

# An Analysis of Parental Quality of Life Following an Autism Diagnosis for their Children

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**Abstract:-** The primary goal of this study's contents is to systematically review earlier studies on the quality of life in parents of autistic children and provide a significant analysis of the ways in which societal themes and facets influence the current state of affairs. Using the four dimensions of the quality of life—the physical, psychological, social, and environmental domains—as a guide, this analysis has attempted to address significant and noteworthy aspects as indicated by World Health Organization (2012). In the present study, I intend to explore the parents' opinions regarding their quality of life towards diagnosis of their children with autism. This systematic review, which adhered to PRISMA principles, sought to find and evaluate pertinent studies on parents of autistic children's quality of life (QoL). Twenty-five studies were found to be potentially relevant after a preliminary search. 12 studies were eliminated after the preset inclusion and exclusion criteria were applied because they did not meet methodological requirements, did not focus on the same demographic, or did not fall within the relevant timeframe. As a result, six papers were left in the final pool for additional synthesis and analysis. According to this review, mothers reported lower levels of physical, psychological, and environmental comfort than fathers. In the psychological and physical dimensions of QOL level, mothers and fathers differ significantly from one another. The majority of parents expressed dissatisfaction over their family life and relationships being negatively impacted by their inability to obtain funds, specialist intervention programs, and prompt diagnosis. Nonetheless, parents concurrently expressed favourable views of transformation resulting from diagnosis and successful intervention. Families with children diagnosed with autism spectrum disorder may face additional stressors due to delays and challenges in diagnosis and service availability. Families' social and professional lives, as well as their connections with friends and relatives, are all impacted by raising a child with autism. The study suggests that raising awareness about the quality of life for families of children with autism is necessary. To protect the most vulnerable families, the state should enact laws and policies pertaining to disabilities and educate the public about the various kinds of disabilities. These initial results add to our understanding of the perspectives of parents of disabled children on their child's quality of life.

**Keywords:-** Autism; Diagnosis; Services; Parent; Qualitative.

## I. INTRODUCTION

According to Nandini et al. (2015), autism is a neurodevelopmental illness that affects speech, communication, social interaction, behavior, sensory abnormalities, and intellectual capacity. The American Psychiatric Association (APA, 2013) defines autism as a neurodevelopmental disorder that affects a person's ability to grow socially, verbally, cognitively, behaviorally, and in daily life. Autism is a lifelong condition. Among the signs are poor social communication skills, narrow interests, and repetitive actions (APA, 2013). The Virginia Department of Education (VDOE) lists social interaction, communication, imitation, restricted repetitive stereotyped patterns of behavior, theory of mind, motor, sensory, and executive functions as characteristics of autism in Models of Best Practice in the Education of Students Preschool and Elementary (2011:13). Atypical restrictions in social communication, an overall adaptable and flexible structure of activities and interests, and atypical sensory sensitivity are characteristics of autism spectrum disorders (ASC) (APA, 2013). Autism is a developmental condition that can have a wide range of effects on both adults and children. Autism-related terms like "aloof" or "withdrawn" might be used to describe children who seem uninterested in the world around them. In contrast to other children, the unwillingness to participate in what is considered "normal" daily life poses an urgent challenge for caregivers and practitioners: how to gain entry to the child's world in order to provide assistance and appropriate resources (Wall, 2004)?

It is well recognized that having a child with autism spectrum disorder (ASD) puts extra strain on parenting styles, siblings who are not impacted, and family quality of life (Hock, 2012). Parents may face considerable difficulties as a result of the traits associated with Autism Spectrum Disorder (ASD), which include sensory preferences, communication difficulties, and a desire for ritualistic or repetitive behaviors (Karst & Vaughan Van Hecke, 2012). A person's view of their place in a particular cultural, social, and environmental context, as well as in connection to their own objectives, standards, expectations, and interests, is referred to as their quality of life. It is a fairly broad phrase that is influenced by a person's mental and physical well-being, as well as their degree of autonomy and independence, social context, beliefs, and interactions with the environment (WHO, 1998). A low-quality of life (QoL) is more likely for caregivers of children with ASD due to the dynamic nature of the obstacles they face. Parents must learn to accept, adjust, and deal with new knowledge and requirements when an ASD diagnosis is first made (Nik Adib et al., 2019). Parents face difficulties when a child reaches the four to eight-year-old age range due to new co-morbidities and the child's

heightened emotional or behavioural symptoms (Saito et al., 2017).

