

Determining the Efficacy of Interventions to Improve the Quality of Life for Children with Autism and their Families

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Abstract:- The idea of quality of life has developed into a core idea in both theoretical and practical research to the point where it is now used as a key framework for developing and evaluating supports and services. For persons with disabilities and their families, it also serves as a theoretical research model, a guideline for creating evidence-based practices, and a way to put into practice and redefine professional practices. The study set out to explore the efficacy of interventions to improve the Quality of Life (QOL) for Children with Autism (CWA) and their families. The study aimed to examine in depth parents' perspectives (past and present experiences) and expectations (on future) towards raising their children with autism; and effectiveness of interventions towards improving the QOL of CWA and their families. A systematic review of the literature was done to locate pertinent information and locate various literature to support the QoL of CWA. The study was guided by the theory of Social Constructivism by Vygotsky in 1978. The research criteria was met by a total of 39 papers, which were then reviewed. Research gate, EBSCO, ERIC, google scholar, social services abstracts were used in an electronic database search. In comparison to parents of usually developing children or to the general community, this review found that parents of children with ASD had lower quality of life. Child behavioural issues, unemployment, being a woman, and a lack of social support were all factors linked to lower parental quality of life in this group. The study's findings further show that contextual intervention significantly increased children's engagement in activities that parents found valuable, and that working together to develop strategies for achieving goals makes parents feel more capable in their parenting roles. In comparison to adults who were not parents of children with ASD, it was discovered that QOL was lower among parents of children with ASD in terms of physical, psychological, social, and spiritual wellbeing. The greatest risk for parental QOL was the severity of the diagnosis of ASD. Education levels of the parents and the child's ASD severity levels were protective factors for parental QOL.

Keywords:- Autism, Efficacy, Interventions, Quality, Families.

I. INTRODUCTION

Autism is a neuro developmental condition affecting speech, communication, social interaction, behaviour, sensory abnormalities, and intellectual capacity, according to Nandini et al (2015, p3). When the disorder was first discovered, sensory issues-also known as difficulties processing, integrating, and responding to sensory stimuli-have been noted as a characteristic of autism spectrum disorders (ASD) (Kanner, 1944). The American Psychiatric Association describes autism as a lifelong neuro developmental disorder that can affect a person's everyday functioning and social, verbal, cognitive, and behavioural growth (APA, 2013). ASD presents as a trifecta of deficits, including difficulties with social interaction, communication, and restricted and/or repetitive behaviour, according to the three classifications. Researchers and medical professionals refer to a group of neurodevelopmental disorders as "autism spectrum disorders" (ASDs), which are characterised by qualitative impairments in social-communicative and repetitive behaviours as well as limiting behaviour and interest (Matson & Sturmey, 2011, p 37).

According to current estimates, between 45 and 90% of children with ASD exhibit these sensory impairments, which range from excessive or inadequate responsiveness to impaired perception and differentiation of feeling (Leekam et.al, 2007; Ben-Sasson et.al, 2008). The confined, repetitive patterns of behaviour, interests, or activities criteria in the DSM 5 now includes sensory problems (American Psychiatric Association, 2013). Families claim that these sensory issues cause them and their children to become socially isolated, limit their ability to participate in daily activities, and have an adverse effect on social engagement (Dickie et.al, 2009; Schaaf et.al, 2011). The most frequently requested and highly rated interventions by parents of children with ASD are therefore those that address sensory issues (Goin-Kochel et.al 2009; Mandell et al, 2005). According to survey results, more than 60% of children with ASD receive some kind of sensory intervention. Although sensory therapies for ASD are frequently used, a variety of regimens are used with conflicting evidence of their effectiveness.

According to the Centers for Disease Control and Prevention (CDC), autism spectrum disorder (ASD) is characterised as having "impairments in social, communicative, and behavioural development that typically begin before the age of three years and are frequently accompanied by abnormalities in cognitive functioning, learning, attention, and sensory processing" (Centers for Disease Control and Prevention, 2011). According to Marchant et al. (2006), three characteristics must be present in order to diagnose autism: impairment of social connections, rigidity and inflexibility of thought processes, and specific language impairment (p.230). One of those widespread illnesses, such as autism, often goes unrecognised or undiagnosed during a child's formative or developing years (Nandini et.al. 2015 p45).

