



Comparing parent support training as occupational therapy vs. Counselling to improve psychosocial QOL in ASD parents

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Abstract

Background: ASD is a common neurological condition that affects social interaction, communication, learning, and behavior. According to the World Health Organization's ICD-11, The hallmarks of ASD include ongoing deficiencies in social interaction and communication, along with restricted, repetitive behaviors. Although symptoms begin in the beginning stages of childhood., they cannot completely show themselves until later. The disorder causes significant impairment in social, academic, professional, and personal functioning, with individuals showing a broad spectrum of linguistic and intellectual skills.

A review of 10 studies found that ASD significantly impacts family dynamics, leading to caregiver overload, especially for mothers. Up to 70% of mothers and 40% of fathers of children with severe ASD report elevated degrees of discomfort. This stress negatively affects parents' psychosocial quality of life. A client-centered occupational therapy approach, specifically Parent Support Training, has been shown to improve parents' quality of life and reduce psychological stress. This research is being conducted to gain more evidence regarding this field.

Objectives: This objective of this study is to review and analyze the effect of implementation of Parent Support Training along with Occupational Therapy Intervention on ASD Children's parents Psychosocial Quality of Life and compare with effectiveness of verbal counselling.

Study Design: Systematic Review

Methods: Preferred Reporting Items for Systematic Reviews and Meta-analyses, or PRISMA standards were followed in the conduct of this systematic review. The search was done on five databases (PubMed, Scopus, CINAHL, Web of Science & Google Scholar) to identify studies where ASD Children's Parents Psychosocial Quality of Life is affected and effect of Occupational Therapy on ASD Children's parents Psychosocial Quality of Life using a combination of keywords Parental Psychosocial Distress, Psychosocial Quality of Life, Pediatrics, Occupational Therapy (O.T.), Autism Spectrum Disorder (ASD).

Results: Out of the 250 potentially pertinent publications in the review research, 190 were eliminated as duplicates, and 5 were eliminated because they did not fit the inclusion and exclusion criteria. criteria, 15 articles didn't mention the intervention and forty of the studies were reviewed.

Conclusion: After going through with all the review included in this literature, the literature is supporting the effectiveness of implementation of Parent Support Training along with Occupational Therapy Intervention on ASD Children's parents Psychosocial Quality of Life. So, it is concluded that a proper study will give positive outcomes on parents whose children have ASD.

Keywords: Parent support training, parental psychosocial distress, psychosocial quality of life, pediatrics, Occupational Therapy (O.T.), Autism Spectrum Disorder (ASD)

Introduction

Description of ASD: Autism spectrum disorder (ASD) is a neurological and developmental illness that impacts a person's behavior, learning, communication, and social interactions. A diagnosis of autism can be made at any age, but because symptoms often manifest throughout the initial two years of life, it is referred to as a "developmental disorder." The World Health Organization's International Classification of Diseases (11th Revision), ICD – 11th, was released in June 2018 and came into full effect as of January 2022. Its description of ASD is provided in *ICD-11, chapter 6, section A02. ICD – 11 was created by experts from 55 nations among the 90 that participated and is the most commonly utilized reference globally.*

Common Autism Spectrum Disorder Symptoms

The subsequent are frequent symptoms of autism: -

- Swaying, rotating or other repeated actions
- Refraining from physical touch
- Less frequent eye contact
- Delayed development of speech
- Repetitively uttering words or brief phrases
- Inability to handle minor alterations in a daily schedule
- Limited or no involvement with peers

Prevalence: It is on average observed that around 1 in hundred children globally suffers with autism. This estimate signifies an average number, and the documented prevalence differs significantly among studies. Some

rigorously controlled studies, nevertheless, have indicated numbers that are notably greater. The frequency of autism has also changed over time, increasing significantly in the past few decades around the world. For instance, the prevalence of ASD in the America has increased from 1 in 150 children in 2000 to 1 in 44 children in 2018. India has an autism rate of 290.95 per 100k, ranking one-hundred-ninety in terms of autism rates. The total population diagnosed with autism in India is 4,046,199, and the autism rate among children is 330.89 per 100k, with a total of 1,301,859 children diagnosed with autism. The evolution of the autism rate in India is difficult to determine due to the lack of accurate and consistent data. However, recent studies suggest an increase in the autism rate in the country. Factors such as increasing awareness, better diagnosis and access to healthcare, and changes in diagnostic criteria may have contributed to the rise in autism prevalence in India.

