

The Impact of Autism Spectrum Disorder on the Quality of Life of Parents

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DOI: <https://dx.doi.org/10.47772/IJRISS.2025.905000366>

Received: 11 May 2025; Accepted: 15 May 2025; Published: 17 June 2025

ABSTRACT

The impact of autism spectrum disorder (ASD) on the quality of life of parents represents an established scientific reality, which transcends a passing effect to touch the essence of daily life. The concept of quality of life here is not a mere term, but a comprehensive framework that encompasses interconnected psychological, social, physical, and economic aspects. It can be assessed through precise indicators that reflect the extent of the impact on parents, such as emotional well-being, which can be shaken under the weight of pressures, parental roles that require constant adaptation, family interaction that can undergo radical transformations, and the support provided in caring for these children who face the challenges of disability.

In this study, we seek to analyze this impact in depth and explore its various dimensions on the quality of life of parents. Our analysis is not limited to observing the impact, but extends to examining the close relationship between this impact and the sex of the parents, asking: Does the degree of impact differ between mothers and fathers? Do mothers bear a heavier burden in the face of the challenges of ASD in their children? Answering these questions requires us to delve into the nature of each parent's social and cultural roles and analyze the extent of their impact on their ability to adapt to this new reality.

Our in-depth understanding of these dynamics will open broader perspectives for developing effective and targeted interventions, aimed at supporting parents and enabling them to face the challenges of ASD, thereby improving their quality of life and that of their children.

Objective: This intervention aims to present a field study that assessed the level of impact of autism on the quality of life of parents of children with autism and to show the close relationship between this impact and the sex of the parents.

Study Methodology: Data were collected using the Beach Center Quality of Life Scale, which includes five indicators to assess the quality of life of parents, including their emotional well-being. The study sample consisted of 50 cases of parents of children with ASD (25 mothers and 25 fathers) using statistical analysis software, where we analyzed the impact of autism on the quality of life of parents according to their sex.

Results: The study results showed statistically significant differences between mothers and fathers regarding quality-of-life levels in the five domains mentioned previously, where the results showed a superiority of fathers in the quality-of-life averages compared to mothers, and thus a greater impact on them by the child's disability.

Conclusion: These results highlight the importance of providing psychological and social support to mothers of children with ASD, and it is necessary to develop training programs and specific support services to help them face the challenges they encounter in order to improve their quality of life and alleviate their burden.

Keywords: Quality of Life, Autism Spectrum Disorder

INTRODUCTION

The arrival of a newborn in a family represents an exceptional event and a considerable responsibility for the parents. However, This event can quickly turn into a heavy burden, and the family's responsibility increases significantly if the child suffers from autism. Parents find themselves facing continuous care tasks and a constant presence with the child, as the diagnosis of autism in a child is a violent shock. From the observation of the first symptoms to the confirmation of the diagnosis, and through the child's access to appropriate therapeutic interventions, parents go through long and exhausting stages that negatively affect their mental health and quality of life. This event represents a real ordeal for parents and a major challenge for the balanced exercise of parenthood. In this context, numerous researches and studies have highlighted the challenges and pressures faced by parents in caring for a child with autism, and have revealed the impact of this on the parents' quality of life. Although the concept of quality of life is recent, it has acquired crucial importance in families facing the challenges of disability. This quality can be measured through multiple indicators, including emotional well-being, parental roles, family interaction, and the support provided to people with disabilities. Recent years have seen a notable increase in studies aimed at deepening our understanding of quality of life, making it a point of interest in various disciplines such as psychology, sociology, medicine, philosophy, and education. The interest in the quality of life of parents who face the challenges of raising a child with autism is entirely justified, as it allows us to better understand the psychological mechanisms that support their ability to adapt. Moreover, the measurement of quality of life is an effective tool for assessing their degree of adaptation to this event, as it comprehensively encompasses the different aspects of their lives, as we will explain in this scientific article.¹

To better understand the impact of autism on the quality of life of parents, numerous studies have been conducted, some of which have adopted a comparative approach between the sexes. These studies aimed to determine whether the impact of autism on parents' quality of life was the same, or if there were differences in this regard between mothers and fathers.

