

Exploring Psychological Well-being in Indian Mothers of Children with Autism Spectrum Disorder- A Qualitative Study

Menezes Ida Sylvia¹, N. Vidya² & D'Mello Laveena³

¹ Doctoral Research Scholar in Clinical Psychology, Institute of Social Sciences and Humanities, Srinivas University, Mangalore, India.

ORCID: 0000-0001-7654-9217, Email ID: dishaasd2006@gmail.com

² Assistant Professor, Institute of Social Sciences & Humanities, Srinivas University, Mangalore, India.

ORCID: 0000-0002-3390-567X, Email ID: vidyan.cssh@srinivasuniversity.edu.in

³ Associate Professor, School of Social Sciences & Humanities, Srinivas University, Mangalore, Karnataka, India.

Orcid ID: 0000-0003-1935-002X; Email: lavyrononha@gmail.com

Area/Section: Psychology.

Type of the Paper: Research Case Study.

Number of Peer Reviews: Two.

Type of Review: Peer Reviewed as per [C|O|P|E|](#) guidance.

Indexed in: OpenAIRE.

DOI: <https://doi.org/10.5281/zenodo.13333126>

Google Scholar Citation: [PIJTRCS](#)

How to Cite this Paper:

Sylvia, M. I., D'Mello, L. & Vidya, N. (2024). Exploring Psychological Well-being in Indian Mothers of Children with Autism Spectrum Disorder- A Qualitative Study. *Poornaprajna International Journal of Teaching & Research Case Studies (PIJTRCS)*, 1(1), 113-125. DOI: <https://doi.org/10.5281/zenodo.13333126>

Poornaprajna International Journal of Teaching & Research Case Studies (PIJTRCS)

A Refereed International Journal of Poornaprajna Publication, India.

ISSN: 3107-8494

Crossref DOI: <https://doi.org/10.64818/PIJTRCS.3107.8494.0007>

Received on: 19/07/2024

Published on: 27/08/2024

© With Authors.



This work is licensed under a [Creative Commons Attribution-Non-Commercial 4.0 International License](#) subject to proper citation to the publication source of the work.

Disclaimer: The scholarly papers as reviewed and published by Poornaprajna Publication (P.P.), India are the views and opinions of their respective authors and are not the views or opinions of the PP. The PP disclaims of any harm or loss caused due to the published content to any party.

Exploring Psychological Well-being in Indian Mothers of Children with Autism Spectrum Disorder- A Qualitative Study

Menezes Ida Sylvia ¹, N. Vidya ² & D'Mello Laveena ³

¹ Doctoral Research Scholar in Clinical Psychology, Institute of Social Sciences and Humanities, Srinivas University, Mangalore, India.

ORCID: 0000-0001-7654-9217, Email ID: dishaasd2006@gmail.com

² Assistant Professor, Institute of Social Sciences & Humanities, Srinivas University, Mangalore, India.

ORCID: 0000-0002-3390-567X, Email ID: vidyan.cssh@srinivasuniversity.edu.in

³ Associate Professor, School of Social Sciences & Humanities, Srinivas University, Mangalore, Karnataka, India.

Orcid ID: 0000-0003-1935-002X; Email: lavyoronha@gmail.com

ABSTRACT

Purpose: *This qualitative study explores the psychological well-being of Indian mothers who are primary caregivers of children with Autism Spectrum Disorder (ASD). The research investigates the unique challenges, coping strategies, and emotional experiences of these mothers within the cultural and familial context of India.*

Design/Methodology/Approach: *Through in-depth interviews of 61 mothers, and thematic analysis, the study aims to uncover the multifaceted aspects of psychological well-being, including autonomy, competence, healthy relationships, self-acceptance, personal growth, and purpose in life by cross-sectional design with interpretivism and an inductive approach.*

Finding/Result: *Psychological well-being (PWB) was assessed by measuring the fulfillment of personal desires, meaning and acceptance of life, learning new experiences in life, connectedness or positive relations, goal setting, achievements, and satisfaction. The 6 items PWB1, PWB2, PWB3, PWB4, PWB5, and PWB6 of the PWB as a construct demonstrated to measure the psychological well-being of mothers of autistic children. Despite the challenges, it explores how mothers perceive their ability to meet their child's desires and needs through sacrifices in caring for their child with special needs.*

Originality/Value: *The objective of investigating the factors that provide meaning, purpose, and fulfillment to mothers in their roles as primary caregivers to children with ASD carried out. Themes of autonomy, competence, healthy relationships, self-acceptance, personal growth, and purpose in life emerged as critical components influencing their psychological well-being. These themes collectively aimed to provide a comprehensive understanding of the psychological well-being of Indian mothers caring for children with ASD, informing future research, on intervention strategies to better support these mothers and their families.*

Paper Type: *Case study-based analysis*

Keywords: Autism spectrum disorder, Mother, Primary caregivers, Psychological well-being, Psychological components, Psychological health.

1. INTRODUCTION :

1.1. Autism Spectrum Disorder:

A neurodevelopmental disorder called autism spectrum disorder (ASD) is characterized by deficiencies in social interaction and language as well as the appearance of constrained interests and repetitive behavior. One in 100 children worldwide is thought to have ASD, according to a WHO review on 29 March 2023 [1]. About 1 in 36 children of the population have ASD, according to the CDC and ADDM Network 2023 [2]. Since 2000, the prevalence of autism has climbed by 178%. By 2018, 23 out of every

1,000 children have received a diagnosis, or around 1 in 44. Approximately four times as many as in the year 2000. In the 2020s, there are 50 - 100 times more diagnosed instances of autism than there were in the 1970s. Boys are diagnosed with autism at a rate of around 4 times that of girls (Maenner, M. J. (2020). [3].