Global research has consistently shown that parents of children with ASD experience lower quality of life (QoL) than parents of children who are typically developing or even parents of children with different disabilities (Alhazmi et al., 2018). The parents also have to deal with their child's emotional difficulties and frequently unpredictable range of behaviour. This behavior may cause problems for parents, which could result in the development of chronic stress and parent burnout (Woodgate et al., 2015; Smith et al., 2010). There are a number of known factors that affect caregiver quality of life. These include the degree of general developmental delay and impairment in daily living activities; the severity of the core features of ASD; the presence of comorbidities, especially maladaptive behaviors like hyperactivity; oppositional defiant and conduct problems; anxiety and emotional symptoms.

## II. OBJECTIVE

This study aims at exploring quality of life in parents of children diagnosed with autism. The objectives of the study are:

- To explore the parents' opinions regarding their quality of life towards diagnosis of their children with autism.
- To examine how parents perceive that a child with autism affects their quality of life.

## III. REVIEW OF LITERATURE

Asahar, Abd Malek and Isa (2021) conducted a cross-sectional study to determine the factors associated with perceived quality of life and how problematic a child's autism-specific difficulties are, among the caregivers of children with ASD who attend specialized preschool programs at the National Autism Society in Malaysia. The following were some of the study's hypotheses: What is the quality of life like for primary carers of children with ASD? What are the elements that influence the quality of life of primary carers of children with ASD? The children in the study were between the ages of three and nine, and the child's clinical diagnosis of ASD had been confirmed by either a child psychiatrist, pediatrician, or family medicine specialist at least three months prior to the start of the study. Main caregivers whose child's ASD diagnosis was either unknown or suspected were excluded from the study. Quality of Life in Autism (QoLA) surveys were self-administered by the researchers. SPSS Version 24.0 was used to analyze the data. The factors linked with caregivers' perceptions of QoLA were determined using univariate and multivariate analysis, while the components associated with how problematic the child's ASD-specific issues were studied using simple linear regression (SLR). The researchers discovered that more than half of the children had at least one co-morbidity and that all children with autism had eating disorders, which were followed by ADHD. Many children went to specialty clinics, the most prevalent of which was speech treatment. Significant factors linked to QoL were identified using the regression model. When the participants reported that they

lived in an apartment as opposed to the main caregivers who lived in a single-story house, these considerations were taken into account. When compared to those who only attended training once, the main caregiver's perceived QoL was higher when they attended multiple training sessions. In their post hoc analysis, they discovered a substantial difference between families living in a tiny, congested house environment and those living in a spacious living setting, using multivariate analysis. Apart from space, housing problems such as insufficient living space and a lack of fundamental standards, for example, have been linked to greater psychological distress among mothers of children with ASD.

Heiman (2021) looked at parents' voices, as well as their emotional and practical dealing with a child with special needs. The study focused on the emotions of parents of children with autism spectrum disorder, attention deficit hyperactivity disorder, or learning difficulties. Their study was qualitative, and it examined the thoughts and feelings of 41 parents (34 mothers and 7 fathers) who were individually interviewed in their homes or at their children's schools. The mothers in their study were between the ages of 40 and 60, whereas the fathers were between the ages of 45 and 56. The sample was chosen using a convenient sampling technique. Ten children with ASD, 23 children with ADHD, and eight children with difficulties problems were among those with disabilities (29 boys and 12 girls). Their ages ranged from three to thirty-four years old. The qualitative data were analyzed utilizing interviews with 41 parents. The interviews with the parents were recorded, and the transcripts were read by two evaluators who were familiar with qualitative analysis. The primary topics were noticed, as well as the recurring sentences and terms. The evaluators listened to the recordings again and reviewed the transcripts again, noting the parents' distinct language as well as certain patterns or concepts from the participants' interviews. The evaluators examined the cases until theoretical saturation was reached. The majority of parents viewed the diagnosing process as a tough emotional experience accompanied by dread, stress, and a sense of personal failure that led to a sense of guilt, according to their findings. In addition, the authors discovered that most parents lacked social and emotional support from their families. Parents of children with ASD remarked that extended family communication has a negative impact on their core family, interfering with or even contradicting family rules of behaviour. As a result, some parents have developed a fear of discussing ASD with their wider family. The majority of parents expressed complicated emotional reactions such as humiliation, embarrassment, anger, and despair, as well as a great deal of effort to improve their child's social, behavioural, and academic surroundings, as well as high expectations for the school period.

