

Exploring Quality of Life Dimensions Among Indian Mothers of Children with Autism Spectrum Disorder- A Qualitative Analysis

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ABSTRACT

Purpose: *This study aims to explore the comprehensive understanding of the quality of life (QoL) of Indian mothers raising children with Autism Spectrum Disorder (ASD). Given the cultural and socio-economic context of India, this research seeks to analyze how having a child with ASD affects family dynamics, including relationships within the family and overall family functioning.*

Design/Methodology/Approach: *A qualitative research design was employed, utilizing in-depth, semi-structured interviews with 61 Indian mothers of children diagnosed with ASD. Participants were recruited through autism support groups and clinics across various regions of India. Thematic analysis was used to identify and interpret patterns and themes within the interview data.*

Finding/Result: *QoL was constructed to measure positive emotions, support systems, and social relationships, with acquired additional skills and knowledge, to improve quality of life concerning leisure activities as one of the primary indicators of QoL. The concept of "Leisure Becoming" revolves around activities and practices that foster relaxation and stress reduction, contributing to overall well-being. These activities are integral to maintaining balance in life and can help individuals manage stress and enhance their quality of life.*

Originality/Value: *The construct QoL is the 5-item Quality of Life measure (QoL). The 5 items QoL1, QoL2, QoL3, QoL4, and QoL5 of the QoL construct measure, QoL construct specific to the leisure domain. Leisure activities are one of the primary indicators of QoL, which measures the subjective well-being of an individual and influences life values and needs.*

Paper Type: Case study-based analysis

Keywords: Autism spectrum disorder, Mother, Primary caregivers, Psychological well-being, Quality of Life.

1. INTRODUCTION :

1.1. Autism Spectrum Disorder:

Autism spectrum disorder (ASD) is a neurodevelopmental condition marked by challenges in social interaction and communication, along with restricted interests and repetitive behaviors. In 1911, Eugen Bleuler used the term autism in characterizing the symptoms of schizophrenia. Later in 1938, Leo Kanner observed 11 of his patients (3 girls and 8 boys) and described the condition as Kanner syndrome later called early infantile autism (Kanner, L. (1943). [1]. The DSM-5 a fifth edition in 2013 updates the diagnostic criteria for autism spectrum disorder (ASD) from the preceding fourth edition (DSM-IV), 1994 (Regier, D. A. et al. (2013).[2].

1.2. Mother as Primary Caregiver:

Motherhood, in its most profound sense, often extends beyond the nurturing of children to encompass the role of primary caregiver. For many mothers, this role involves not just the day-to-day tasks of raising children but also a comprehensive commitment to their well-being and development. The role of a primary caregiver entails a range of responsibilities emotional support, physical care, and often managing complex medical or developmental needs. This dedication, while deeply rewarding, can significantly impact the quality of life for these mothers. On one hand, caregiving can foster a deep sense of fulfillment, pride, and connection. Mothers experience the joy of witnessing their children's growth and accomplishments, and their sacrifices often strengthen familial bonds (Menezes, I.S. & D'Mello, L. (2021). [3]. On the other hand, the demands of caregiving can be taxing, affecting their physical health, emotional well-being, and social lives. Mothers in caregiving roles frequently juggle multiple responsibilities, which can lead to feelings of isolation and stress. They may face challenges such as lack of personal time, financial strain, and the constant pressure to meet their children's needs. These factors can affect their mental health, leading to higher rates of anxiety and depression compared to their peers. Supporting the quality of life for these mothers involves addressing both the rewards and challenges they face. Access to respite care, social support networks, and mental health resources are crucial in helping them maintain a balanced and fulfilling life. Recognizing and valuing the multifaceted contributions of caregiving mothers is essential for fostering their well-being and ensuring that they receive the support they need to thrive both as caregivers and as individuals.

