



Multifactorial Assessment of Quality of Life among Moroccan Parents of Children with Autism Spectrum Disorders

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Abstract

The present study aims to investigate the quality of life of parents of autistic children in the child psychiatry department of AR-RAZI hospital in Salé, Morocco. By utilizing the SF12 questionnaire, the research examines the physical and mental health of parents. Additionally, the Hospital Anxiety and Depression Scale (HADS) measures symptoms of depression and anxiety, while the Parental Quality of Life Arabic version (PAR-AR-QOL) assesses the impact of the child's disorders on the parents' quality of life. PAR-AR-QOL results indicate similar levels of quality of life between mothers and fathers, with mean emotional scores of 3.21 for fathers and 3.53 for mothers, and mean adaptive scores of 3.35 for fathers and 3.47 for mothers. About 29.7% of mothers and 13.2% of fathers showed symptoms of depression, with a significant difference between sexes ($p < 0.001$). The research findings suggest that both parents have comparable quality of life levels, as indicated by PAR-AR-QOL, but mothers have higher levels of depression symptoms, as indicated by HADS scores. The physical and mental components of SF12 were impaired in all parents, with mothers experiencing more significant impacts than fathers, particularly in families with low income and more than three children. The results of this study indicate that parents of children with autism are facing significant challenges in various aspects of their lives, including social, financial, mental, physical, and psychological. The presence of an autistic child in the family has a far-reaching impact on parents' well-being, underscoring the need for tailored interventions and support strategies for these families.

Keywords: Quality of life, Parents, Children, Autism Spectrum Disorders, Morocco.

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1. Introduction

Autism, identified by Léo Kanner in 1943, is a neurodevelopmental disorder characterized by difficulties in socialization, communication, and restricted and repetitive behaviors [1]; [2]. These symptoms have a significant impact on the child's development and, consequently, on the lives of their families [3]; [4]. Parents of children with ASD face numerous challenges, such as managing their child's specific needs and adapting to new daily routines [5]. These challenges can negatively affect their quality of life and lead to stress, anxiety, and sometimes depression [6]; [7]. The global prevalence of autism is estimated to be 1% of the population [8]. In Morocco, the number of autistic individuals is estimated to be around 680,000, including 216,000 children

[9]. Autism is one of the pervasive developmental disorders (PDD) [10]. The autism spectrum includes disorders such as Asperger syndrome and Rett syndrome, characterized by difficulties in social interaction and communication [8]; [11]. The presence of an autistic child in the family presents unique challenges that can impact the mental health of parents, particularly mothers, with high rates of stress, distress, and depression, surpassing those of parents of children with other types of disabilities ([12];[13]. Autism Spectrum Disorder (ASD) can have a significant impact on the quality of life (QOL) of parents, leading to financial, communication, and social challenges, as well as an increased risk of marital conflict [14];[15]. To address these challenges,

interventions should focus on reducing stress and improving overall family well-being [16], [17], [18], [19].

Quality of Life (QOL) is a complex and subjective concept that has been studied across various fields [20]; [21]; [22]; [23]; [24]. For parents of sick children, factors such as the child's health status, social support, and coping mechanisms can influence their QOL [25]; [26]. There are numerous interpretations of QOL, including satisfaction in life domains and perceived place in life [27]; [28]; [29]; [30]. Several studies have highlighted the impact of ASD on parents' QOL [31]; [32]; [33]; [34]. Parents' physical and mental health are often linked to their child's behavioral problems [35]. ASD can affect parents' social and professional lives, leading to exhaustion and emotional stress [36]; [37]; [38]; [39]. This research aims to analyze the quality of life of a sample of Moroccan parents of children with ASD, with a particular focus on the family, economic, psychological, and socio-professional consequences. It addresses a significant lack of studies in this area, particularly in the Moroccan context [40].

2. Materials and methods

Setting of the Study: The research was conducted at the child psychiatry department of AR-RAZI hospital, located in Salé, Morocco. This hospital, recognized for its expertise in treating and preventing mental illnesses, provided an ideal setting to study the quality of life of parents of autistic children. AR-RAZI hospital, part of the IBN-SINA university hospital center (CHUIS), is a national reference for certain disciplines and serves the population of the Rabat-Salé-Kenitra region.

Reason for Choice of Site: The investigation was conducted in AR-RAZI hospital for several reasons, including its position as a major university hospital in Morocco, the personal interest of researchers in its child psychiatry department following previous internships, and its accessibility to carry out the study. The hospital has a reputation for excellence in the treatment of mental disorders, making it a relevant setting for the study.

Nature of the Study: The objective of this descriptive study was to assess the quality of life of parents of autistic children, focusing on their specific challenges and support needs.

Targeted Population: The target population for the study comprised parents with an autistic child, with precise criteria established for selecting this specific population.