Pathophysiology

Although a number of factors have been linked to the pathophysiology of autism disorders, the precise pathomechanism of ASD is still unknown. The genetic origin has long been considered a solid evidence-based explanation among these. According to the scientific data currently available, a child's risk of developing autism is likely influenced by a variety of factors, including genetic and environmental ones. There is evidence that ASD is associated with abnormalities in several brain regions, including the amygdala, hippocampus, and cerebellum. These brain regions are involved in social and emotional processing, memory, and motor control, respectively. According to research published in the journal *Molecular Psychiatry*, excessive synaptic activity may contribute to social interaction, communication, and repetitive behavior deficits in autism. Children with autism had about 2.5 times the number of synapses in a specific brain part known as the cerebrum, which is involved in movement and coordination, according to a study published in *Nature*.

Etiology: It is believed that both hereditary and non-genetic factors contribute to the complex etiology of ASD. Both syndromic and non-syndromic forms of ASD exist. Monogenic changes or chromosomal abnormalities are frequently linked to syndromic ASD. Because of its genetic heterogeneity, the etiology of non-syndromic ASD is still largely unknown, in contrast to syndromic ASD. It is expected that a combination of prenatal and postnatal environmental influences and de novo mutations will be involved.

Description of the intervention

Rehabilitation is a collective process. An essential and vital component of the rehabilitation processes are occupational therapy interventions (OTIs) and occupational therapists (OTs). Occupational therapy (OT), which is one of the rehabilitation professions, is a client-centered profession that helps people who are suffering participation and occupational performance limitations. OT provides a variety of rehabilitation techniques for various medical and social diagnoses. The percentage of children with ASD is steadily increasing, which significantly affects parents' overall quality of life. Their basic and instrumental ADL activities are therefore impacted by this. Therefore, this study looks at how parental social functioning distress affects social environment engagement. Psychoeducational intervention

has been shown to dramatically reduce psychological distress and enhance parents' mental health. According to Suravi Patra (2019), a module for a parent psychoeducation intervention on ASD improves comprehension of the illness and lessens parenting stress. Using psychoeducation intervention modules to empower parents is a credible and feasible approach. Parent psychoeducation intervention modules on ASD reduce parenting stress and increase understanding of ASD, according to Suravi Patra (2019). An approach to parent empowerment that is both practical and acceptable is the psychoeducation intervention module. These days, the number of cases of psychological health and quality of life decrease is increasing everyday as occupational therapy evolves in tandem with time, new technology advancements, and changes in lifestyle. Therefore, this study is required to ascertain the level of psychosocial distress that parents of autistic children spectrum disorders experience, as well as the effects of parent support training and occupational therapy interventions on their quality of life.

Methods

The systematic review adhered to the PRISMA guidelines for conducting systematic reviews. A comprehensive search was conducted in electronic databases, including PubMed, Online Journals, Google Scholar, and ResearchGate, to identify relevant articles. The following keywords were used in the search: Psychosocial Quality of Life, Pediatrics, Occupational Therapy (O.T.), Autism Spectrum Disorder (ASD). The inclusion and exclusion criteria were pre-defined to ensure the selection of studies that directly addressed the research question.

Inclusion criteria

- Parents of ISAA Diagnosed ASD Children.
- Parents of the children who were prepared to be a part in the study.
- One parent of either gender (male/female)
- Parents from Urban Areas
- Parents with no impairment in speech, hearing and vision.
- All race/religion/socioeconomic status/caste people were included.

Exclusion criteria

- Parents of ASD Children with other co-morbidities.
- Parents who were severely ill.
- Parents who refused to provide consent.

There were two independent reviewers that extracted the data and evaluated its quality. The chosen articles were assessed on approach, appropriateness, relevancy, and clarity. Articles that didn't fit the requirements for inclusion were not reviewed.