The mediating role of mindfulness and acceptance was examined in a study by Jones et. al (2014) titled Child Behavior Problems and Parental Well-Being in Families with Children with Autism. The association between child conduct and parental distress was examined by the authors to see if psychological acceptance and mindfulness could act as mediators. Involved were 71 mothers and 39 fathers of

children with ASD who provided information on their own psychological well-being, both good and negative, as well as their child's behavioral issues. It was discovered that psychological acceptance acted as a mediating factor for both paternal depression and mother anxiety, depression, and stress. Maternal stress, anxiety, and depression were significantly mitigated by mindful parenting and general mindfulness. With implications for parent assistance, these findings add to the body of literature suggesting that acceptance and mindfulness are significant psychological processes for parents.

Islam et al. (2021) investigated the impact of behavioural issues in children on the autistic spectrum on parental QoL. The study's major goal was to look at the link between parental QoL and the severity of autism symptoms. The scientists also wanted to know if sociodemographic characteristics, a child's cognitive level, or a child's behavioural profile could explain this association. Parents and their children aged two to six years who were enrolled in an early intervention program at the KU Marcia Burgess Autism Specific Early Learning and Care Centre (ASELCC) Liverpool, Sydney, Australia were involved in the study. The study included a total of 97 children and 97 parents who identified as primary carers. Within eight weeks of starting the early intervention program at ASELCC, the child was assessed. The researchers employed the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) and the Mullen Scale of Early Learning as assessment instruments (MSEL). The VABS (2nd edition) was designed to measure adaptive/functional ability levels in four broad domains: communication, socialization, activities of daily living, and motor abilities. As an extra behavioural comorbidity assessment, the Child Behaviour Checklist (CBCL) was used. At enrolment, parents or carers filled out questionnaires that rated the child's behaviour as well as the parents' quality of life. Participants' sociodemographic and clinical characteristics were presented using descriptive statistics. To investigate the relationships between sociodemographic characteristics and baseline scores from parents' reported Quality of Life in the autism Questionnaire, bivariate and correlational analyses were used (QoLA). Only variables that were substantially different from zero were included in the multivariate Wald test analysis. After that, each level of analysis was subjected to linear regression. The researchers discovered that mothers of children with more autism symptomatology were more likely to be depressed and to report a negative impact on their interactions with spouses, extended family, and friends. Autism was discovered to have a negative relationship with parents' perceptions of their own quality of life. Furthermore, as the severity of autism increases, the child's caretaking and educational needs increase, potentially jeopardizing the parents' social interaction with their family, family, and work. Parents of autistic children with at least one sibling were found to have a higher overall opinion of life quality.

Dong et al (2019) investigated the link between sleep issues in children with autism and parental quality of life. The study's major goal was to see how and to what extent sleep issues in children with autism affected their parents'

quality of life. A case-control study was used by the authors. The study included 440 children with ASD, ranging in age from 4 to 10. The Children's Sleep Habit Questionnaire (CSHQ) was used to assess sleep difficulties in the children, while the Short Form 36 Health Survey Questionnaire Version 2.0 was utilized to assess parental QoL. (SF-36v2). The Zarit Caregiver Burden Interview (ZBI) was used to assess the parents' childcare burden. To investigate the influence of sleep issues on parental QoL, the authors utilized linear regression and route analysis. The total CSHQ scores were negatively linked with the maternal mental health summary, according to the linear score regression model. Sleep issues in ASD children had both direct and indirect consequences on maternal health, according to the pathway analysis. When the ZBI scores of fathers and mothers of children with ASD were compared to those of parents of typically developing children, it was discovered that fathers and mothers of children with ASD had considerably higher ZBI scores. CWA was divided into two groups by the authors: good sleepers and poor sleepers. The parental SF-36v2 scores of good sleepers and poor sleepers were compared. Parents of good sleepers had a considerably higher physical health score than parents of bad sleepers in the ASD group, but the mental health scores were not statistically different.