Sampling Procedure: Sampling was limited to parents of children with ASD, with a total of eighty families participating in the study.

Ethical Considerations: The data was collected anonymously, respecting the rights and confidentiality of the participants, and all ethical and professional rules.

Data Collection and Evaluation Instruments: The data was collected using three measurement instruments: the SF12 to assess physical and mental health, the PAR-AR-QOL to measure the impact of mental disorders on parents' quality of life, and the HADS to assess depressive and anxious symptomatology.

PAR-QOL (Parental Adjustment and Quality of Life) is designed to assess the impact of childhood disorders on parents' quality of life, addressing emotional, social, and

physical aspects [41]. The PAR-AR-QOL Questionnaire (parental quality of life Arabic version) [42]. **HADS (Hospital Anxiety and Depression Scale)** is a bipartite scale for screening anxiety and depressive disorders, with subscales for anxiety and depression, consisting of seven items each [43]. **SF-12 (Short Form Health Survey)** is a concise version of the SF-36, measuring health-related quality of life through twelve questions covering physical and mental health.

The tools for assessing families' well-being and quality of life are crucial in clinical and research settings, providing a comprehensive and nuanced evaluation.

Translation and validation of tools: These tools have been adapted into Moroccan dialect following World Health Organization guidelines, which include forward translation, expert panel review, back-translation, pre-testing, and cognitive interviewing. The standard format of the SF-12 was translated into dialectal Arabic and validated [44], which was utilized in the current study.

Statistical Analysis: The data collected will be analyzed using SPSS11.0 software, with appropriate statistical tests such as the ANOVA test for comparing means and the linear correlation coefficient to examine variables affecting quality of life.

3. Results and Discussions

Out of the 90 questionnaires distributed to parents, 80 responses were obtained, representing 68 families who participated in the study.

3.1. Description of the Study Sample

3.1.1. Description of the Demographic and Socio-economic Characteristics of Parents

The descriptive analysis of the demographic and socio-economic characteristics of the parents (Table 1) revealed significant aspects that shape the family and social context of the participants.

Gender of Parents: The gender distribution showed a majority of mothers (76.25%) compared to fathers (23.75%), highlighting a female predominance in the sample studied.

Age of Parents: The data displayed a varied age distribution, with parents aged 25-35 making up 37.5%, those aged 36-45 making up 36.25%, and an older group over 45 amounting to 26.25%. This age diversity suggests distinct parental life phases within the sample.

Consanguinity and Family Size: Consanguinity was reported in 33.75% of cases, while family composition was mainly concentrated on families with 2 or 3 children (61.25%), followed by those with 4 children (25%) and a single child (13.75%), indicating specific family structures.

Knowledge of the Illness and Marital Situation: In the surveyed sample of parents, approximately 78.75% were aware of the illness in question. The marital status of these parents varied, with 60% being married, 23.75% being divorced, and 16.25% being widowed, which may have implications for family support.

Education and employment: The educational background of parents was diverse, with 41.25% having received formal education and 58.75% being illiterate. A minority of parents worked in the civil service (23%),

reflecting a variety of educational and professional backgrounds.

Income and Housing: More than half of families (53.75%) had a monthly income of less than 3,000 dirhams, with the majority residing in urban areas (63.75%), followed by semi-urban (22.5%) and rural (13.75%) areas. This has implications for access to resources and health services.

Medical Coverage: A majority of families (61.25%) had AMO coverage, followed by affiliations with the CNSS (18.75%) and the CNOPS (15%), indicating a significant level of access to healthcare.

3.1.2. Description of Demographic, Clinical, Functional and Therapeutic Characteristics of Children (n=80)

Table 2 provides a comprehensive overview of the demographic, clinical, functional, and therapeutic characteristics of eighty children.

Distribution by Sex and Age: The sample consisted of 61.25% girls and 38.75% boys, with most children aged between 7 and 12 years (62.5%), followed by those aged 13 to 16 years (21.25%) and 6 years old (16.25%), indicating a concentration in the period from middle childhood to early adolescence.

Distribution in Siblings: The family order of children was diverse, with a slight predominance of younger children (37.5%), closely followed by youth children (36.25%) and elders (26.25%), reflecting a variety of family dynamics.

Clinical and Behavioral Profile: Behavioral analysis revealed high rates of irritability (88.75%), social withdrawal (91.25%), stereotypic behaviors (86.25%), and hyperactivity (95%). Additionally, psychiatric comorbidities included emotional problems (86.25%), anxiety (83.75%), attention deficit (78.75%), oppositional (96.25%), somatic (43.75%), and conduct (41.25%).

School Status: The majority of children (80%) are enrolled in school, underscoring the significance of school integration.