1.2. Mother and Caregiving:

Navigating the early stages of a child's Autism Spectrum Disorder (ASD) diagnosis poses profound challenges for mothers, influencing their psychological well-being and reshaping family dynamics (Menezes, I., S. & D'Mello, L. (2021). [4]. This period encompasses a series of emotional hurdles, including accepting the diagnosis, comprehending the complexities of ASD, and struggling with societal stigmas associated with the disorder. Mothers often confront intense feelings of fear, anxiety, and psychological trauma as they adjust to this new reality. The responsibilities associated with caring for a child with ASD can significantly impact the psychological well-being of mothers. The demanding nature of caregiving, which includes managing behavioral challenges, navigating therapy sessions, and coordinating educational interventions, can lead to heightened stress levels and emotional strain. Moreover, the caregiving role extends beyond immediate family dynamics to encompass interactions with extended family members, who may have varying levels of understanding and expectations regarding the child's condition affecting the entire family's adaptation to a revised family system. Siblings and extended family members also undergo a period of adjustment, recalibrating their roles and expectations within the household. These early stages are characterized by cycles of acceptance, resilience-building, and the gradual integration of support systems to navigate the complexities of raising a child with ASD. Understanding the psychological well-being of mothers raising children with Autism Spectrum Disorder (ASD) is crucial, particularly in the context of India, where cultural norms and support systems may influence caregiving experiences.

1.3. Family Dynamics:

When individuals anticipate becoming parents, they often harbor numerous hopes and dreams for their future children. These expectations, while often unspoken, form a significant part of their emotional preparation for parenthood. These dreams typically encompass a wide range of aspirations, from imagining their child's achievements and milestones to envisioning their future successes and happiness. However, when parents receive an autism diagnosis for their child, these preconceived notions and dreams can undergo a profound transformation (DeJong, P., & Berg, K. (2008). [5]. The diagnosis may bring with it a realization that the path ahead may not align with their initial expectations. Parents may confront a sense of loss for the imagined future they had envisioned, which may have included academic achievements, social milestones, and other conventional markers of success. This shift in perspective can lead to a period of adjustment and grieving for the future they had envisioned. Parents may experience a range of emotions, including sadness, frustration, and even guilt. They may grapple with feelings of uncertainty about their child's potential and capabilities, questioning whether the aspirations they held before the diagnosis are still attainable. Navigating this journey involves coming to terms with the new reality of parenting a child with autism. It requires parents to shift their focus from traditional benchmarks of success to embracing their child's unique strengths, interests, and potential. It involves seeking out resources, support networks, and information that can empower parents to advocate for their children's needs and foster their development in ways that honor their individuality. Ultimately, while the initial dreams and expectations may evolve after an autism diagnosis, parents have the opportunity to redefine what success means for their family. By embracing their child's journey and celebrating their accomplishments, no matter how different they may be from their initial expectations, parents can cultivate a supportive and loving environment where their child can thrive.

1.4. Psychological Health:

Mothers grapple with intense emotions such as sadness, frustration, or guilt due to the challenges of caring for a child with ASD. These emotions can arise from witnessing their child's difficulties, navigating complex healthcare and educational systems, and managing the impact of ASD on family dynamics. The ongoing effort mothers exert in managing stress and uncertainty associated with caregiving, adapting to the daily demands of caring, balancing caregiving responsibilities with personal needs, and seeking effective coping strategies to maintain their own well-being is strenuous. Mothers

of children with ASD fulfill multiple roles crucial to their children's well-being. In many cases, it is the mothers who first recognize the signs and symptoms of autism in their children. They take proactive steps to seek a proper diagnosis and access necessary treatments and interventions. When treatment programs are effective, mothers often become highly motivated and deeply involved in their child's training and development and ensure that the skills learned during therapy are transferred to the family setting. This dedication and involvement play a crucial role in the ongoing progress and adaptation of their child with ASD. When treatment programs are effective, mothers often become highly motivated and deeply involved in their child's training and development. They take proactive steps to ensure that the skills learned during therapy are transferred to the family setting. This dedication and involvement play a crucial role in the ongoing progress and adaptation of their child with ASD.

Mothers of ASD children as caregivers, experience significant physical and emotional stress due to the demanding nature of their role. Caregiving often involves physically demanding tasks such as lifting, bathing, feeding, and assisting with mobility (Huang, Y. T., et al. (2011). [6]. Over time, these activities can lead to physical strain, fatigue, and even injuries, especially if proper techniques and equipment are not utilized. The repetitive nature of caregiving tasks can exacerbate these physical challenges, leading to chronic pain and exhaustion. They experience a wide range of intense emotions, including sadness, guilt, frustration, and anxiety as they witness the suffering or decline of a loved one which is emotionally distressing. They may also feel overwhelmed by the constant responsibility and worry about their children's well-being, which can contribute to chronic stress and burnout. Caregiving expenses, such as medical costs, medications, therapies, and home modifications, can impose financial strain on mothers. Balancing caregiving responsibilities with work commitments may result in reduced income or career opportunities, adding to financial stress and uncertainty about the future. Studies have linked caregiving to higher rates of chronic conditions such as hypertension, cardiovascular disease, and weakened immune function. Neglecting their own health needs while prioritizing the needs of the care recipient can lead to neglect of preventive care and exacerbation of existing health issues. Furthermore, societal perceptions and stereotypes about autism can exacerbate these feelings. There may be a prevailing belief that individuals with autism are limited in their abilities. This societal narrative can further shape parents' perceptions of their child's future and influence their expectations.