Early intervention may have a corrective or preventive purpose (Corsello, 2005). Remedial services are intended to aid the kid in moving forward, overcoming the obstacles presented by their condition, and minimising the effects of their impairment. Therapy, dietary issues, and behaviour management are just a few of the demands that remedial services may assist parents address (Corsello, 2005). The goal of a preventative intervention is to stop a child who is at risk from developing an impairment. The child alone or the family as a whole may be the subject. Early intervention programs might be centre-based, school-based, home-based, hospital-based, or a combination of these, according to Mortimer, Hover, and Ogden (2005). Services include hospital identification, screening at schools, referral services, and programs for diagnostic and direct intervention. Early intervention can start whenever a child is born until they are in grade school.

Relationship Development Intervention (RDI), a popular play-based early intervention technique used by parents, first helps children bond with their parents before assisting them in forming relationships with others (Gutstein, 2001). This is a play-based therapy intervention for people with relationship-based disorders like autism spectrum disorder. This programme is built on the paradigm of Experience Sharing created by Steven Gutstein. Before he created RDI, Gutstein (2001) researched the processes through which typical children learn to understand and form connections with others. People with autism spectrum disorders have a path to friendship, empathy, and a joy of sharing their environment with others thanks to the RDI Program (Gutstein and Sheely, 2002). When true emotion is incorporated into language, it comes to life. People with Autism and Asperger's learn to not only endure but also to appreciate change, transition, and going with the flow, according to Gutstein et al. (2002). It carefully teaches the skills necessary for competence and fulfilment in a complicated world, such as sharing playthings and waiting one's turn in play, by starting at the edge of each person's existing capabilities.

QoL is described as "individuals' assessments of their place in life in respect to their ambitions, aspirations, standards, and fears in the context of the culture and value systems in which they live" by the World Health Organization (WHO, 2012:11). A person's physical health,

physiological state, level of independence, social contacts, personal perspectives, and linkages to important environmental factors are all included in this broad term. A person's quality of life (QoL), which encompasses several aspects of functioning related to health, happiness, self-esteem, mental health, and life satisfaction, is measured by their level of happiness, self-esteem, mental health, and life satisfaction (Cummings et. al, 1994).

The fundamental QoL domains vary depending on the researcher's field and expertise. Schlock and Alonso's (2002) Quality of Life model for intellectual impairments lists physical well-being, material well-being, rights, social inclusion, interpersonal connections, self-determination, personal growth, and emotional well-being as essential categories. A person's quality of life can be evaluated using the indicators that make up each of these indicators. The administration and implementation of interventions for individuals with disabilities have been improved by using quality of life indicators for more than three decades (Burgess & Gutstein, 2007). Many studies, programs, and initiatives have used QoL measurements to assess treatment success and improve service delivery strategies (e.g., Varni 1998).

II. REVIEW OF LITERATURE

Asahar, Abd Malek, and Isa (2021) conducted a cross-sectional study among the caregivers of children with ASD who attend specialised preschool programs at the National Autism Society in Malaysia to ascertain the factors associated with perceived quality of life and how problematic a child's autism-specific difficulties are. Some of the study's hypotheses were as follows: How would you rate the quality of life for parents of children with ASD? What factors affect the primary caregivers of children with ASD in terms of their quality of life? The children in the trial ranged in age from three to nine, and at least three months before the study's launch, either a child psychiatrist, paediatrician, or family medicine expert had verified the children's clinical diagnosis of ASD. The data was examined using SPSS Version 24.0. Using univariate and multivariate analysis, caregivers' views of QoLA were identified, and simple linear regression was used to identify the characteristics related to how difficult the child's ASD-specific concerns were (SLR). The researchers found that more than half of the children had at least one co-morbidity and that eating disorders were the most common comorbidity in children with autism, followed by ADHD. Many children visited speciality clinics, with speech therapy being the most popular.