In this context, this article aims to investigate which of the two parents, mothers or fathers, experiences a deeper and more significant impact on their quality of life due to the presence of a child with an autism spectrum disorder. To achieve this, we will assess the degree of this impact using the BEACH Quality of Life Scale, a recognized measurement tool for evaluating the quality of life of parents of children with disabilities.

Research Problem:

Building upon the aforementioned points, we can formulate the central research question as follows: Is the quality of life of parents raising a child with an autism spectrum disorder affected similarly, or are there differences based on the parents' gender?

Research Hypothesis:

This study posits that statistically significant differences exist in the quality of life experienced by parents of a child with an autism spectrum disorder, contingent upon their gender. Specifically, we hypothesize that mothers will report a lower quality of life compared to fathers. To examine this hypothesis, we employed the BEACH Center Family Quality of Life Scale, which encompasses five domains assessing parents' perceived importance and satisfaction concerning: 1) their role as parents; 2) their emotional well-being; 3) family interactions; 4) their physical and material well-being; and 5) the external support available to families of children with disabilities.

Study Objective:

This study aims to measure the impact of an autism spectrum disorder diagnosis on the quality of life of parents, with a specific focus on the differences between mothers and fathers. The research seeks to understand

¹ Gattegno, J.-L., Adrien, M., & Pilar, M. (2011). *L'autisme de l'enfant : Évaluations, interventions et suivis* (2e éd.). Bruxelles, Belgique : Mardaga

how parents' quality of life and psychological well-being are affected, and whether substantial differences exist between mothers and fathers in this impact.

The study will be divided into two main parts: a theoretical section that will examine the fundamental concepts of quality of life, and an experimental section that will present the results of the study conducted on a sample of 50 cases of parents of children with autism. The research aims to provide precise data on the impact of an autism diagnosis in a child on the quality of life of parents and to evaluate this impact based on the parents' gender.

To assess the parents' quality of life, the BEACH Center Family Quality of Life Scale, a recognized measurement tool for evaluating the quality of life of parents of children with disabilities, will be used.

Theoretical Framework:

The Concept of Quality of Life:

The term 'quality,' originating from the Latin word 'qualitas,' was first used by Cicero. It is derived from the word 'qualis' to describe the way something exists and its essential characteristics. Consequently, the concept of quality of life should refer to how people live and the characteristics of life that lead to a better existence. This was enough to prompt American scientists in the 1960s to embark on the development of social indicators for the quality of life of Americans. The concept of quality of life is not new, as the discussion about what constitutes well-being or happiness dates back to Plato and Aristotle. However, over the past three decades, the concept of quality of life has become increasingly prevalent in research and application centers within the fields of education, special education, healthcare (physical and behavioral), social services (disability and aging), and families.

Definition of Quality of Life According to the World Health Organization (WHO):

Quality of life is an individual's perception of their position in life, within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. This definition combines both a subjective and objective perspective on quality of life.²

It demonstrates that an individual's sense of satisfaction with their life is influenced by their values and expectations, as well as their health, social, and environmental conditions. In other words, quality of life is a personal and internal feeling unique to each individual, yet it is influenced by surrounding factors. It is not isolated from the individual's social and cultural environment. This definition underscores the importance of examining quality of life from an individual standpoint and considering cultural and social factors when assessing it, as well as focusing on personal goals and expectations when seeking to improve quality of life. It pertains to how an individual feels about their life, and this feeling is influenced by their culture, values, goals, expectations, as well as anxiety and stress, which can negatively impact quality of life.³

Other definitions of quality of life focus on specific aspects of human existence, such as well-being, happiness, life satisfaction, or personal fulfillment. Quality of life can be defined as a composite measure of the physical, mental, and social well-being perceived by each individual or group of individuals, as well as the degree of satisfaction and fulfillment in areas such as health, hygiene, family, work, education, self-esteem, and interpersonal relationships.

Quality of life is a concept with multiple definitions, but it is often measured by a set of indicators related to an individual's psychological, physical, and social health, as well as their sense of satisfaction with their life.