2. OBJECTIVES :

The objectives framed are:

- (1) To provide a comprehensive understanding of the psychological well-being of Indian mothers caring for children with ASD.
- (2) To explore the lived experiences of Indian mothers caring for children with ASD uncovering the day-to-day challenges, emotional experiences, and coping mechanisms.

3. REVIEW OF LITERATURE/ RELATED WORKS :

3.1. Psychological distress:

3.1.1. Introduction: Individuals have different personal experiences with psychological suffering. In other words, the circumstances and our perception of them determine the level of psychological pain we feel. On a continuum that reflects psychological discomfort, mental health, and mental disease might be seen as being at opposite ends. We go back and forth on the continuum throughout our lives as we continue to encounter new experiences. Consequently, no two individuals will ever have the same experience of a certain event. Psychological discomfort is what those of us who experience negative emotions and struggle to cope are going through. Generally speaking, psychological distress is regarded as a temporary phenomenon that is connected to particular stressors. It normally goes away whenever the stressor is eliminated source when the person adjusts to it.

3.1.2. Definition and Meaning: Unpleasant sentiments or moods that affect our ability to function are together referred to as psychological discomfort. In other words, it is psychological distress that prevents us from carrying out our regular tasks. Psychological discomfort can result in inaccurate judgments of oneself, the outside world, and others. Worry, melancholy, diversion, and signs of mental illness are manifestations of psychological distress [7].

3.1.3. Causes: Psychological distress is a result of traumatic events like losing a loved one or losing a career. One way to conceptualize psychological distress is as a maladaptive reaction to a stressful circumstance. When we are faced with demands that we are unable to meet due to pressures or events

beyond our control, psychological anguish results. Moving to a new state or finishing college are two examples of major life transitions that can cause psychological stress if you are unable to handle the responsibilities, they put on you or are having trouble getting used to the new environment. Psychological distress can be brought on by several factors or stressors, including everyday ones like traffic, bad experiences at school or work, beginning a new career, being ill, getting divorced, etc.

3.1.4. Symptoms: Since psychological distress is a personal feeling, two people will never express it in the same manner or have the same event experience. Although some signs of psychological distress include gaining weight, management of anger issues, ideas or urges that are obsessive, bodily pains, less sexual gratification, hallucinations, delusions, reckless acts, the conviction that the thoughts can be heard by others, the belief that the thoughts don't truly belong to you, strange or unusual behaviors, etc.

3.1.5. Determinants: Loneliness, workplace discontent, and conflict between job and family were the top risk factors for psychological discomfort. It was discovered that protective characteristics included having children, being actively involved, successful ability to balance job and family obligations, and social assistance. Psychological distress, which is more prevalent in women, is defined as generalized signs of stress, anxiety, and sadness (Viertiö, S., et al. (2021). [8]. Stressors are conditions that put the caregiver or family unit under more strain and therefore lead to distress. Common stressors for ASD parents include the severity of a child's illness, caregiving obligations, and the most significant problem behaviors in the kid. On the other side, some pressures are specific to being a parent or caregiver, such as a lack of knowledge and understanding, less psychosocial support, and poor physical health. Education, financial means, and health are further factors affecting caregivers (Minz, D. L. (2020). [9].

3.1.6. Coping Strategies: Finding the potential reasons for the distress and making a decision to take action to lessen or overcome it are the first steps in effective psychological distress coping. Addressing the underlying causes of psychological suffering may entail receiving psychological counseling. Stepping outside and spending at least 20 minutes in a green area. Consider providing hugs to protect against the unfavorable effects involving interpersonal conflict and discomfort. Decide what's required, focus on what you desire to take care of yourself, and use other preventative coping mechanisms [10].

3.2. Psychological Wellbeing (PWB):

3.2.1. Introduction: Well-being is a phrase used by psychologists to refer to the happy state that results from finding meaning in one's life, having a purpose, and reaching one's potential. These well-being pillars can be difficult to cultivate. It might be challenging to adhere to our moral values, particularly when other people don't agree. It might be tough to deal with daily expectations. There are sensitive, uneasy moments in even the healthiest partnerships. In its simplest form, the concept of psychological well-being (PWB) resembles other expressions used to describe good mental emotions, including happiness or satisfaction.

3.2.2. Definition: The perception of each person's physical, cognitive, and societal well-being as a whole is referred to as their psychological well-being.