Results: A preliminary search showed up 250 potentially relevant articles. After eliminating duplicates and applying the inclusion and exclusion criteria, 10 research was included into the systematic review. The systematic literature review led us to configure and subdivide features regarding effectiveness of Parent Support Training as Occupational Therapy Intervention to parents having ASD diagnosed children in improving their psychosocial quality of life.

Table 1: Studies published between 2014 to 2024 were included in the review

S. No.	Author	Year of Publication	Research Design	No. of Participants	Sample Characteristics	Theme (conclusion)	Sub – Theme (objective)
1.	Erica Howell <i>et. al.</i>	2015	A mixed methodology design	15	families with higher functioning autism	In terms of offering useful tools for families dealing with HFA/AS, the findings have consequences for healthcare providers, family as well as neighborhood collaborators.	This study looked at the effects of families with preschoolers (15 overall) who had Asperger Syndrome (AS) and High Functioning Autism (HFA).
2.	Rabea begum <i>et. al.</i>	2019	Narrative review	10	Family having ASD children	Autism significantly alters each family member's lifestyle and has a long-lasting effect on siblings, the family, and financial standing. The results of this study clearly showed that the condition of children with autism affects the entire family.	The purpose of this study was to determine how autism affects families. This study was carried out using a narrative review.
3.	Renske Hoefman <i>et. al.</i>	2014	Descriptive Study	224	Primary caregivers of children with ASDs	The results of this study demonstrated that although many of the parents in our sample found satisfaction in caring for their kid with an ASD, this caregiving had a significant and varied impact on their own life. Furthermore, this study validated the CarerQoL's construct validity among parents of kids with ASDs.	Our study's primary goal is to document the effects of raising a kid with an ASD on parents.2. We want to find out if the CarerQoL can quantify how caring for children with ASDs affects the people who provide care.
4.	Eleni Vasilopoulou and Joy Nisbet	2015	Review survey	15229	Parents having ASD diagnosed children	This review identified possible sources of help and confirmed earlier findings of decreased quality of life for parents of kids with ASD. Future research, policy, and practice implications are examined.	The purpose of this study was to methodically look at research that assessed parents of children with ASD's quality of life.
5.	Alya Mohammed Said ALBusaidi <i>et. al.</i>	2022	Descriptive cross-sectional study	304	parents of children diagnosed with ASD	Coping skills are thought to be a favorable indicator of mental health overall, and many coping strategies are used by parents of children with ASD. In terms of coping mechanisms or quality of life, there were no discernible variations between Omani mothers and fathers.	The intent of this study was to evaluate the coping mechanisms and QoL of parents of ASD children in Oman.
6.	Sean Brim	2019	Pilot Study	6	Autism	The pilot study's findings show that attending the four support group sessions successfully decreased self-reported stress as determined by the PSS. These findings suggest that parents of disabled children may experience less stress when they participate in peer support groups facilitated by occupational therapists and use relevant and interesting activities. Crucially, parents can learn stress-reduction techniques that may help them achieve better occupational balance by implementing an occupational therapy approach.	By means of occupational therapy and a support group, this non-blinded study aimed to lessen the stress experienced by parents of disabled children.
7.	Nirbhay N. Singh <i>et. al.</i>	2023	Experimental Design Study	216	Caregivers of ASD Children	According to the findings, teaching caregivers various self-care techniques may have varying effects on their clinical status as well as on quality assurance indices at the system level.	Examining changes in quality assurance factors pertaining to clients and caregivers in community-based group homes from a systems approach was the goal of the current study.
8.	Elisabeth M. Dykens <i>et. al.</i>	2019	Randomized Control Trial	243	Parents of kids with neurodevelopmental disorders	It is necessary to conduct further research on unfulfilled mental health requirements for moms of children with developmental impairments and how qualified mentors and experts may help. By doing this, mothers' health improves and they are better equipped to provide long-term care for children with complex behavioral, physical, and developmental requirements.	To see how primary caregivers of disabled children respond to the use of Positive Adult Development (a positive psychology technique) or Mindfulness-Based Stress Reduction (a mindfulness practice).
9.	Kenneth Curley <i>et. al.</i>	2023	Literature review	11	parents of children with ASD	Practitioners and educators who want to learn more about stress management techniques for parents of children with ASD will find value in the findings.	To understand which methods for reducing parental stress have been shown effective in the literature.
10.	T. Holmberg Bergman <i>et. al.</i>	2022	Open Trial Study	94	parents of children with disabilities.	The well-being of parents improved dramatically, based on a preliminary analysis of the outcome measures. As per the results, the therapy is feasible and should be evaluated in a randomized controlled research.	This study set out to evaluate the effectiveness of Navigator ACT, a newly developed manualized group intervention for Acceptance and Commitment Therapy, among parents of children with disabilities.
11.	Jennifer S.	2021	qualitative	8	parents of young	The findings emphasize the need of	The study's findings highlight