Masaba, Taisawa, and Mmusi-phetoe (2021) investigated the difficulties faced by carers of children with autism spectrum disorder. A systematic review was used by the writers. The researchers employed a qualitative study based on meta-aggression methodologies and theme analysis. A systematic search for the articles was from the following databases Scopus, Science direct, PUBMED, OVID and google scholar. The authors conducted the search from February 2019 to January 2020. The data was then organized into themes. The Critical Appraisal Skill Program was used to assess the quality of the studies included (CASK). The search yielded 909 articles, 9 of which met the criteria and were included in the study. The authors classified their findings into three major thematic areas namely: stigma, financial burden, and caregiver burden. The authors stated in their discussion of the review's findings that the communities where the participants dwell think that ASD is caused by women's previously forbidden cultural behaviors or marriage to members of certain forbidden tribes. Because the child's mother is divorced, the stigma and rejection have sometimes resulted in family breakups. Furthermore, the authors discovered that the caregiver is stigmatized by the community and friends as a result of their rejection. Some have also been accused of bringing the sickness into the neighbourhood. This is due to the general public's lack of knowledge of the ASD condition.

#### IV. PROBLEM STATEMENT

Even though autism spectrum disorder (ASD) is becoming more common, there are still a lot of unanswered questions about how raising an ASD child may affect parents' quality of life over the long run (QoL). Compared to parents of children who are usually developing, parents of children with autism spectrum disorder (ASD) are known to endure a

considerable deterioration in their quality of life (QoL) (Ma, R., et al. (2016). Many times, this drop is linked to things like more stress, financial hardship, and social isolation (Hastings, R. P., et al. 2009). Nevertheless, current research paints a fragmented picture of parental QoL and does not provide a comprehensive explanation of the elements that affect it or how these factors change depending on the setting. Inconsistencies and unsolved questions persist, despite research painting a largely negative picture, with parents of children with ASD experiencing worse QoL compared to the general population. These encompass the diverse effects contingent on variables such as child attributes, parental qualities, and the availability of support networks. In order to create supportive networks and interventions that empower parents and enhance their general well-being, it is imperative to address these gaps. This will eventually benefit the entire family.

## V. SIGNIFICANCE

It is critical to comprehend the difficulties parents of children with ASD encounter and the variables affecting their quality of life. The creation of focused treatments and support networks for this demographic can be guided by this understanding. In the end, these interventions can provide a more pleasant environment for parents and children with ASD by addressing specific needs and enhancing parental welfare.

## VI. RESEARCH METHODOLOGY

For this systematic literature review study, papers on culture, autism, and quality of life were found using the databases ResearchGate, ERIC, EBSCO, and Google Scholar. To obtain a comprehensive picture of societal views and QoL for CWA, articles using mixed methods, quantitative, and qualitative approaches that were pertinent to culture and QoL were included (Miles et al., 2014). To make sure that our review was systematic, we followed the

Preferred Items for Systematic Reviews and Meta Analysis (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009). To do this, we did the following steps: defining pertinent studies and creating inclusion/exclusion standards; (2) creating the search plan; (3) finding possible studies by searching and screening; (4) characterizing and evaluating included studies; and (5) evaluating included studies. These procedures are explained below;

### ➤ *Identification of Relevant Literature Material*

The search was conducted using Google Scholar (25th–5th Sept.), ERIC (7th–20th Oct.), and ResearchGate (2nd–20th Nov.) between September 25, 2023, and January 25, 2024. There were no limitations on the year the work may be released.

### ➤ *Inclusion and Exclusion Criteria*

Articles that were taken into consideration for this preliminary literature assessment included reviews on parental quality of life and autism spectrum disorder. Moreover, this study did not incorporate the diagnostic criteria for CWA that were referenced in the articles. Articles that evaluated the quality of life of parents of children diagnosed with autism and made further references to the keywords used during the search were included. Excluded were articles that mostly discussed the opinions of caregivers regarding increasing CWA and general teaching methods for children with autism.

### ➤ *Search Results*

The search method's findings, which included 25 papers published between 2012 and 2021, are displayed in Figure 1. Fifteen items in all were found during the first round of inclusion and exclusion. In the second round (screening), there were only 12 items total; six of those were removed in the third round (eligibility). As a result, six papers were included in the final selection.

