people with autism,

as well as construct and manage educational programs for those on the spectrum. Its administration time varies based on the components used; the Autism Behavior Checklist might take anywhere from 10 to 20 minutes to complete. Component 1 is performed by a parent/teacher, and the findings indicate which of components 2-5 should be administered directly to the child. The test yields standard scores and percentile ranks. Based on split-half reliability, intrarater reliability was reported as a Spearman-Brown coefficient of .94, and interrater reliability as 95% agreement.

4.1.2 Gilliam Autism Rating Scale (GARS)

GARS is one of the most extensively used instruments in the world for assessing Autism Spectrum Disorder. The GARS-3 aids teachers, parents, and clinicians in recognizing autism and determining its severity in individuals (Karren, 2017). The GARS-3 is based on the American Psychological Association's (APA) 2013 diagnostic criteria for autism spectrum disorder, which were published in the Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition in 2013. (DSM-5). The GARS-3 generates standard scores, percentile ranks, severity levels, and Autism Probability. The measure is made up of 56 clearly stated items that describe the typical behaviors of people with autism. Restrictive/Repetitive Behaviors, Social Interaction, Social Communication, Emotional Responses, Cognitive Style, and Maladaptive Speech are the six subscales (Gilliam, 2014). The correlation coefficient between the GARS communication disturbance and the ABC language subscale was .63. The coefficient between social interaction on the GARS and the related ABC subscale was .69. Internal consistency was reported as quite high an alpha coefficient of .95.

4.1.3 Full-Scale Intelligence Quotient

The Intelligence Quotient (IQ) is a metric that assesses a person's cognitive abilities. The average of the scores is set to 100. The FSIQ test takes between 60 and 80 minutes to complete. If the supplemental subtests are administered, some children may take longer. The FSIQ score ranges from 40 to 160, with 40 being the lowest and 160 being the greatest. Typically, the average mean score is 100.

4.1.4 Neonatal Behavioral Assessment Scale (NBAS)

The NBAS evaluates a newborn's behavioral repertoire by scoring 28 behavioral items on a nine-point scale. It also includes a 20-item questionnaire that assesses the infant's neurological status on a four-point scale. It's been used to look into the effects of prematurity, low birth weight, undernutrition, and a variety of other pre-and perinatal risk factors, as well as the effects of prenatal substance exposure, environmental toxins, temperament, neonatal behavior in various cultures, prediction studies, and primate behavior studies (Brazelton, & Nugent) (2011). The Scale examines a wide range of activities and is appropriate for newborns and infants up to the age of two months. The examiner will have a behavioral "picture" of the infant by the end of the assessment, describing the baby's strengths, adaptive reactions, and developmental milestones.

4.1.5 Social Responsiveness Scale (SRS-2)

The SRS-2 is a 65-item rating scale developed by the Diagnostic and Statistical Manual for Mental Disorders to assess social behavior deficiencies in people with Autism Spectrum Disorder (4th ed text rev, DSM-IV-TR: American Psychiatric Association, 2000). To complete the record forms, it is believed that average reading ability is required. (Constantino & Gruber, 2021, p3).

5. DISCUSSION

Low QoL was connected to greater levels of autism features and EF deficiencies, according to De Varies and Geurts (2015), and this was owing to their parents' lack of exposure to CWA due to cultural beliefs and social attitudes regarding parenting a CWA, according to the authors. Because of this assumption, CWA is unable to receive critical therapies like occupational therapy, which would dramatically enhance their quality of life. These findings are consistent with those of Rainy et al. (2016), who discovered that a lack of exposure to their children due to a lack of discrimination from the community has a significant impact on the majority of parents' quality of life.

Rainy et al. (2016) discovered that there is growing concern that CWA and their parents face societal discrimination, which is a problem in most places of the world. Some parents avoid exposing and/or taking their children to important educational services such as specialized schooling, vocational programs, and even some home-based programs to improve their children's quality of life because they are afraid of being victimized by cultural norms. Their findings support those of Seo (1992), who said that "the difference in social impairment and developmental anomalies resulted from variances in autistic symptoms, not parental perception."

According to Enea and Rusu, CWA parents have parenting stress and mental health concerns as a result of their children's behavioral and sensory deficits (2020). The majority of their CWA have sensory integration difficulties, which makes executive functioning difficult. This has an effect on how CWA interacts with one another and does their daily jobs. This is one

factor that has an impact on their overall happiness. These findings are congruent with those of Wambui (2005), who discovered that when Kenyans with autism were 3–7 years old, they had fewer difficulties on the sensory subscale of the ABC. Kenyans aged 8–12, according to Wambui, had fewer concerns with the GARS' social participation. Furthermore, the study discovered that there was no discernible difference in symptoms between the two groups.

Parents of CWA in Kenya and the United States have distinct opinions, despite the fact that their behavioral indicators differ significantly (Wambui, 2005). Kenyan parents, according to this study, had a negative perception of the CWA's behavioral symptoms. As a result, they hide their CWA from the public eye, denying them access to educational and other related services such as occupational therapy and speech and language therapy, lowering their quality of life. The findings contrast with those of Enea and Rusu (2020), who discovered that single young moms with maladaptive coping methods who have an ASD kid with problem behaviors and sensory issues are more likely to have high levels of parenting stress and mental health concerns. The researchers came to the conclusion that parental stress has a negative impact on parents' mental health and quality of life.

6. CONCLUSION & LIMITATIONS

The systematic study of the literature has provided new and important information about society perceptions of CWA and their parents' quality of life. The new data relates to how parents feel about raising a child with autism, as well as how society regards CWA and their parents, all of which have a direct impact on a CWA's upbringing and, as a result, their

quality of life. It may be concluded that parents' attitudes on CWA resigning are diverse. The quality of life of CWA and their parents is harmed by society's cultural ideals.

Behavioral and sensory integration challenges intensify parental stress, which can lead to psychological and/or mental health concerns that negatively impact their children's quality of life. It is possible to conclude that parents' perspectives on CWA resigning are varied. CWA and their parents' quality of life is affected by society's cultural values. Parental stress is exacerbated by behavioral and sensory integration challenges, which can lead to psychological and/or mental health issues that severely impact their children's quality of life.

The database examined as a whole is inconsistent and constrained from a variety of angles. Despite the fact that research was conducted all over the world, a large number of papers, precisely 10, focus on the United States. Five studies come from China and Greece, four from the United Kingdom and Israel, and more come from the same researchers or even use the same samples. It's worth noting, though, that research is also coming from a further eleven countries, indicating a growing worldwide interest. Furthermore, there is a plethora of research on the impression of having a disabled child. The evidence base on public perceptions of CWA and their parents, particularly in the African context, is very limited, which may send the message to stakeholders that additional study on CWA and their parents' quality of life is needed. There was also an imbalance in the examined literature when it came to the investigation of distinct parental perspectives, as most studies used them as a proxy. The early literature search included a

modest number of research that used qualitative and quantitative approaches.

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