1.3. Role of Caregiver:

The term "caregivers" in this context refers to the mother, father, grandfather, and grandmother who are fully committed to addressing the requirements of an ASD child and who have lived in the same home with the kid for at least six months (Renford, N. G. R. (2021). [4]. Autism Spectrum Disorder (ASD) presents unique challenges and opportunities for caregivers, requiring a multifaceted approach to support individuals on the spectrum. Caregivers, often parents or guardians, play a pivotal role in managing the complexities associated with ASD. Their involvement is crucial in enhancing the quality of life for individuals with ASD and in fostering their development and integration into society. Mothers are often the first to recognize developmental concerns and seek professional evaluation. They play an essential role in coordinating and facilitating early interventions, which are vital for improving developmental outcomes. Individuals with ASD often have unique needs and sensitivities. Caregivers are responsible for creating a supportive environment tailored to these needs. This can involve developing individualized routines, managing sensory sensitivities, and implementing strategies to address behavioural challenges. Mothers frequently serve as advocates for individuals with ASD, working to ensure they receive appropriate educational services, medical care, and social support. Educating themselves about ASD and related resources empowers mothers to make informed decisions and advocate effectively.

1.4. Quality of Life:

QOL, according to WHO, is a measure of how people view themselves, and their position in the world in terms of objectives, aspirations, and concerns in addition to the value systems they adhere to. It is an encompassing idea that is complicatedly dependent on one's physical and mental well-being, independent degree, social connections, and personal views, as well as their relationship to key environmental elements. The term emphasizes the subjective, multifaceted, and both good and negative aspects of quality of life (Whoqol Group. (1995). [5]. Every person strives to live their best life. Numerous scientists have spent the previous several centuries attempting to define a high quality of life, and as a result, a new notion known as "quality of life" was born. QOL is the whole universal state of well-being comprised of purpose attributes, and subjective judgments of their external, material, social, and sentimental well-being collectively as well as their degree of individual development and fixated activity, all of which are weighed by their own set of moral standards (Felce, D., & Perry, J. (1995). [6]. The improvement of daily living is a key component of quality of life. Shearer (Brown, R. I. et al. (2010). [7]. contends that while individual wants and preferences should be prioritized, societal and environmental elements also impact people's life quality. Additionally, it was determined that the framework contains three fundamental, essential features: subjective and objective, life circumstances, and personal values effects. Life quality is both a personal and a measurable concept according to

Cummins (Cummins, R. A. (1997). [8]. He believed that it was important to investigate both the objective and subjective axes. The seven domains that make up those axes, which number, are efficiency, material well-being, intimacy, health, community emotional well-being, safety, and other domains. This objective axis summarises the individual's prior living circumstances, and the subjective axis expresses the individual's opinion and assessment of the various facets of their lives. To improve one's quality of life, one must first adopt a general view of what constitutes a good life and then incorporate both subjective and objective markers (Exenberger, S., & Juen, B. (2014). [9]. Subjective indicators include things like personal ideas, sentiments, and beliefs, whereas objective indicators are items that can be measured.

2. OBJECTIVES :

The objectives framed are:

- (1) To provide a comprehensive understanding of the quality of life of Indian mothers caring for children with ASD.
- (2) To analyze how having a child with ASD affects family dynamics, including relationships within the family and overall family functioning.
- (3) To evaluate the general quality of life experienced by mothers of children with ASD in India, including physical, emotional, and social well-being.

3. REVIEW OF LITERATURE/ RELATED WORKS :

3.1. Quality of Life (QOL):

3.1.1. Definition: The extent to which a person enjoys significant opportunities in his or her life. Possibilities are the outcomes of the opportunities and constraints that each encounters in life and are a reflection of the interaction of environmental and personal factors. The phrase "She enjoys good health" serves as an example of how enjoyment consists of two elements: the sense of satisfaction and the possession or achievement of some quality [10].