3.2.2.1. Two Facets: Two main factors affect psychological health. The first of these is subjective well-being, which is the degree to which individuals feel happy and have good emotions, i.e: **Hedonic Wellbeing**. The foundation of hedonistic wellness is the idea that a balance between pleasure and suffering makes people happier. The idea of subjective well-being serves as the foundation for hedonic notions. The phrase "happy or good life" refers to what is often referred to as subjective well-being in science. In addition to a feeling-based element, it has a cognitive component. According to some theories, happiness is a state of high positive affect and life satisfaction (Carruthers, C., & Hood, C. D. (2004). [11]. The second is the conviction that our lives have some sort of significance and direction (Diener, E. (2000). [12]. i.e: **Eudaimonic Wellbeing**. Eudaimonic well-being heavily relies on Roger's concept of the fully functioning individual and their subjective well-being as well as Maslow's ideals of self-actualization. Eudaimonic happiness is thus predicated on the idea that people enjoy satisfaction if they encounter difficulties, growth, and a purpose in life. The theory of self-determination is used in this strategy to conceptualize happiness. According to the self-determination theory, fulfillment in the areas of autonomy and competence is associated with happiness (Ryan, R. M., et al. (2008). [13].

3.2.3. Six Components:

Six key elements of psychological wellness have been established through research.

3.2.3.1 Autonomy: The ability to think and act without regard to others' opinions and acceptance is what

is meant by autonomy. Autonomous people fend off social pressures that go against their values or preferences. They put effort into achieving goals that they voluntarily choose and genuinely cherish.

3.2.3.2. Competence: The ability to use knowledge, skills, and abilities to solve problems and complete desirable activities is what is meant by competence. Competent individuals can handle the obligations, and daily life requirements, and complete tasks. They take advantage of their possibilities and customize their living spaces to suit them.

3.2.3.3. Healthy Relationship: Most people need to interact with others. Having extensive social networks of peers, relatives, and coworkers is a significant draw for some people; others value independence and solitude more. Whether you seek many relationships or merely a few, the ability to forge dependable, kind, and supportive bonds is a critical aspect of mental wellness.

3.2.3.4. Self-acceptance: Self-accepting individuals are cognizant of their strengths and weaknesses. They understand that there are highs and lows in life, that everybody blunders and squanders chances, and that they all experience regret disappointment, and other negative feelings. They accept themselves as they are and do not pass judgment on the course their lives have taken thus far.

3.2.3.5. Personal Growth: People who emphasize personal development are receptive to new information and experiences. They understand that viewpoints alter as we age and perceive ourselves as growing and changing. They want to expand their horizons and reach their full potential.

3.2.3.6. Purpose in Life: People feel they have direction in life when they have a sense of purpose. They are aware of what is most important to them, such as being a kind parent, a dependable friend, a successful employee, or an active part of the community. They have a sense of accomplishment when they set and accomplish goals that give them a purpose in life.

When combined, these six dimensions represent a wide range of wellness that includes having a positive opinion of oneself and life goals, feeling like one is still developing as a person, believing that life has a purpose and is meaningful, having positive relationships with other people, having the capacity to successfully manage one's life and environment, and feeling self-determined (Menezes, I., S. & D'Mello, L. (2021). [14]. According to studies, those who are more psychologically well are more likely to be healthier and live longer (Heintzelman, S. J. (2018). [15].

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

Social support and family functioning were compared in a cross-sectional study of Chinese households with ASD children. 167 caregivers of children with ASD were polled on how their families functioned and how they felt about social support by measuring the use of support, both objective and subjective, and family cohesion. The results showed that social support positively correlated with family cohesion and adaptation. The study's results demonstrated the significance of various forms of social care that may be applied to create focused assistance programs for families with children who have ASD to enhance family dynamics and maintain the family structure (Lei, X., & Kantor, J. (2022). [16].

Typically, ASD mothers report poorer mental health and decreased household functioning. This study builds on earlier research by examining whether various neighborhood factors, both beneficial and harmful, influence mothers' mental states and the general functioning of ASD families. Neighborhood support is favorably and significantly correlated with mothers' mental health and the overall functioning of ASD families, according to a simultaneous equation path analysis of children in the US drawn from a nationally representative sample. The general family functioning and mental state of ASD mothers are found to be lower. It has been demonstrated that neighborhood characteristics have a positive impact on the family performance and mental well-being of the general population. Mothers who have children on the autistic spectrum can experience a significant improvement in their subjective quality of life through community support (Whitehead, A. L. (2017). [17].

The current study's goal was to contrast parental stress, family functioning, and social support between parents who believed their child's autism symptoms were severe and a control group. Parental impressions of autistic children and generally developing children were examined to assess these variations. When compared to parents who have children with little significant autistic symptoms and parents of children who are developing normally, parents who have children with extreme autistic behavior patterns reported increased levels of parental anxiety and lower perceptions of overall performance in the family. The groups did not differ when it came to how well the parents reported that the family was operating or how useful they viewed family social support to be, suggesting that more research is necessary (Kissel, S. D., & Nelson III, W. M. (2016). [18].

Tung et al. (2014) [19] sought to determine whether there was a relationship between parents of autistic children's HRQOL and the occurrence of autism, behavioural issues, and parenting stress, as well as the relevance of the HRQOL categories to the parents. The PSI-SF was used to assess stress, the CARS to assess the severity of autism, the WHOQOL-BREF to assess HRQOL, and the SDQ to assess behaviour. The results showed that caregivers of children with autism had significantly poorer scores in the social, psychological, and physical dimensions.

A mixed analysis was used to assess 224 parents of ASD-affected children's HRQOL, its impacts, and areas of concern. HRQOL, which includes independence, self-care, routine care, pain/discomfort, and nervousness, was evaluated using the SF6D and EQ-5D. While the SF-6D was much worse than the general population, the EQ-5D was not noticeably different. Caregiving stress was higher in early-diagnosed children (2 years) than later diagnosed, which was the only finding connected with QOL scores among the child features. Family functioning is a challenging factor in families with ASD. Intense stressors lead to higher distress as problem-solving is stressful on a long-term basis. Many parents are at risk of psychological distress due to heightened healthcare expenses, and unemployment due to consistent child care. These are the major determinants that contribute to depressive illness and psychological distress in parents (Kuhlthau, K., (2014). [20].