² World Health Organization (WHO). (1993). *WHO Global Strategy for Health and Environment*. Geneva, Switzerland: World Health Organization

³ Tobelem-Zanin, C. (1995). *La qualité de la vie dans les villes françaises. publications de l'Universités de Rouen*(208), 288

It remains difficult to discuss quality of life without considering the psychological dimension that connects it to happiness and satisfaction with the current situation, the feeling of enjoying life and fulfilling needs to achieve well-being. Therefore, discussing quality of life means addressing a subjective, emotional, and personal element that cannot be measured solely by material possibilities, as it is linked to how an individual perceives and evaluates their life.⁴

With the aim of better understanding the impact of autism on the quality of life of parents, numerous studies have been conducted, some of which have adopted a comparative approach between genders. These studies sought to determine whether the impact of autism on parents' quality of life was the same, or if there were differences in this regard between mothers and fathers.

In this context, this scientific article undertakes to investigate which parent experiences a deeper and more significant impact on their quality of life due to the presence of a child with an autism spectrum disorder. To do this, we will assess the extent of this impact using the BEACH Center Family Quality of Life Scale, a recognized measurement tool for evaluating the quality of life of parents of children with disabilities.

Within the context of our study, this concept refers to the characteristics that contribute to an improved quality of life. It is a comprehensive measure of physical, mental, and social well-being, as perceived by individuals or groups. This well-being is manifested in the level of satisfaction individuals experience in areas such as health, family relationships, work, education, self-esteem, and social connections.

In our study, we define 'quality of life' as the subjective evaluation of parents' emotional well-being, encompassing their happiness, and the extent of their suffering and burden. We pay particular attention to the sense of support experienced by parents of a child with an autism spectrum disorder.

Utilizing the BEACH Center Family Quality of Life Scale, we will measure the various components of quality of life within our parent sample. This scale will allow us to identify the specific areas in which parents encounter difficulties, based on its five main dimensions, namely:

- ⇒ **Family Interactions:** This domain measures the degree of parental satisfaction with their relationships with their children, spouses, and other children. It also evaluates the quality of shared family activities.
- ⇒ **Parenting Role:** This domain measures the degree of parental satisfaction with their role as parents of a child with autism, their ability to meet their child's needs, their capacity to manage stress related to their child's disability, and their ability to balance their personal and professional lives.
- ⇒ **Emotional Well-being:** This domain measures the level of parents' emotional well-being, including their happiness, their levels of stress and fatigue, and their sense of support.
- ⇒ **Physical and Material Well-being:** This domain measures the degree of parental satisfaction with their physical health, financial situation, and housing.
- ⇒ **Disability-Related Support:** This domain measures the degree of parental satisfaction with the support they receive from their family, friends, professionals (doctors, therapists, autism specialists), and community services (support from organizations and institutions that offer services to individuals with disabilities).

STUDY METHODOLOGY

In this study, we selected the Beach Center Family Quality of Life Scale as our data collection instrument. This scale was chosen for its ability to measure quantitative data, ensuring precision. Therefore, this selection was made due to its significance in assessing various aspects of quality of life. The Beach Center Scale was

⁴ Khoulood sbai. (2016). *La femme et la violence*, Casablanca. Éditions les Écoles, page 367

initially developed to evaluate the quality of life of American families with a child who has special needs. However, its adaptability has allowed its use in numerous countries, including Spain, Australia, and Quebec.⁵

As previously mentioned, our choice of this scale stems from its excellent suitability for the subject of this study. To process and analyze the data collected, we will utilize the Statistical Package for the Social Sciences (SPSS) software to obtain precise and objective scientific results.

Participants: The study sample consists of 50 parents of children diagnosed with an autism spectrum disorder, selected randomly. The parents will participate in individual interviews during which their family situation and their reactions to their children's diagnosis will be examined. They will also be asked to complete a questionnaire to assess their quality of life.

Target Group: This group comprises 50 parents of children diagnosed with an autism spectrum disorder. These parents were contacted on a voluntary basis to participate in this research. To gather accurate data, the sample will be divided into two halves: 25 direct individual interviews with fathers and 25 direct individual interviews with mothers.

Research Setting:

We conducted interviews with parents of children from the Moroccan Association for Listening and Personal Development (AMEDP) in Casablanca. AMEDP is a socio-educational center that provides support for children with autism spectrum disorders (ASD) from the age of 3. Located in Aïn Sebaâ, Casablanca, this association serves as a care, rehabilitation, and education center for children with ASD.