3.1.2. Indicators of QOL: Quality of life (QoL) is a comprehensive concept that encompasses various dimensions of an individual's well-being. It can be assessed through both objective and subjective indicators, each providing valuable insights into different aspects of a person's life. **Objective indicators** are measurable and often quantifiable aspects that can be observed and recorded. They provide concrete data about an individual's living conditions and overall well-being. Some key objective indicators include physical health metrics such as chronic illness, disability status, overall physical health assessments, and access to healthcare facilities like availability and quality of medical services and treatments. Economic factors include total household income and financial stability, living conditions, housing stability, and adequacy of living space. Educational attainment with the highest level of education completed. Environmental factors include safety and security, access to amenities, family and social connections, and participation in community activities and organizations. **Subjective indicators** are based on personal perceptions, feelings, and experiences. They reflect how individuals view and interpret their own lives and well-being. Some important subjective indicators include overall satisfaction with contentment and happiness i.e. Feelings of joy and contentment on a day-to-day basis. Emotional well-being on levels of anxiety, depression, and overall emotional health as well as perceived stress and coping mechanisms. It also includes self-perceived health as how individuals rate their self-health compared to others or how they feel about their health status. Personal fulfillment with a sense of purpose and accomplishment in personal and professional life. Work-life balance indicates satisfaction with the balance between work and personal life. Quality of relationships that measures satisfaction with relationships with family, friends, and colleagues. Perceived level of support from social networks and their effectiveness. Autonomy and control have a feeling of control over one's life and decisions with a level of independence and the ability to make personal choices [11].

3.1.3. Three Major QOL Domains: Quality of Life Research Unit [12] (1994-1996), University of Toronto.

Being: Three sub-domains make up the Being domain, which encompasses the fundamental facets of "who one is." Physical well-being encompasses matters related to nutrition, exercise, personal hygiene, dressing appropriately, and physical appearance. The term "psychological being" refers to a person's psychological well-being, emotional stability, self-awareness, and self-control. "Spiritual Being" expresses individual morals, ethics, and spiritual convictions that may or may not be connected to

formal faiths.



Fig 1: Quality of Life [12]

Belonging: Along with having three sub-domains, belonging also refers to how well a person fits into their surroundings. The connections a person has with their physical environment, such as their house, place of employment, neighbourhood, school, and community, are referred to as their physical belonging. Social connections and the acceptance of close friends, family, coworkers, neighbours, and other members of the community are all parts of social belonging. Access to resources that are typically available to community members, such as appropriate income, health, and social services, employment, educational and recreational opportunities, and communal activities, is referred to as community belonging.

Becoming: The term "becoming" describes the deliberate actions taken to fulfill one's objectives, aspirations, and desires. Daily activities including household chores, paid jobs, extracurricular or volunteer activities, and attending to social or health needs are all considered to be part of "practical becoming." Activities that encourage relaxation and stress reduction are included in "Leisure Becoming." These can be shorter-term activities like card games, neighbourhood walks, and family visits, or longer-term ones like trips or holidays. Activities that support "growth becoming" encourage the maintenance or advancement of knowledge and skills [12].

Being	Belonging	Becoming
Physical Being *physical health *personal hygiene *nutrition *exercise *grooming and clothing *general physical appearance	Physical Belonging *home *workplace/school *neighbourhood *community	Practical Becoming *domestic activities *paid work *school or volunteer activities *meeting health or social needs
Psychological Being *psychological health and adjustment *emotions *feelings *self-esteem, self-concept and self-control	Social Belonging *relationships *family *friends *co-workers *neighbourhood and community	Leisure Becoming *activities that promote relaxation and stress reduction
Spiritual Being *personal values *personal standards of conduct *spiritual beliefs	Community Belonging *adequate income *health and social services *employment *educational programs *recreational programs *community events and activities	Growth Becoming *activities that promote the maintenance or improvement of knowledge and skills *adapting to change

Fig. 2: Quality of Life [12]

3.1.4. Improved Quality of Life: An American Recreation Coalition Study conducted in 2000 found that people who prioritize recreation are more inclined to feel pleased utilizing their lives as a whole. To balance the rigors of the classroom with one's holistic health, one should engage in recreational activities. There are many different effects of recreation. It improves one's capacity for identity, self-fulfillment, social graces, diversion activities, athletic ability, artistic sensibility, and creativeness. These qualities benefit people who experience limitations in daily life. Consequently, it is acceptable to use recreation as a therapeutic strategy. Participant recovery from the physical weakness brought on by inactivity is aided by activity-based recreation, which also fosters the development of the latent capacity for self-realization. Additionally, because it fosters optimism and a good attitude in life, this helps

people deal with everyday issues more successfully (Blackledge, J. T., & Hayes, S. C. (2006). [13].