Firat et al., (2002) [21] assessed the general psychological symptoms of 40 mothers with ASD children and 38 mothers with mental retardation children, using psychometric tests and concluded that 27.5% of ASD children mothers were without psychopathology compared with 55.3% of mothers with mental retardation kids, which explains that the mothers with autism children experience more psychological distress than the MR conditions. Similarly, various studies to identify the distress factors showed that low family support, while raising a child with disruptive behavior and infrastructure as well as single parenting contributed to the illness. Poorly available healthcare facilities to meet the core symptoms of ASD made it highly challenging.

Table 1: Literature Review Summary

S. No.	Area & Focus of the Research	The result of the Research	Reference
1	Social support and family functioning.	The results showed that social support positively correlated with family cohesion and adaptation. The study's results demonstrated the significance of various forms of social care that may be applied to create focused assistance programs for families with children who have ASD to enhance family dynamics and maintain the family structure.	(Lei, X., & Kantor, J. (2022). [16]
2	Neighborhood support, mothers' mental health, and the overall functioning of ASD families.	The general family functioning and mental state of ASD mothers are found to be lower. It has been demonstrated that neighborhood characteristics have a positive impact on the family performance and mental well-being of the general population.	(Whitehead, A. L. (2017). [17]
3	Parental stress, family functioning, and social support.	When compared to parents who have children with little significant autistic symptoms and parents of children who are developing normally, parents who have children with extreme autistic behaviour patterns reported increased levels of parental anxiety and lower perceptions of overall performance in the family.	(Kissel, S. D., & Nelson III, W. M. (2016). [18]
4	Relationship between parents of autistic children's HRQOL and the occurrence of autism, behavioural issues, and	The results showed that caregivers of children with autism had significantly poorer scores in the social, psychological, and physical dimensions.	Tung, et al. (2014). [19]

	parenting stress, as well as the relevance of the HRQOL categories to the parents.		
5	Assessed the general psychological symptoms of 40 mothers with ASD children and 38 mothers with mental retardation children, using psychometric tests.	Concluded that 27.5% of ASD children mothers were without psychopathology compared with 55.3% of mothers with mental retardation kids, which explains that the mothers with autism children experience more psychological distress than the MR conditions. Low family support, while raising a child with disruptive behavior and infrastructure as well as single parenting contributed to the illness. Poorly available healthcare facilities to meet the core symptoms of ASD made it highly challenging.	Firat, et al., (2002) [21]

4. MATERIALS AND METHODS :

A cross-sectional study of 61 respondents was carried out to identify and categorize various components of the psychological well-being of mothers of children with autism. In the explorative stage, an inductive research approach (Ganesh, H. R., & Aithal, P. S., (2022). [22], using open-ended questions was carried out to understand the phenomena through online and offline structured interviews, using a convenience sampling method. By investigating their lived experiences, including daily challenges, emotional responses, and coping strategies, the study aims to provide a comprehensive understanding of the psychological well-being of Indian mothers caring for children with ASD.

5. RESULTS AND DISCUSSION :

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

Feeling happy enables one to function in day-to-day life, fostering emotional health. Simple strategies to maximize psychological well-being affect positivity and total mental health. Happiness where positive emotions are experienced, and satisfaction with life, are considered the key facets of PWB. PWB was assessed by measuring the fulfillment of personal desires, meaning and acceptance of life, learning new experiences in life, connectedness or positive relations, goal setting, achievements, and satisfaction (Heintzelman, S. J. (2018). [15]. The 6 items PWB1, PWB2, PWB3, PWB4, PWB5, and PWB6 of the PWB as a construct demonstrated to measure the psychological well-being of mothers of autistic children (Menezes, I. S., & Shwetha, K.T., (2022). [23]. In the last stage, 61 people were surveyed using monomethod with organized in-depth interviews with informed consent. PWB1 measures the fulfillment of the desires despite more demanding care of the child than the typical child. PWB2 was constructed to examine the meaning and acceptance of life as they have realized or sensed multiple aspects both good and bad. People with positive attitudes, develop the necessary skills to combat stress. Cultivating acceptance with competency skills lowers the risks of any distress and raises self-esteem. Learning new experiences in life requires the competency to make use of the resources wisely and to adapt to situations. The potential to cope, adjust, and adapt to learning new experiences was measured using PWB3. Positive and supportive relationships strengthen feelings of security. A mother with ASD children will be more secure with the quality of relationships while handling these children. Whether countable or many relationships, the ability to connect with independence weighs on psychological health. The item PWB4 was constructed to measure whether they were appreciated, more connected, respected, more loved, and secure in social life, with friends and others. PWB5 was developed to measure the skills and competencies to cope with and solve problems. PWB6 was constructed to measure satisfaction with goal setting and working on them as they have higher self-esteem and greater satisfaction with their lives.