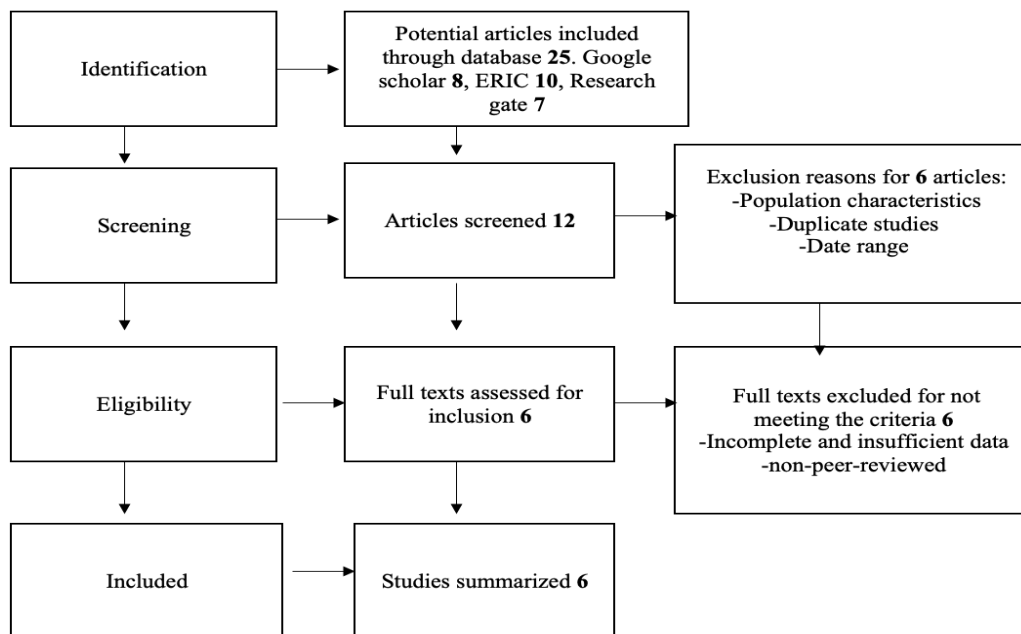


Fig 1: Results of literature review  
Source : Author

Table 1 A Summary Table of Coherent and Contradictory Indication of Quality of Life in Parents of Children Diagnosed with Autism

Author	Year	Search word	Participants	Significant findings	Search data base	Data Analysis
Asahar, Abd Malek and Isa	2021	Quality of life (QoL)	children in the study were between the ages of three and nine and care givers	more than half of the children had at least one co-morbidity and that all children with autism had eating disorders, which were followed by ADHD. There was greater psychological distress among mothers of children with ASD.	ERIC	Quality of Life in Autism (QoLA) surveys SPSS Version 24.0 was used to analyze the data. Regression analysis and post hoc analysis
Heiman	2021	Parental QoL	Ten children with ASD, 23 children with ADHD, and eight children with difficulties problems, 41 parents	The majority of parents viewed the diagnosing process as a tough emotional experience accompanied by dread, stress, and a sense of personal failure that led to a sense of guilt. parents lacked social and emotional support from their families. interfering with or even contradicting family rules of behaviour.	Research gate	Qualitative analysis: Interviews and observation (Triangulation)
Jones et al	2014	Parents & QoL	71 mothers and 39 fathers of children with ASD	Psychological acceptance acted as a mediating factor for both paternal depression and mother anxiety, depression, and stress. Maternal stress, anxiety, and depression	Google Scholar	SPSS Version 24
Islam et. al	2021	Parental QoL	97 children and 97 parents	Mothers of children with more autism symptomatology were more likely to be depressed and to report a negative impact on their interactions with spouses, extended family, and friends. Autism was discovered to have a negative relationship with parents' perceptions of their own quality of life.	Research gate	Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) and the Mullen Scale of Early Learning as assessment instruments (MSEL). multivariate Wald test analysis and linear regression
Dong et al	2019	Autism & Parental QoL	440 children with ASD, ranging in age from 4 to 10.	The total CSHQ scores were negatively linked with the maternal mental health summary, according to the linear score regression model. Sleep issues in ASD children had both direct and indirect consequences on maternal health, according to the pathway analysis.	Google Scholar	Children's Sleep Habit Questionnaire (CSHQ), Health Survey Questionnaire Version 2.0, Zarit Caregiver Burden Interview (ZBI) . linear regression and route analysis
Masaba, Taisawa, and Mmasi-phetoe	2021	Autism & Parental QoL	A systematic searchdatabases Scopus, Science direct, PUBMED, OVID and google scholar.909 articles, 9 of which met the criteria	ASD is caused by women's previously forbidden cultural behaviors or marriage to members of certain forbidden tribes.	ERIC	Thematic Analysis

## VII. DISCUSSION

The results of the study demonstrated that parents of children in good health had a statistically significantly higher quality of life than mothers of children with ASD. They stated as much in their own report. The parents' assessments indicated that daily tasks, anxiety, emotional functioning, and communication presented the largest obstacles for them. Mothers with children with chronic illnesses and autism have a lower quality of life than mothers of healthy children, according to a previous study.