Mc Stay, Trembath, and Dissanayake (2014) assessed stress and family quality of life among parents of children with an autism spectrum disorder within the context of the ABCX paradigm. The study's objectives were to examine the impact of stressors—such as child problem behaviour, child ASD severity, child adaptive functioning, and life stress—resources—such as family hardiness, family environment, marital support, and social support—appraisals—such as family sense of coherence—and coping mechanisms—such as family coping—on parental stress and

family quality of life when raising children and adolescents with ASD. The study involved 196 parents (98 mother-father pairs) of Australian children and teens (84 boys and 14 girls) with community-based ASD diagnosis. Children with ASD ranged in age from 3 to 16 years old. Parents responded to questionnaires that used a cross-sectional approach to examine components of the double ABCX model associated with family adaptation. Among the questionnaires administered to the parents were the Social Communication Questionnaire (SCQ), Behaviour Assessment System for Children (Second Edition), Vineland Adaptive Behavior Scale (Second Edition), Sense of Family Coherence Scale (FSOC), and Family Quality of Life Survey (FQOL). To analyse the relationship between the child, mother, and paternal reports of variables, Pearson Product Moment Correlation Coefficients were calculated within the Double ABCX model. Using descriptive statistics, percentage means and standard deviations were computed. High levels of ASD symptomatology were shown to predict high stress and low family quality of life in mothers, while high levels of adaptive functioning were found to predict high stress and low family quality of life in fathers. Also, fathers who received less social support were more likely to be under a lot of stress. The researchers also found that a child's externalising behaviours can account for a significant portion of variation in maternal stress. The same study also discovered that the child's externalising behaviours and the family's sense of coherence were distinct predictors of maternal stress. A clinical analysis of parental scores revealed that mothers of autistic children experienced higher levels of stress than fathers.

The challenges faced by caregivers of children with autism spectrum disorder were examined by Masaba, Taisawa, and Mmusi-phetoe (2021). The writers conducted a thorough review. The study's authors used a randomised controlled trial to examine the effectiveness of the drug. The following databases, Scopus, Science direct, PUBMED, OVID, and Google Scholar, were thoroughly searched for the publications. The search was done by the writers between February 2019 and January 2020. Next, the information was categorised into themes. The effectiveness of the studies included was evaluated using the Critical Appraisal Skill Program (CASK). Nine papers that fit the requirements and were included in the study were found among the search's 909 results. The authors divided their research into three main theme areas: caregiver burden, financial burden, and stigma. The communities where the participants live believe that ASD is caused by women's previously taboo cultural activities or marriage to members of specific forbidden tribes, according to the authors' interpretation of the review's findings. The stigma and rejection associated with the child's mother being divorced have occasionally led to family dissolution. The authors also found that because of their rejection, the caregiver is stigmatised by the community and friends. Others have been charged with spreading the disease around the neighbourhood. This is a result of the general populace's ignorance of the ASD condition.

One of the most significant explanations of art-based intervention was written by O'Sullivan (2015), who examined the results of using theatre as an art-based intervention for children with autism. "Drama intervention tries to create unique, enjoyable, and engaging chances for persons with an autistic spectrum condition to practise a wide variety of social skills in the safety and protection of a working environment," he noted while outlining the implications of his research. The use of drama, according to him, can range from a large group to a one-on-one setting, and it works by constructing a false framework (a pretend scenario) that grabs participants' attention and encourages interaction and conversation.

Schaaf et al. (2012) did a study on the use of occupational therapy and sensory integration to increase engagement in an autistic child: In this case study, a 10-week intense occupational therapy program using a sensory integrative approach is detailed along with changes in one autistic child's adaptive behaviours and engagement (OT-SI). The Sensory Integration and Praxis Tests findings showed improvements in sensory processing, and parent-rated goal achievement scores showed increased participation in activities at home, at school, and with the family.

Cale, et al. (2009) did a study on context-based evaluation and intervention for problem behaviour in children with autism spectrum disorder: In order to determine whether context-based therapies reduce problem behaviour in ecologically sound environments, this study used a context-based model of assessment and intervention (i.e., typical routines implemented by typical education personnel in neighbourhood schools). In order to detect problematic situations, eight children with autism spectrum disorder's parents and teachers were given the Contextual Assessment Inventory (CAI) and a post-assessment interview. Then, in three priority situations, namely transitions, the end of desired activities, and the presence of a feared stimulus, environmental modification approaches were put into practice. The outcomes showed that issue behaviour in the priority settings had nearly entirely disappeared, and that tasks and routines pertaining to those contexts had been successfully completed. The importance of conceiving problem behaviour as a function of context for assessment and intervention, as well as the necessity to increase the breadth of effects to measure the approach's overall effect on encouraging meaningful behaviour change in the community, were emphasised.