3.1.4. Measures to Improve Quality of Life: Work-life balance, relationships, the home, and health will all benefit from eating nutrient-dense foods, receiving adequate sleep, and finding time to work out. Governments may improve people's quality of life by providing access to inexpensive, high-quality healthcare, supporting schooling, supporting affordable housing, enacting family-friendly laws, and funding these programs.

3.2. Studies Related to the Psychological Health of ASD Parents:

Nancy, G. et al. (2021).[14] used a non-experimental cross-sectional research design and a quantitative research method on 120 samples in India Lucknow city. The WHOQoL-BREF was accustomed to measuring caregivers' QOL (World Health Organization, (1996). [15]. When the data was analyzed, In the psychological and physical domains, it was found that 59.1% and 56.6% of people had low and poor QOL, respectively. The caregiver's QOL in the psychological domain varied significantly depending on the length of child care. Under the environmental domain, there was no discernible variation in the QOL of the caregivers based on age. The study has found a need for long-term, need-based strategies that could improve caregivers' QOL.

Increased stress levels were seen in caregivers of people with ASD who had delayed diagnosis, difficulty managing ASD problem behaviours, and a lack of social and recreational opportunities. The study found that family quality of life, caregiver self-efficacy, caregiver social network, and caregiver stress were all factors that affected caregivers' physical and emotional well-being. The quantitative study found positive correlations between social networks, and QOL as well as social networks and caregiver self-efficacy. Stress and family QOL, social networks, and self-efficacy were found to be negatively correlated. As a result, the more stress caregivers reported, the lower their quality of life, social network, and self-efficacy (SooHoo, A. A. (2019). [16].

Bateman, J. K. (2017). [17] examined how a parent coaching kit based on adult learning theory and the Positive Behaviour Strategy enhanced the quality of life for families with young ASD children. The findings of this investigation suggest that effective parent coaching activities may improve schedules created during early intervention. Numerous beneficial outcomes of this intervention included greater parent knowledge and confidence in carrying out the intervention at home, increased fidelity in the application of the targeting ability, decreased child involvement in demanding behaviour at home, and parents' credibility. Furthermore, the findings contribute to an improved belief in intervention strategies for their children. Overall, the safe delivery of well-organized parent care kits allows parents to gain knowledge and adopt interventions, giving beneficial results for both parents and children in a variety of behaviours.

Khanna, et al. (2011). [18] assessed six characteristics of problem-solving, interaction, roles, affective responsiveness, effective and useful engagement, and behavioral issues to assess the HRQOL of main carers of children with autism spectrum disorders. A child's daily functioning, social assistance, nonadaptive functioning, and dominating were linked to caregivers' mental health. Low social connection and problems with maladaptive behavior were significant predictors of worsening physical health in caregivers.

Web-based surveys with a cross-sectional design were completed by 387 parents. According to the Transactional model, obscurity and social forums were causal predecessors of the stress connected with the diagnosis, possible treatments, and outlook for children with ASD. It is believed that social networks can reduce stress and improve parental well-being (Norah, L., J. (2009). [19].

Table 1: Literature Review Summary

S. No.	Area & Focus of the Research	The result of the Research	Reference
1	Measuring caregivers' QOL.	Non-experimental cross-sectional research analyzed, the psychological and physical domains, it was found that 59.1% and 56.6% of people had low and poor QOL, respectively. The caregiver's QOL in the psychological domain varied significantly depending on the length of child care.	Nancy, G. et al. (2021).[14]