Their findings showed that most parents saw the diagnosis process as a difficult emotional experience that was accompanied by stress, anxiety, and a sense of personal failure that resulted in guilt. The authors also found that the majority of parents did not receive social or emotional assistance from their families. The communication between extended family members interferes with or even goes against the rules of behavior inside the core family, according to parents of children with ASD. Because of this, some parents are afraid to talk about ASD with their extended family (Heiman, 2021). Most parents described complex emotional responses such as shame, embarrassment, rage, and hopelessness in addition to exerting a lot of effort to enhance their child's social, behavioral, and academic surroundings as well as high expectations for schools.

Because they did not feel positive emotions like joy, pleasure, loveliness, pride, or hope fulfilment, parents of children noticed a significant increase in depressed symptoms and unfavourable emotional conditions. Over time, it was found that parents of autistic children complained about severe and chronic stress, emotional and cognitive problems, and a range of physical impairments more frequently than parents of healthy children. Mothers of children exhibiting higher levels of autism symptomatology also reported higher rates of depression and poor effects on their relationships with friends, spouses, and extended family. It has been found that parents' assessments of their own quality of life are negatively correlated with autism (Islam, 2021). In addition, the child's care and educational needs escalate with the degree of autism, which may put the parents' ability to socialize with their relatives, coworkers, and other family members at risk. It was discovered that parents of autistic children who had at least one sibling had a better overall perception of life quality.

The maternal mental health summary and the total CSHQ scores were found to be adversely correlated by Dong et al. (2019) using a linear score regression model. The pathway analysis revealed that sleep problems in children with ASD had an impact on maternal health, both directly and indirectly. It was shown that fathers and mothers of children with ASD had significantly higher ZBI scores than parents of typically developing children when the ZBI scores of these parents were compared. Mothers with autistic children are living less fulfilling lives on a physical and psychological level. Mothers of children who are generally developing have more leisure time and engage in more employment, entertainment, and social activities.

Furthermore, the parental SF-36v2 ratings of individuals with good and bad sleep quality were compared. In the ASD group, parents of better sleepers scored much higher on physical health than parents of worse sleepers, but there was no statistically significant difference in the mental health scores. Mothers of autistic children experience psychological strain, tension, despair, and anxiety for the future of their kid. The majority of their time is also devoted to meeting the child's nutritional, medical, therapeutic, and rehabilitative needs.

ASD is brought about by women marrying into specific taboo tribes or engaging in previously prohibited traditional activities. Family dissolution has occasionally occurred as a result of the stigma and rejection associated with the child's divorced mother. Additionally, the authors found that because of their rejection, friends and the community stigmatize the caregiver (Masaba, Taisawa, and Mmusiphotoe, 2021). One of the main sources of stress for parents is their inability to take advantage of the latest choices for child treatment and rehabilitation due to budgetary limitations. As a result, there might be conflict and a family crisis in addition to guilt feelings brought on by fatigue, lack of sleep, and a disability, all of which lead to neglected parental responsibilities.

## VIII. IMPLICATIONS

There were not many studies using mixed, qualitative, and quantitative methods in the literature search. Because there are many different kinds of interventions and terms used to describe them, the collection of papers found is diverse. Early and accurate diagnosis combined with good care may not only improve child-specific results but also reduce some of the stressors that negatively impact family dynamics and quality of life. The quality of life of these families is investigated in relation to the financial aspects, health, values, family support, occupation, relationships within the family, and individual support components of developmental impairments.

## IX. LIMITATION

Although PRISMA advises scanning several databases, the selection of certain databases can affect the number of research found. Furthermore, the overall rigour of the review was compromised by the quality and variability of the selected papers. Disparities in research design, methodology, and reporting standards among various publications impeded the comparability of results, thereby resulting in the introduction of bias into the results synthesis.