A study on the effects of contextual intervention on parental competence and child engagement in autistic spectrum disorders: According to Dunn et al. (2012), a pretest-posttest repeated measures design was used: In this study, occupational therapy contextual interventions were utilised to increase parental competence and increase the engagement of children with autism spectrum disorders. With the help of 20 parents, the effectiveness of an occupational therapy intervention involving three elements—authentic activity environments, everyday routines of the family, and the child's sensory patterns—was assessed. In order to help parents find ways to achieve their

goals and create shared plans for the upcoming week, sessions included reflective dialogue with them. Parental competence was assessed using Parenting sense of competence and Parenting Stress Index, while child engagement was assessed using COPM and GAS. The findings suggested that this approach is effective in occupational therapy intervention because parents reported feeling more competent and children dramatically increased their participation in daily activities.

III. SOCIAL CONSTRUCTIVISM THEORY

The Social Constructivism theory put forth by Vygotsky in 1978 served as the foundation for this research. This hypothesis affirms "Every aspect of a child's cultural development manifests twice: once on the social level and again on the individual level; this is known as the interpsychological stage, and the other is the intrapsychological stage. This holds true for all cognitive processes, including concept creation, logical memory, and voluntary attention. All higher functions start out as genuine connections between people." (1978:57; Vygotsky). Since it considers learning as an active process where the kid actively interacts with the environment in the process of learning, this theory proved crucial in early intervention for children with autism.

IV. PROBLEM STATEMENT

Autism is a developmental disorder that can be managed if it is discovered early and the child is given the right kind of care. Yet, parents frequently lack the knowledge necessary to recognize these children and take appropriate action for them in the early years, wasting a key window of opportunity when development is at its peak. In many cases, professionals do not collaborate with parents to identify problems early and take action. The application of the construct of quality of life to children and adolescents with Autism Spectrum Disorder (ASD) has been rare and limited, despite the strides made in recent decades in its implementation and assessment in the field of disability. The majority of research on the idea of quality of life in children and adolescents with ASD has narrowly equated it to health and has concentrated on people without intellectual disabilities. According to the few research that are currently available, children with ASD have lower quality of life scores than their classmates who are typically developing or those who have other related problems. Studies examining individual quality of life in this category are even more rare; this concept encompasses not only health-related factors like the preceding one, but all domains that affect a person's life broadly.

V. RESEARCH OBJECTIVES

- To investigate the parents' perspectives (past and present experiences) and expectations (on future) towards raising their children with autism
- To examine effectiveness of interventions towards improving the QOL of CWA and their families

VI. METHODOLOGY

The databases Research Gate, ERIC, EBSCO, and Google Scholar were used to look up articles on quality of life, autism, and intervention. Quantitative, qualitative, and mixed-method articles pertaining to interventions and QoL for CWA were included to provide a thorough understanding of these interventions and QoL. (Miles et.al. 2014).

A. Identification of Literature

From 25 September 2022 to 25 October 2022, the search was conducted using GoogleScholar, ERIC, and ResearchGate (25 September – 5 October), respectively. There were no limitations on what year the publications might be released.

B. Inclusion and Exclusion Criteria

This preliminary literature review took into account articles on quality of life studies, reviews of interventions for children with ASD, and reviews of autism spectrum disorder. Moreover, this study did not take into account the diagnostic standards for CWA that were specified in the articles. In order to evaluate interventions in determining the QoL of CWA and their parents, articles were only included if they were addressed and further related to the keywords used throughout the search.

C. Search Results

The search method's findings, which included 39 papers published between 2000 and 2021, are displayed in Figure 1.14 items in all were found during the first round of inclusion and exclusion. At the second stage (screening), the number of articles was decreased to 15, and seven of them were dropped in the final stage (eligibility). This led to a final set of eight studies being included in the systematic literature review.