2	Factors that affected caregivers' physical and emotional well-being.	The study found that family quality of life, caregiver self-efficacy, caregiver social network, and caregiver stress were all factors that affected caregivers' physical and emotional well-being. The quantitative study found positive correlations between social networks, and QOL as well as social networks and caregiver self-efficacy. Stress and family QOL, social networks, and self-efficacy were found to be negatively correlated.	(SooHoo, A. A. (2019). [16].
3	Parent coaching kit based on adult learning theory and the Positive Behaviour Strategy enhancing the quality of life for families with young ASD children.	The findings of this investigation suggest that effective parent coaching activities may improve schedules created during early intervention. Overall, the safe delivery of well-organized parent care kits allows parents to gain knowledge and adopt interventions, giving beneficial results for both parents and children in a variety of behaviours.	Bateman, J. K. (2017). [17]
4	Assessment of six characteristics like problem-solving, interaction, roles, affective responsiveness, effective and useful engagement, and behavioural issues to assess the HRQOL of main carers of children with autism spectrum disorders.	A child's daily functioning, social assistance, nonadaptive functioning, and dominating were linked to caregivers' mental health.	Khanna, et al. (2011). [18]
5	Stress reduction and improvement of parental well-being.	According to the Transactional model, obscurity and social forums were causal predecessors of the stress connected with the diagnosis, possible treatments, and outlook for children with ASD.	(Norah, L., J. (2009). [19].

4. MATERIALS AND METHODS :

A cross-sectional study was conducted to explore and categorize various components of parental well-being among mothers of children with Autism Spectrum Disorder (ASD) in India. This research utilized an inductive approach (H. R. Ganesh., & Aithal, P. S. (2022). [20] to gain a comprehensive understanding of the quality of life (QoL) of these mothers by investigating their lived experiences. The study included 61 respondents, selected through a convenience sampling method (H. R. Ganesh., & Aithal, P. S. (2022). [21]. Participants were mothers of children diagnosed with ASD. Efforts were made to include a diverse range of respondents regarding socio-economic background and geographical location. Both online and offline structured interviews were conducted to gather qualitative data. Open-ended questions were used to allow participants to share their experiences in their own words, providing depth and richness to the data. The interviews focused on understanding daily challenges, emotional responses, and coping strategies related to caregiving. Thematic analysis was used to identify and categorize recurring themes and patterns in the interview responses with informed consent.

5. RESULTS AND DISCUSSION :

5.1. Findings: Assessment of the Various Components of the QOL of Mothers of Children Diagnosed with ASD:

The Quality-of-Life Research Unit (1994-1996) at the University of Toronto made significant contributions to the field of QoL research. By developing measurement tools, creating conceptual frameworks, and influencing healthcare practices and policies, the unit advanced the understanding of

how various factors impact individuals' overall well-being. Their work remains influential in the ongoing efforts to assess and improve the quality of life in diverse populations. The concept of "Leisure Becoming" revolves around activities and practices that foster relaxation and stress reduction, contributing to overall well-being. These activities are integral to maintaining balance in life and can help individuals manage stress and enhance their quality of life. Leisure activities are one of the primary indicators of QoL, which measures the subjective well-being of an individual and influences life values and needs. QoL was constructed to measure positive emotions, support systems, and social relationships, with acquired additional skills and knowledge, to improve quality of life concerning leisure activities as one of the primary indicators of QoL. The construct QoL is the 5-item Quality of Life measure (QoL). The 5 items QoL1, QoL2, QoL3, QoL4, and QoL5 of the QoL construct measure, QoL construct specific to the leisure domain. QoL1 was developed to measure the home support or the manpower to assist her in planning a certain amount of leisure in her daily schedule for the respondent despite the demanding care of her ASD child. The item QoL2 was developed to examine the financial constraints for involvement in leisure activities. The financial burden due to the early intervention measures and the therapeutic reasons in the long run, as well as the difficulty in meeting the working status of the mother, due to the demanding care of the child, along with the family income category, were the main reasons for framing QoL2. With the notion that lack of money could obstruct them from reaching the leisure activities of their choice, due to the additional expenses of the child with autism directly or indirectly. The indirect source could be like hiring an additional caregiver during respite hours to take of the child when hindered due to manpower. Through participation in leisure activities, people build social relationships and interpersonal relationships with positive emotions. Close relationships with the spouse not only increase intimacy but also give a sense of security. QoL3 dimension measures satisfaction with close relationships, despite the child's constant care as satisfaction with close relationships (spouse). The subjective perception increases life value and needs. Item QoL4 to measure the level of happiness and achievements when given time for self-care towards feeling happy and content about achieving something better than usual whenever they have spent some time for themselves despite the demanding childcare. As demanding care requires total focus and continuous monitoring, mothers often neglect personal space that could raise their overall well-being. A certain amount of scheduled leisure time helps, in self-replenishing and better nurturing the child. QoL5 was created to measure a certain amount of scheduled leisure time, for self-replenishing and better nurture of the child.