## X. CONCLUSION

The findings offer valuable perspectives into the perspectives of parents of autistic children, which could aid in the creation of suitable therapies to assist these parents. Healthcare professionals, including nurses and doctors, can improve the health outcomes of families whose children have been diagnosed with autism by offering them support and understanding. Healthcare providers should concentrate on

determining the needs of families in order to develop and carry out programs that are suitable. The findings demonstrated that families of children with ASD/ASD concerns reported worse Social and Psychological QoL and lower Environmental and Physical QoL than families of children with typical development and other issues. Moreover, Social QoL was substantially poorer than Physical and Environmental QoL and Psychological QoL was significantly worse than Environmental QoL among families of children with ASD/ASD concerns. Future research should focus on enhancing the quality of life for parents with autistic children and determining how special it is for encouraging parental upbringing of their CWA.

### REFERENCES

- [1]. Alhazmi, A.; Petersen, R.; Donald, K.A. (2018). Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatr*, 30, 226–231.
- [2]. Asahar, S, F., Abd Malek,K., & Isa, M. R.(2021). Quality of Life and Child's Autism Specific Difficulties among Malaysian Main Caregivers: A Cross-sectional Study. *International Journal of Environment Research Public Health* 18(18), 9861
- [3]. APA [American Psychiatric Association] (2013) *Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-5)*. American Psychiatric Association, Washington DC
- [4]. Dong Huixi, Wang Ying, Lu Xiaozhi, Li Yamin, Xun Guanglei, Xia Kun, Zhao Jingping, Ou
- [5]. Jianjun, Shen Yidong . (2019 ).The Association of Sleep Problems with Children with Autism and Parental Quality of Life. *Preliminary Report: Central South University Xiangya*
- [6]. Eapen, V.; Guan, J. (2016). Parental quality of life in autism spectrum disorder: Current status and future directions. *Acta Psychopathol*: 2, 1.
- [7]. Hastings, R. P., et al. (2009). The impact of autism on quality of life for parents of children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 39(4), 621-628.
- [8]. Heiman, T. (2021) Parents' Voice: Parents' Emotional and Practical Coping with a Child with Special Needs. *Psychology*, 12, 675-691
- [9]. Hock R, Timm T, Ramisch J. (2012). Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child Fam Soc Work* ;17:406-15.
- [10]. Islam, R, Azim, S.; Masi, A.; & Klein,L. (2021). Behavioural Concerns of Children on the Autism Spectrum and the Impact on Parental Quality of Life. Univesity of New South Wales and South Western Sydney
- [11]. Jones,L; Richard, P; Hastings,V; Keane,L; Rhula; N (2014).Child Behavior Problems and Parental Well-being in Families of Children with Autism :The Mediating Role of Mindfulness and Acceptance. *American Journal of Intellectual and Developmental Disabilities*. 119(2):171-185
- [12]. Karst J, Vaughan Van Hecke A. (2012). Parent and family impact of autism spectrum disorder: A review of a proposed model for intervention evaluation. *Clin Child Fam Psychol Rev*;15:247-77.
- [13]. Ma, R., et al. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Quality of Life Research*, 25(11), 2677-2690.
- [14]. Masaba,B.B., Taiswa,J. & Mmusi-phetoe, R.M (2021) Challenges of Caregivers Having Children with Autism Spectrum Disorder in Kenya: Systematic Review.*Iranian Journal of Nursing and Midwifery Research*: 26 (5) 373-379
- [15]. Nik Adib, N.A.; Ibrahim, M.I.; Ab Rahman, A.; Bakar, R.S.; Yahaya, N.A.; Hussin, S.; Wan
- [16]. Mansor, W.N.A. (2019). Predictors of caregivers' satisfaction with the management of children with autism spectrum disorder: A study at multiple levels of health care. *Int. J. Environ. Res. Public Health*, 14, 1684.
- [17]. Saito, A.; Stickley, A.; Haraguchi, H.; Takahashi, H.; Ishitobi, M.; Kamio, Y. (2017). Association between autistic traits in preschool children and later emotional/behavioral outcomes. *J. Autism Dev. Disord*; 47, 3333–3346.
- [18]. Smith, L.E.; Hong, J.; Seltzer, M.M.; Greenberg, J.S.; Almeida, D.M.; Bishop, S. (2010).
- [19]. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *J. Autism Dev. Disord*: 40, 167–178.
- [20]. The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med*. 1998;28(3):551-8.
- [21]. Woodgate, R.L.; Edwards, M.; Ripat, J.D.; Borton, B.; Rempe, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatr*, 15, 197.
- [22]. Wall, K (2004)A Guide for Early Years Professionals, Teachers and Parents. Sage Publication: Thousand Oak
- [23]. Virginia Department of Education (2011). Models of Best Practice in the education of students with Autism Spectrum Disorders