5.2. Results:

PWB1 measures the fulfillment of the desires despite more demanding care of the child than the typical child. Parents of children with ASD often face higher demands for more intensive and persistent

caregiving due to the child's behavioral, communication, sensory, and social challenges. PWB1 refers to how well mothers perceive they are meeting their child's needs and desires. This concept reflects the overall satisfaction, emotional state, and sense of fulfillment that parents experience in their caregiving role. PWB2 was constructed to examine the meaning and acceptance of life as they have realized the impact of ASD in the family. How do family members cope with and adapt to the challenges and rewards, feelings of acceptance, stress, and resilience associated with ASD? This could involve shifts in priorities, values, and life goals. It's quite cumbersome for families to come to terms with and embrace the reality of ASD, including societal and personal acceptance. PWB3 assesses how mothers cope with, adjust to, and adapt to new experiences, particularly in the context of challenges by ASD, identifying both adaptive and maladaptive coping strategies to manage stress and difficulties associated with new experiences or challenges. Learning from Experience particularly those related to ASD with new insights or skills as they integrate into their lives and affect their coping and adaptation that helps to assess the psychological well-being of the mother. PWB4 measures aspects of social well-being and interpersonal relationships. Specifically, it measures how mothers perceive their social values and interactions in terms of feeling appreciated, connected, respected, loved, and secure. Appreciation measures whether mothers feel valued and recognized by others valuing their contributions and presence in demanding care of the child. Connection evaluates the sense of social connectedness and the quality of relationships with feelings of belonging, integration within social groups, and meaningful social interactions (Meyer, K. A., et al. (2011). [24]. Respect assesses whether mothers feel respected by others, are treated with dignity, have their opinions valued, and experience respect in social interactions. The sense of being loved and cared for by friends, family, and others evaluates the presence of emotional support, affection, and deep personal bonds. Security measures feelings of safety and stability in social relationships. This includes trust, reliability of social support, and confidence in one's social environment (Menezes, I., S. & D'Mello, L. (2021). [25], (Mays, N. M., et al. (2011). [26]. PWB5 evaluates a mother's skills and competencies related to coping with and solving problems; assessing various dimensions of problem-solving and coping abilities, which are crucial for managing life's challenges effectively. Problem-solving skills analytically evaluate the ability to break down complex problems into manageable parts, identify key issues, and develop logical solutions. It also assesses the ability to think outside the box generating innovative solutions. It approaches problems from different perspectives critically. It helps to develop coping Strategies to manage stress by adapting techniques and maintaining emotional stability when facing difficulties. PWB6 evaluates satisfaction with goal setting and the pursuit of personal objectives, specifically about self-esteem and overall life satisfaction. Goal-setting satisfaction evaluates well-defined individuals' goals and aligns them with personal values and long-term aspirations, impacting motivation and satisfaction. The pursuit of goals measures individuals' satisfaction with their progress by assessing the efforts and commitments individuals invest in working towards achieving their goals.

6. DISCUSSION :

PWB1 measures factors in understanding the holistic impact of caregiving on parents' well-being and can be aimed at improving family dynamics and parental satisfaction. PWB2 aims to provide a comprehensive understanding of how ASD impacts the meaning and acceptance of life from a psychological perspective, offering insights that could inform both support practices and personal coping strategies. This helps professionals and caregivers to understand and address the specific challenges and rewards associated with raising a child with ASD. PWB3 provides a comprehensive assessment of how people cope with, adjust to, and adapt to new and potentially challenging experiences, particularly in the context of ASD, with a focus on resilience and learning. PWB4 provides a comprehensive view of how individuals perceive their social standing and interactions, offering valuable insights for enhancing social well-being and strengthening personal connections. PWB5 focuses on evaluating and improving the skills and competencies necessary for effectively coping with and solving problems. By assessing problem-solving abilities, coping strategies, decision-making, resilience, and resource utilization, PWB5 provides a comprehensive framework for understanding and enhancing one's capability to manage life's challenges. PWB6 assesses how satisfaction with goal setting and progress towards personal objectives influences self-esteem and overall life satisfaction. By examining various aspects of goal-related activities and their impact on personal well-being, PWB6

provides valuable insights into enhancing personal growth and achieving a more satisfying and fulfilling life.

7. NEW KNOWLEDGE :

Children with ASD have unique needs and desires compared to typically developing children, and parents face additional challenges in understanding and fulfilling these needs. PWB was assessed by measuring the fulfillment of personal desires, meaning and acceptance of life, learning new experiences in life, connectedness or positive relations, goal setting, achievements, and satisfaction [13]. The 6 items PWB1, PWB2, PWB3, PWB4, PWB5, and PWB6 of the PWB as a construct demonstrated to measure the psychological well-being of mothers of autistic children. Despite the challenges, it explores how mothers perceive their ability to meet their child's desires and needs through sacrifices in caring for their child with special needs. Having a family member with ASD influences personal beliefs about life's meaning and purpose. In the process of adjustments, it is important to modify their behaviours, expectations, and attitudes to these changes as a response to new situations, considering the long-term changes in child's behaviour, resilience, and flexibility in the face of persistent demands measuring the ability to adapt over time to ongoing challenges. Social Support helps to build additional assistance or connections to enhance overall well-being and life satisfaction, increasing feelings of appreciation and respect, and improving overall social security. Thus offers a framework for mothers to reflect on their social relationships and identify areas for personal and relational growth. Mothers' beliefs in their ability to achieve their goals and handle challenges contribute to their self-esteem. Working towards goals impacts their sense of self-worth and confidence. The extent to which mothers feel satisfied with their lives is influenced by their internal drive to succeed in goal setting and achievement. A feeling of fulfillment and contentment derived from making progress towards personal goals and realizing aspirations that set in.