5.2. Results:

QoL1 is designed to assess the support systems available to individuals who are caring for a child with ASD. QoL1 focuses on evaluating the level of home support or manpower that the respondent has in managing their daily routine, including leisure activities. QoL1 looks at the type and extent of assistance available within the home environment. This could include help from family members, friends, or professional caregivers. QoL2 evaluates the financial limitations that may affect a caregiver's ability to participate in leisure activities. This tool focuses on understanding how financial constraints impact the respondent's quality of life, in terms of their engagement in activities outside of caregiving responsibilities. QoL2 assesses the economic challenges faced by caregivers, including the direct costs associated with leisure activities such as expenses for hobbies, outings, or relaxation, and indirect costs such as reduced income due to time spent caregiving. QoL3 is designed to measure how satisfied caregivers are with their close relationships, particularly with their spouse, despite the demanding nature of caring for a child with ASD. This dimension focuses on understanding the impact of caregiving responsibilities on interpersonal relationships and overall relational satisfaction. QoL3 assesses how caregivers perceive and experience their relationships with their spouse or significant other. It looks at whether the caregiving role affects the quality of these relationships, including emotional closeness, communication, and mutual support. QoL4 assesses the level of happiness and sense of achievement that caregivers experience when they can spend time on self-care activities, despite the demanding nature of care. This dimension focuses on how self-care time impacts the caregiver's overall sense of well-being and satisfaction. QoL4 evaluates how caregivers use their limited personal time for self-care activities. This could include hobbies, relaxation, exercise, or other activities that contribute to their personal well-being. QoL5 was created to measure a certain amount of scheduled leisure time, for self-replenishing and better nurture of the child. QoL5 is designed to assess the extent to which caregivers

can schedule and utilize leisure time for self-replenishment and how this, in turn, impacts their ability to nurture their child with ASD more effectively. This dimension focuses on balancing personal time and caregiving responsibilities and its effect on overall caregiving quality.

6. DISCUSSION :

One of the key aspects QoL1 assesses is whether the caregiver has the time and support needed to plan and engage in leisure activities. This involves evaluating if the caregiver can find time for personal relaxation or hobbies, given the demanding nature of caring for a child with ASD. The goal is to understand how much support the caregiver has in managing the household and caring for the ASD child. QoL2 aims to determine how financial constraints affect the caregiver's ability to engage in leisure activities. For example, caregivers might struggle to afford memberships, classes, or other activities that provide relaxation or enjoyment, due to the financial demands of caring for a child with ASD. QoL3 examines how the constant care required by the child with ASD influences the caregiver's satisfaction with their relationship. Caregiving can be all-consuming, and QoL3 seeks to understand whether this demanding role creates strain, reduces the time spent together, or impacts the emotional connection between partners. The item QoL4 assesses how spending time on self-care affects the caregiver's happiness and contentment. It explores whether these moments of personal time lead to increased feelings of joy, satisfaction, and emotional well-being. By focusing on self-care, QoL4 helps understand how caregivers' ability to engage in personal activities, even briefly, impacts their overall well-being. It examines whether these moments of self-care help mitigate the stress and demands of caregiving, providing a valuable counterbalance to the challenges faced. QoL5 evaluates the amount of leisure time that caregivers can schedule and dedicate to themselves. This includes time set aside for relaxation, hobbies, or other activities crucial for self-care and stress relief.