The center assesses each child's abilities and determines the degree and type of their disorder. Subsequently, they are directed and enrolled in a care and treatment program tailored to their capacities and the extent of their disability. The association accommodates a total of 80 children aged 3 to 21 years, who are placed according to their needs and cognitive abilities. Children capable of following educational programs are also integrated into mainstream schools.

RESULTS

In this study, we hypothesize that statistically significant differences exist in the quality of life of parents of children with an autism spectrum disorder, based on gender. We posit that mothers experience a lower quality of life compared to fathers. In other words, we assume that mothers suffer more and that their quality of life is more profoundly affected than that of fathers, due to several factors and reasons that we will detail below. The validity of this hypothesis was confirmed using the Student's t-test, which yielded the following results:

	Gender	N	Mean	Standard Deviation	Standard Error of Mean
Quality of Life Scale	Male	25	62,4800	17,61420	3,52284
	Female	25	61,6800	13,94549	2,78910

This descriptive table shows that fathers exhibit a higher level of quality of life compared to mothers.

The results revealed statistically significant differences between mothers and fathers regarding quality-of-life levels across all five domains mentioned previously. Specifically, the findings indicated that fathers had higher

⁵ Alsa, A., Sovitriana, R., & Ekasari, A. (2021). Psychological Well-being of Mothers with Autistic Children. *Journal of Educational and Social Research.*, 11, 247.

mean scores in quality of life than mothers, suggesting that mothers are more affected by their child's disability.⁶

Within the gender comparison, the results highlighted a disadvantage for mothers, whose quality-of-life level was significantly lower than that of fathers.

This study revealed a slight decrease in the quality of life among mothers of children with Autism Spectrum Disorder (ASD) compared to fathers. Several factors, derived from in-depth interviews with the mothers, explain this difference.

Firstly, accepting their child's ASD diagnosis represents a significant challenge. Secondly, the active search for solutions to promote their child's development and acquisition of adaptive skills is a constant source of worry.

Furthermore, mothers' sustained involvement in therapeutic activities, their close collaboration with healthcare professionals and teachers, their eagerness to learn the latest techniques, and their pursuit of expertise in the field of ASD represent a considerable investment.

These multiple responsibilities weigh heavily on mothers, leading to psychological and emotional exhaustion, as well as a feeling of isolation in managing their child's autism.

Within this framework, we will attempt to highlight studies that have addressed this subject to determine which parent's quality of life is more affected by the presence of a child with autism (mothers or fathers). Among these, we found a recent study by Vernhet, Christelle, et al. in 2022, titled "Parents' Perceptions of the Impact of Autism Spectrum Disorder on Their Quality of Life and Correlates: A Comparison Between Mothers and Fathers." This study compared the perceptions of mothers and fathers regarding the impact of autism spectrum disorders on their quality of life, using the Parental Developmental Disability-Quality of Life (DD-QoL) scale on a population of 130 pairs of parents of children with ASD. The results of this study concluded that mothers were significantly more affected by autism spectrum disorder on their quality of life than fathers. According to the findings, mothers' quality of life was negatively affected by their children's internalizing problems. By these problems, we mean the internal psychological symptoms experienced by a child with autism, often including sleep disorders, psychiatric issues (depression, anxiety), and developmental disorders (learning or attention-deficit/hyperactivity disorder). These are symptoms that are not outwardly apparent and are primarily felt by mothers, who reported that their quality of life was negatively impacted by them. According to the results of this study, fathers' perceived quality of life was negatively associated with their children's externalizing problems, that is, the behaviors that accompany autistic disorders and manifest as stereotyped acts and self-aggression.