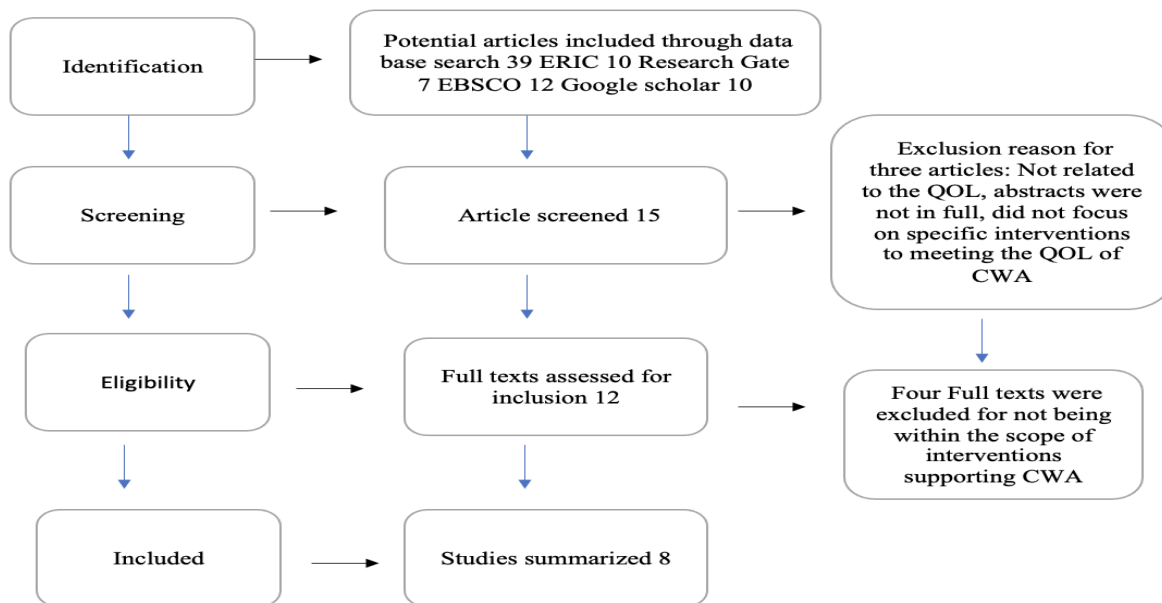


Fig. 1: Results of Literature search

A summary table of the coherent and contradicting indications of interventions towards improving the QoL of CWA and their families.

Author	Year	Search Word	Participants	Significant Findings	Search Database
Asahar, Abd Malek, and Isa	2021	Intervention, QoL, Autism	Caregivers	half of the children had at least one co-morbidity and that eating disorders were the most common comorbidity in kids with autism, followed by ADHD.	ERIC
Mc Stay, Trembath, and Dissanayake	2014	QoL, Families, Intervention/s	196 parents (98 mother-father pairs) of Australian children and teens (84 boys and 14 girls) with community-based ASD diagnosis. Children with ASD ranged in age from 3 to 16 years old.	High levels of ASD symptomatology were shown to predict high stress and low family quality of life in mothers, while high levels of adaptive functioning were found to predict high stress and low family quality of life in fathers.	Research Gate
Masaba, Taisawa, and Mmusi-phetoe	2021	QoL, Families perceptions, Autism	Systematic review (9 papers were identified)	The stigma and rejection associated with the child's mother being divorced have occasionally led to family dissolution. The authors also found that because of their rejection, the caregiver is stigmatised by the community and friends.	EBSCO
O'Sullivan	2015	Intervention, QoL, Autism	Children with Autism	Drama intervention tries to create unique, enjoyable, and engaging chances for persons with an	Google Scholar

				autistic spectrum condition to practise a wide variety of social skills in the safety and protection of a working environment	
Schaaf et al.	2012	Intervention, Autism, QoL, Families	Children with Autism	The Sensory Integration and Praxis Tests findings showed improvements in sensory processing, and parent-rated goal achievement scores showed increased participation in activities at home, at school, and with the family.	ERIC
Cale, et al.	2009	Intervention, Autism, Families, QoL	Eight children with autism spectrum disorder's parents and teachers	The outcomes showed that issue behaviour in the priority settings had nearly entirely disappeared, and that tasks and routines pertaining to those contexts had been successfully completed.	Research Gate
Dunn et al.	2012	QoL, Intervention, Families, Autism	20 parents	The pproach is effective in occupational therapy intervention because parents reported feeling more competitive and children dramatically increased their participation in daily activities.	ERIC

Table 1: Summary of Studies on the Efficacy of Interventions towards improving the QoL of CWA and their families

VII. DISCUSSION

The study's major objective was to evaluate the effectiveness of interventions to raise the quality of life for Patients and their families. Research goals have influenced how this conversation is presented. The most recent research have shown that managing and coping with a CWA with ASD presents social, psychological, as well as minimal environmental and physical obstacles to the family. The necessity to broaden the scope of impacts in order to gauge

the approach's overall effectiveness in promoting meaningful behavior change in the community, as well as the significance of conceptualizing problem behavior as a function of context for assessment and intervention, were emphasized (Cale, et al. 2009).