7. NEW KNOWLEDGE :

Caregiving for an individual with ASD can place strain on family dynamics and personal well-being. Caregivers must balance their responsibilities with self-care, seeking respite when needed, and maintaining mental and physical health. An accepted definition of quality of life and a methodology for conducting an international assessment of the quality of life was established during the first stage of concept clarification. A person's assessment of their place in life concerning their objectives, expectations, standards, and worries, as well as the culture and value systems in which they live, is referred to as their quality of life. It can be assessed through both objective and subjective indicators, each providing valuable insights into different aspects of a person's life. QoL was constructed to measure positive emotions, support systems, and social relationships, with acquired additional skills and knowledge, to improve quality of life concerning leisure activities as one of the primary indicators of QoL. The construct QoL is the 5-item Quality of Life measure consisting of QoL1, QoL2, QoL3, QoL4, and QoL5 specific to the leisure domain. Given the significant demands of caring for a child with ASD, QoL1 aims to measure how well the caregiver can balance these demands with personal well-being. QoL2 provides insights into how financial stressors impact the caregiver's overall quality of life by exploring the link between financial constraints and leisure opportunities. QoL3 helps to gauge how well caregivers can maintain a fulfilling and supportive relationship with their spouse despite the stresses of caregiving as we focus on satisfaction with close relationships. QoL4 measures the sense of achievement that caregivers experience from their self-care activities. This includes feeling that they have accomplished something positive for themselves, which can contribute to a greater sense of personal fulfillment and overall quality of life. QoL5 provides insights into how the ability to schedule and utilize leisure time influences caregiver's well-being and their caregiving capacity. It highlights the importance of personal time in enhancing the caregiver's overall health, towards improved care and support for the child.

8. CONCLUSION :

Indian mothers of children with ASD frequently experience a range of emotional and psychological challenges, including stress, anxiety, and feelings of isolation. The constant demands of caregiving often lead to emotional strain, affecting their overall well-being and quality of life. The availability and accessibility of support systems play a crucial role in shaping the QoL of these mothers. While some mothers benefit from strong familial and community support, others face difficulties due to limited

resources and a lack of structured support systems. The 5-item Quality of Life (QoL) measure, focusing on the leisure domain, provides a comprehensive framework for assessing the well-being of caregivers, particularly those managing the demands of raising a child with ASD. The construct of QoL, incorporating QoL1 through QoL5, offers valuable insights into how various aspects of leisure and personal time impact caregivers' overall quality of life. The QoL measure offers a valuable construct for understanding and improving the quality of life for caregivers of children with ASD. By addressing key areas such as personal balance, financial constraints, relationship satisfaction, self-care, and leisure time, we can enhance the overall well-being of caregivers, leading to a more supportive and fulfilling caregiving experience.

9. SUGGESTIONS :

The suddenly altered lifestyle from being an independent entity to parenting a child is a major transition in any life process. Raising a child with unique demands is challenging for any parent (Crnic, K., & Low, C. (2002). [22]. These rewarding and challenging demands with the responsibility of nurturing a child often led to an additive effect on parental stress (Deater-Deckard, K., & Petrill, S. A. (2004). [23]. Positive coping strategies for stressed parents to sustain adaptive family functioning will be in the end. The findings underscore the need for targeted interventions and support programs to enhance the QoL of mothers caring for children with ASD in India. Addressing their unique challenges and providing tailored support can significantly enhance their quality of life, contributing to better outcomes for mothers and their children.

10. LIMITATIONS OF THE STUDY :

This study's limitations include a small and region-specific sample, which may not represent all Indian mothers of children with ASD. Cultural and socioeconomic factors unique to the participants' areas may affect the generalizability of the findings. The qualitative nature of the research, relying on self-reported data, introduces potential biases and subjectivity. Additionally, the study provides a cross-sectional in time without capturing long-term changes in the quality of life. Language barriers and emotional sensitivity during interviews could also impact data accuracy. The lack of comparative analysis with other caregiver groups further limits the breadth of insights highlighting the need for broader, longitudinal research.

11. SCOPE FOR FUTURE RESEARCH :

Future research could expand on this study by including a larger and more diverse sample of Indian mothers across different regions and socioeconomic backgrounds to enhance generalizability. Future research should focus on quantitative studies to validate the qualitative findings and explore the broader implications for QoL among Indian mothers of children with ASD. Additionally, longitudinal studies could provide insights into the long-term effects of caregiving on maternal well-being and identify effective strategies for sustained support. Further research should explore the dimensions of QoL in larger and more diverse populations to validate these findings and refine support strategies.

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