8. CONCLUSION :

Indian mothers of children with ASD exhibit resilience amidst significant challenges, including navigating societal stigma, accessing appropriate services, and managing emotional stress. The study aimed to explore the lived experiences of Indian mothers caring for children with ASD by uncovering the day-to-day challenges, emotional experiences, and coping mechanisms used by mothers in their caregiving roles. The study also identified the coping strategies utilized by Indian mothers to manage stress and emotional challenges navigating the emotional demands and stressors associated with caregiving for children with ASD. The role of social support networks in supporting maternal psychological well-being was investigated by examining how relationships with family members, friends, and community networks contribute to or alleviate stress and promote resilience among mothers of children with ASD. The perceptions of autonomy and competence among Indian mothers in their caregiving roles towards making decisions, and how these perceptions impact their psychological well-being was examined. The experiences of personal growth and self-acceptance among Indian mothers by understanding how mothers perceive personal growth, self-acceptance, and identity development through their caregiving experiences for children with ASD was observed. The objective of investigating the factors that provide meaning, purpose, and fulfillment to mothers in their roles as primary caregivers to children with ASD carried out. Themes of autonomy, competence, healthy relationships, self-acceptance, personal growth, and purpose in life emerged as critical components influencing their psychological well-being. These themes collectively aimed to provide a comprehensive understanding of the psychological well-being of Indian mothers caring for children with ASD, informing future research, on intervention strategies to better support these mothers and their families.

9. SUGGESTIONS :

It is crucial to acknowledge emotions by recognizing and validating one's feelings and experiences. Mothers need to allow themselves to feel and process these emotions without judgment. It is normal to experience a range of emotions, from joy and pride to frustration and anxiety. Sharing experiences and advice can provide emotional relief and practical insights. Therefore connecting with other parents of children with ASD through Support groups, both online and in-person, can be a valuable resource. It's important to ensure time for self-care activities that rejuvenate and energize like leisure time activities.

This might include hobbies, exercise, meditation, or simply taking breaks when needed. A mother's well-being is crucial for her ability to care for her child effectively.

10. LIMITATIONS OF THE STUDY :

The study's cross-sectional design limits the ability to capture changes in maternal psychological well-being over time, missing insights into the evolving nature of caregiving experiences and adaptation processes. Participants' recall of past experiences and emotions may be imperfect or influenced by current circumstances, potentially affecting the accuracy and reliability of data regarding historical events or emotional responses. Acknowledging these limitations is crucial for interpreting the study's findings appropriately and for guiding future research endeavours aimed at better understanding and supporting the psychological well-being of mothers caring for children with ASD in diverse cultural contexts.

11. SCOPE FOR FUTURE RESEARCH :

Future research needs to conduct longitudinal studies to track changes in psychological well-being among Indian mothers over time as their children with ASD progress through different developmental stages. This would provide insights into the long-term impact of caregiving and adaptation processes. Based on study findings, develop and implement culturally appropriate interventions aimed at enhancing psychological resilience and well-being among mothers of children with ASD. Understanding how variations in cultural practices, resources, and support systems influence psychological well-being can inform tailored interventions. These interventions could include psychoeducation, support groups, mindfulness-based approaches, or family-centered therapies. By pursuing these future directions, the study can contribute valuable insights into enhancing the psychological well-being of mothers of children with ASD in India and globally. This research has the potential to inform policies, practices, and interventions that support families affected by ASD, promote resilience, and improve overall quality of life.

ACKNOWLEDGEMENT :

(a) We are profoundly grateful to Dr. Aithal P. S., Director of Poornaprajna University, Udupi, India. His unwavering support and inspiration have been the cornerstone of our efforts in advancing new research.

(b) Dr. H. R. Ganesh, Research Professor at Srinivas University, Mangalore, India, has been instrumental in shaping this work through his supervision of the Doctoral-Level Research (DDL) program. His guidance and scholarly oversight have significantly influenced both the direction and quality of our research. Dr. Ganesh's expertise and leadership at Srinivas University highlight his dedication to advancing research excellence and fostering intellectual growth among doctoral candidates. His influence is evident in the scholarly rigor and depth of our work under his mentorship and within the DDL program.

(c) Dr. Srinivasan Venkatesan, a former Reader in Clinical Psychology at the All-India Institute of Speech and Hearing in Mysore, India, holds a cherished place in our hearts as a grateful recipient. I deeply appreciate everything he has taught me, his unwavering support, genuine attention, invaluable advice, and continuous encouragement.