	Pitonyak <i>et al.</i>		study		children	<p>considering contextual elements when implementing family-centered, routines-based treatments, given the association between family routines and outcomes like as health and well-being. Additionally, they indicate that a health promotion approach is a suitable intervention.</p>	<p>the complexity and diversity of family routines. Family-centered occupational therapy treatments may be essential in helping parents balance their personal well-being with the welfare of their children in order to optimize the health and function of each family member and the family unit as a whole. In order to provide secure and friendly social spaces for parents and families, occupational therapy practitioners can also serve as crucial consultants when working with neighborhood groups. In order to help parents, overcome challenging social conditions that hinder family engagement, occupational therapy practitioners may also need to work with them on coping strategies and other resources.</p>
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Conclusion

The systematic review offers pertinent findings for the use of parent-targeted or family-based occupational therapy interventions for families with children with ASD and other impairments. The psychological condition of parents whose children have been diagnosed with ASD will be taken into consideration when researchers and physicians create intervention regimens thanks to all of these studies. Based on the information that is currently available, it seems that the literature supports the idea that occupational therapy and parent support training can improve the psychosocial quality of life for parents of children with autism spectrum disorder (ASD). Therefore, it can be said that a proper investigation will yield beneficial results on linked matters.

References

1. Howell E, Lauderdale-Littin S, Blacher J. Family impact of children with autism and asperger syndrome: A case for attention and intervention. *Austin Journal of Autism & Related Disabilities*,2015;1(2):1008.
2. Begum R, Mamin FA. Impact of autism spectrum disorder on family. *Autism Open Access*,2019;9(4):1-6.
3. Hoefman R, Payakachat N, van Exel J, Kuhlthau K, Kovacs E, Pyne J, Tilford JM. Caring for a child with autism spectrum disorder and parents’ quality of life: application of the CarerQol. *Journal of autism and developmental disorders*,2014;44:1933-45
4. Vasilopoulou E, Nisbet J. The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*,2016;23:36-49
5. ALBusaidi AM, ALMasroori SA, Awladthani BM, ALKhaldi SA, Al Alawi N, Al Salmani AA. Quality of life and coping strategies used by parents of children with autism spectrum disorder in Oman. *Autism & Developmental Language Impairments*,2022;7:23969415221142262.
6. Brim S. Occupational Therapist-Led Parent Support Group Using an Occupational Therapy Approach.
7. Singh NN, Lancioni GE, Medvedev ON, Hwang YS, Myers RE, Townshend K. Using mindfulness to improve quality of life in caregivers of individuals with intellectual disabilities and autism spectrum disorder.

- International Journal of Developmental Disabilities,2020;66(5):370-80.
8. Dykens EM, Fisher MH, Taylor JL, Lambert W, Miodrag N. Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*,2014;134(2):e454-63.
9. Curley K, Colman R, Rushforth A, Kotera Y. Stress Reduction Interventions for Parents of Children with Autism Spectrum Disorder: A Focused Literature Review. *Youth*,2023;3(1):246-60
10. Holmberg Bergman T, Renhorn E, Berg B, Lappalainen P, Ghaderi A, Hirvikoski T. Acceptance and Commitment Therapy Group intervention for parents of children with disabilities (navigator ACT): An open feasibility trial. *Journal of autism and developmental disorders*,2023;53(5):1834-49
11. Pitonyak JS, Souza K, Umeda C, Jirikowic T. Using a health promotion approach to frame parent experiences of family routines and their significance for health and well-being. *Journal of Occupational Therapy, Schools, & Early Intervention*,2022;15(4):335-56.