In other studies, Asahar, Abd Malek, and Isa (2021) found out tht CWA had at least one co-morbidity and that eating disorders were the most common comorbidity in children with autism, followed by ADHD. Many children

visited speciality clinics, with speech therapy being the most popular. The current study also discovered a direct, beneficial association between the families' perceived total Family Quality of Life (FQOL) and their family income. The more intriguing discovery in the current study, though, came from how the family valued this income. As contrast to focusing solely on the fiscal amount received, how families felt about their monthly income (i.e., struggling, just getting by, doing okay, managing well, or well off) revealed more consistent correlations with the subdomains of FQOL and suggested a higher impact on the total FQOL.

The conflicting results of earlier investigations may now make sense in light of these findings. Improvements in sensory processing were seen on the Sensory Integration and Praxis Tests, and parent-rated goal attainment scores indicated more activity participation at home, at school, and with the family. Schaaf and associates (2012). According to the study's concluding findings on parents' experiences raising a CWA, families have occasionally broken apart as a result of the stigma and rejection connected with the mother's divorce. The authors also discovered that the caregiver is stigmatized by the neighborhood and friends as a result of their rejection. The spread of the illness throughout the neighborhood is allegedly the fault of others. Masaba, Taisawa, and Mmusi-phetoe explain that this is a result of the general public's ignorance about the ASD condition (2021).

Interventions were offered to Participants and their family as indicated in this study. Depending on the original parents' work obligations and capacity to cope, the nature of ASD forces family members to step in and share the responsibility of care with the biological mothers and fathers, frequently becoming the major caregivers themselves. Research support the necessity for family-centered therapies given the burden and pervasive impacts of ASD on the family, which contribute to a general decline in family welfare. Given that both parents and children significantly increased their participation in daily activities, the results suggested that Canadian Occupational Performance Measure (COPM) and GAS (Goal Attainment Scaling) strategies are successful in occupational therapy intervention.

VIII. IMPLICATION

The results of this study provide a picture of how families with children who have ASD view their quality of life (Family Quality of Life) FQOL) and the wide variety of factors that affect it. There are significant implications for practitioners in particular that may also be applicable in other low-resource environments. Practitioners should be involved in the creation of lower-level interventions that are provided in local settings by non-expert coaches or facilitators. For instance, supportive techniques like parent-delivered interventions or family support groups may help families meet their requirements, particularly their emotional needs. Giving families more affordable options to meet their assistance requirements can be very beneficial to the family as a whole.

Regardless of the level of help required, equipping parents with knowledge and skills can be beneficial for all families. In order to lessen some of the financial burden experienced by struggling families, practitioners should assist families who require financial assistance in obtaining funding from sources that are accessible, such as the Care Dependence Grant. Finally, in order to guarantee that parents or caregivers have access to enough support, practitioners should learn who the family believes to be part of their family (for example, grandparents or other family members living in the same household) and take a family-centered approach. Practitioners must also be mindful of the potential differences between single-parent and two-parent families' conditions.

IX. LIMITATIONS

The review search identifies significant trends regarding the effectiveness of various interventions in enhancing CWAs' quality of life according to international standards used in schools, hospitals, and therapeutic facilities; however, given the nature of the articles included in each search term, the results should be carefully considered. The set of articles discovered is heterogeneous due to the numerous types of interventions and the terminologies used to describe them. The literature search included a modest number of research that used qualitative, quantitative, and mixed approaches.

X. CONCLUSION

According to the findings, 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 significantly worse than Environmental and Physical QoL among families of children with ASD/ASD concerns, and Psychological QoL was significantly lower than Environmental QoL. Together, our findings show that Social QoL—defined as happiness with close relationships and friend support—and Psychological QoL—defined as happiness with oneself, anxiety, and depression—are notably compromised for families of children with ASD or ASD concerns. Further, the study came to the conclusion that early intervention not only helped autistic children, but also their siblings, friends, and parents. Siblings also learn how to help their parents and how to deal with the unpleasant feelings that come with having an autistic sibling. Parents, particularly mothers, learn how to deal with and satisfy the demands of their children. According to the study, a range of interventions are being employed to raise CWAs' quality of life. The majority of the interventions were based on art as well as occupational therapy and had many similarities. All of the interventions had the same fundamental goals: to lessen autistic symptoms, enhance communication, social comprehension, and daily living skills. The fundamental tenets were to foster a joyful learning environment for kids, reward good behaviour, and punish bad behaviour.

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