REFERENCES :

- [1] <https://www.crossrivertherapy.com/autism-statistics#chapter-1:-autism-prevalence-statistics>. Retrieved on 14th September 2023.
- [2] <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>. Retrieved on 13th September 2023.
- [3] Maenner, M. J., Warren, Z., Williams, A., R. et al. (2020). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States. *MMWR Surveill Summ* 2023, 72(No. SS-2):1–14. [Google Scholar x⁷](#)
- [4] Menezes, I., S. & D'Mello, L. (2021). A study on the leisure activities in mothers of children with autism. *Bi-Annual Peer Reviewed Journal of Social Work*, 19(I), 101-109. [Google Scholar x⁷](#)

- [5] DeJong, P., & Berg, K. (2008). *Interviewing for Solutions (3rd ed.)*. 57-64. Belmont, CA: Brooks/Cole. [Google Scholar](#)
- [6] Huang, Y. T., Ososkie, J., & Hsu, T. H. (2011). Impact on Marital and Sibling Relationships of Taiwanese Families Who have a Child with a Disability. *Journal of Comparative Family Studies*, 42(2), 213-232. [Google Scholar](#)
- [7] <https://study.com/learn/lesson/what-is-psychological-distress.html>. Retrieved on 21st August 2023.
- [8] Viertiö, S., Kiviruusu, O., & Piirtola, M. *et al.* (2021). Factors Contributing to Psychological Distress in the Working Population, with a Special Reference to Gender Difference. *BMC Public Health* 21, 611. [Google Scholar](#)
- [9] Minz, D. L. (2020). Determinants of Psychological Distress among the Mothers of Children with Autism Spectrum Disorder and Pervasive Developmental Disorder: A Comparative Study. [Doctoral dissertation, Central Institute of Psychiatry (India), *Ranchi University*]. 1-14. [Google Scholar](#)
- [10] <https://psychcentral.com/lib/factors-linked-to-psychological-distress#1>. Retrieved on 02nd September 2023. [Google Scholar](#)
- [11] Carruthers, C., & Hood, C. D. (2004). The Power of the Positive: Leisure and Well-Being. *Therapeutic Recreation Journal*, 38(2), 225-245. [Google Scholar](#)
- [12] Diener, E. (2000). Subjective Well-Being: The Science of Happiness and a Proposal for a National Index. *American Psychologist*, 55(1), 34-43. [Google Scholar](#)
- [13] Ryan, R. M., Huta, V., & Deci, E. L. (2008). Living Well: A Self-determination Theory Perspective on Eudaimonia. *Journal of Happiness Studies*, 9(1), 139-170. [Google Scholar](#)
- [14] Menezes, I., S. & D'Mello, L. (2021). Leisure and Quality of Life among Parents of Children with Autism Spectrum Disorder – A Review Based Analysis. *International Journal of Management, Technology, and Social Sciences (IJMTS)*, 6(1), 176- 188. [Google Scholar](#)
- [15] Heintzelman, S. J. (2018). Eudaimonia in the Contemporary Science of Subjective Well-Being: Psychological Well-Being, Self-Determination, and Meaning in Life. *Handbook of Well-Being*. 1-14. Salt Lake City, UT: DEF Publishers. [Google Scholar](#)
- [16] Lei, X., & Kantor, J. (2022). Social Support and Family Quality of Life in Chinese Families of Children with Autism Spectrum Disorder: The Mediating Role of Family Cohesion and Adaptability. *International Journal of Developmental Disabilities*, 68(4), 454-461. [Google Scholar](#)
- [17] Whitehead, A. L. (2017). Neighborhoods, Family Functioning, and Mothers' Mental Health for Families with a Child with an Autism Spectrum Disorder. *Applied Research in Quality of Life*, 12(3), 633-651. [Google Scholar](#)
- [18] Kissel, S. D., & Nelson III, W. M. (2016). Parents' Perceptions of the Severity of their Child's Autistic Behaviors and Differences in Parental Stress, Family Functioning, and Social Support. *Focus on Autism and Other Developmental Disabilities*, 31(2), 152-160. [Google Scholar](#)
- [19] Tung, L. C., Huang, C. Y., Tseng, M. H., Yen, H. C., Tsai, Y. P., Lin, Y. C., & Chen, K. L. (2014). Correlates Health-Related Quality of Life and the Perception of its Importance in Caregivers of Children with Autism. *Research in Autism Spectrum Disorders*, 8(9), 1235-1242. [Google Scholar](#)
- [20] Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., Tilford J. K. (2014). Quality of Life for Parents of Children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 8(10), 1339-1350. [Google Scholar](#)
- [21] Firat, S., Diler, R. S., Avci, A., & Gulsah, G. (2002). Comparison of Psychopathology in the Mothers of Autistic and Mentally Retarded Children. *Journal of Korean Medical Ccience*, 17(5), 679-685. [Google Scholar](#)

- [22] Ganesha, H. R., & Aithal, P. S., (2022). The DDLR Model of Research Process for Designing Robust and Realizable Research Methodology During Ph.D. Program in India. *International Journal of Management, Technology, and Social Sciences (IJMTS)*, 7(2), 400- 417. [Google Scholar](#)
- [23] Menezes, I. S., & Shwetha, K.T., (2022). Development of LsPQM-12 Instrument to Measure Leisure Specific Psychological Well-being and Quality of Life of Mothers of Children with Autism Spectrum Disorder. *International Journal of Health Sciences and Pharmacy (IJHSP)*, 6(2), 20-40. [Google Scholar](#)
- [24] Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors Influencing Adjustment in Siblings of Children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 5(4), 1413-1420. [Google Scholar](#)
- [25] Menezes, I., S. & D'Mello, L. (2021). The Impact of the Diagnosis of Autism on the Family. *International Research Journal of Modernization in Engineering Technology and Science*, 3(2), 1297-1300. [Google Scholar](#)
- [26] Mays, N. M., Beal-Alvarez, J., & Jolivette, K. (2011). Using Movement-Based Sensory Interventions to Address Self-Stimulatory Behaviors in Students with Autism. *Teaching Exceptional Children*, 43(6), 46- 52. [Google Scholar](#)