Finally, certain parental factors, such as being a member of a family association, having received autism training, and experiencing interruptions in professional activity, were associated with a more significant positive impact on their parental quality of life.⁷

Contrary to the above, a study conducted in Jordan by Eiman A. Ahmed 1, Sireen M. Alkhaldi et al., titled "Quality of Life of Mothers and Fathers of Children with Autism Spectrum Disorder in Jordan" in 2023 on a sample of 215, aimed to evaluate the quality of life among mothers and fathers who have children with ASD in Jordan and to identify associated factors using the World Health Organization Quality of Life (WHOQOL – BREF) scale. The first part of the results of this study shows that parents of children with autism had a lower level of quality of life compared to other parents who have children with typical development, which explains that the quality of life of parents of a child with autism is negatively affected by the presence of autism in the family. In the second part, the results of this study showed that mothers reported a higher quality of life

⁶ Ghezlane El Hajri (2024) : La qualité de vie des parents d'un enfant atteint de trouble de spectre autistique (TSA), thèse de doctorat, Université Hassan II, Casablanca.

⁷ Vernhet C, et al : Perceptions of parents of the impact of autism spectrum disorder on their quality of life and correlates : comparaison between mothers and fathers. Qual Life Res. 2022 May ;31(5) :1499-1508

compared to fathers within this sample. This finding might be explained by the fact that the children receive rehabilitation and education in specialized centers, meaning they receive care and attention from these centers. This alleviates a significant portion of the caregiving responsibility for the mother, providing her with some time to attend to her own needs.⁸

We observe from the studies presented earlier those significant differences exist in the quality-of-life levels between parents of a child with autism based on their gender. While these differences might be as slight as those found in our current study's results, they can also be profound, as seen in the findings of the previously presented studies. In contrast to these studies and their results, we will now review a 2017 study by Ewa Pisula and Anna Porębowicz Dołrsmann, titled "Family functioning, parental stress and quality of life of Polish mothers and fathers of children with high-functioning autism or Asperger Syndrome," conducted on a population of 202 individuals. The aim of this study was to evaluate family functioning and coping, parental stress, and the quality of life of parents of children with autism.

The research in this study included assessing gender differences in parental experiences within this group of parents, in terms of stress and quality of life. Subsequently, by comparing these parents with parents of typically developing children, the results of this study showed that differences exist between parents of children with autism and those of typically developing children in parental evaluations of family performance, parenting, and stress. These evaluations indicated that parents of typically developing children had lower stress levels and a higher quality of life than parents of children with autism. Furthermore, higher stress levels were reported among parents of a child with autism compared to parents of typically developing children. Regarding the level of differences between the genders of parents of children with autism, no difference in the level of quality of life between mothers and fathers was found in the control group. The results of this study highlighted that there were no gender differences among parents of children with autism, with the findings showing consistency in the evaluation of family performance in terms of the level of quality of life in social relationships and environmental domains.⁹

CONCLUSION

In this study, we examined the impact of having a child with an autism spectrum disorder (ASD) on the quality of life of parents. Our initial hypothesis was that statistically significant differences exist in the quality of life of parents of children with ASD, based on gender, with mothers reporting a lower quality of life than fathers.

The results confirmed this hypothesis, highlighting significant differences in the quality of life between fathers and mothers of children with ASD, differences clearly influenced by the parent's gender.

This disparity in quality-of-life levels has been observed in various studies, where the differences range from slight, as in our current study, to substantial, as seen in previous research.

The existence of these differences, even when minor, underscores the urgent need for more in-depth and large-scale studies. These studies should focus on understanding the factors influencing parents' quality of life, whether psychological, social, or economic.

The objective of these studies is to provide comprehensive and sufficient evidence to design effective interventions supporting parents psychologically and materially. These interventions should include awareness and training programs, psychological and social support services, as well as financial assistance, particularly for families where a single parent bears the responsibility of caring for the child with ASD.

⁸ Ahmed EA : Quality of Life of Mothers and Fathers of Children with Autism Spectrum Disorder in Jordan. Clin Pract Epidemiol Ment Health. 2023 Jun

⁹ Pisula E, et al : Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. PLoS One. 2017 Oct. 16 ;12(10) : e0186536. doi : 10.1371/journal.pone.0186536.

Furthermore, future studies should focus on developing sensitive assessment tools to measure parents' quality of life and precisely identify their needs. They should also aim to evaluate the effectiveness of different interventions and determine the best practices applicable in various contexts.

Through these integrated efforts, we can ensure that parents receive the necessary support to enable them to better care for their children with ASD and improve their overall quality of life

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