3.2. Impact of the child's pathology on the couple and the family

Table 3 provides statistical data on the psychological impact of a child's illness on parents' quality of life, examining anxiety, depression, and physical and mental well-being.

3.2.1. Psychological Impact: The Hospital Anxiety and Depression Scale (HADS) results reveal high levels of anxiety and depression among parents, with mothers displaying higher mean scores (anxiety: 12.02 ± 2.63 ; depression: 12.95 ± 1.68 ; $p < 0.01$) than fathers (anxiety: 9.78 ± 2.45 ; depression: 11.13 ± 1.13 ; $p < 0.01$).

3.2.2. Physical and Mental Quality of Life: In terms of quality of life assessed by the SF12 questionnaire, mothers generally have better physical health (59.80 ± 14.94) than fathers (48.03 ± 8.57), but mental health is more affected among mothers (39.95 ± 12.65) than fathers (41.1 ± 6.2). These distinctions are also statistically significant ($p < 0.01$).

3.2.3. Emotional and Adaptive Scores: While there are no significant differences in emotional and adaptive scores between fathers and mothers, these findings highlight

the notable psychological impact of a child's illness on parents, with distinct differences between mothers and fathers in terms of anxiety, depression, and physical and mental quality of life. This analysis emphasizes the need for tailored support and interventions for parents facing a child's illness.

3.3. Impact of the child's pathology on the family depending on the number of children

The analysis of the data presented in the Table 4 indicates that the impact of a child's pathology on parents varies depending on the number of children in the family

3.3.1. Psychological Impact and Number of Children: A comparative study of HAD scale scores indicates that parents of three children experience higher levels of anxiety and depression (anxiety: 11.89; depression: 12.55) than parents with only one child (anxiety: 10.41; depression: 10.01), with statistically significant differences ($p < 0.01$). These results suggest a correlation between the number of children and the intensity of psychological stress experienced by parents.

3.3.2. Physical and Mental Quality of Life in Relation to the Number of Children: The results show that parents of one child have a better quality of life, both physically (PCS: 54.71) and mentally (MCS: 57.96), compared to parents of three children (PCS: 41.54; MCS: 38.65). These differences are statistically significant ($p < 0.01$) and suggest that the number of children in the family significantly affects the quality of life of parents facing a child's illness.

3.3.3. Emotional Well-being and Adaptability: However, the PAR-QOL scores for emotional and adaptive capacity do not show significant differences between the groups, indicating that emotional well-being and adaptive capacity are similar among parents, regardless of the number of children. This finding suggests that parents demonstrate resilience in terms of emotional well-being and adaptability, regardless of family size.

3.4. Influence of Financial Status on Parents' Psychological Well-Being

Faced with the financial constraints observed among the majority of families interviewed, we analyzed the score results according to the parents' salary. Analysis of the data in Table 5 reveals key insights into the correlations between family income and different aspects of parental psychological well-being.

Impact of Income on Anxiety and Depression: The results reveal that parents in the lower income bracket (<3000 DH) have higher anxiety and depression scores than those in the higher income bracket. This pattern is observed in both mothers and fathers, suggesting that lower income exacerbates negative psychological states.

Quality of Life and Income: Quality of life scores, measured by the SF-12 PCS and MCS, also show a significant improvement with increasing income for both mothers and fathers.

Parental Quality of Life (PAR QoL) Score: However, the variations in PAR-QOL scores by income are less pronounced, indicating that emotional and adaptive support may be less directly linked to financial status.

Specific Correlations: Maternal anxiety and depression scores, as well as the overall family score, are correlated with financial and social difficulties, while

children's age and sibling rank do not show any correlation. direct correlation with these factors.

Table 5 highlights the importance of considering financial aspects in assessing the psychological well-being of families, particularly among mothers, and highlights the need for support tailored to their economic situation.

3.5. Correlation study between parents' psychological state, family difficulties and quality of life

Table 6 in this study investigates the relationships between parental psychological well-being, as measured by the Hospital Anxiety and Depression Scale (HAD), and various aspects of quality of life, including the Parenting Stress Index (PAR-QoL) and the Short-Form 12 (SF-12).

Correlations with PAR- QoL: The results indicate a moderate positive correlation between parental anxiety and coping skills ($r = 0.305$, $p < 0.01$), as well as a positive correlation between anxiety and emotional well-being ($r = 0.436$, $p < 0.05$). However, the correlation between depression and these factors is weaker ($r = 0.165$ and -0.07 , respectively).

Correlations with SF-12: Moreover, the study finds that physical health (PCS) and mental health (MCS) are moderately correlated with anxiety ($r = -0.412$ and $r = 0.386$, respectively), but show weaker or non-significant links with depression ($r = 0.012$ and 0.073). These results highlight the complex relationship between parental psychological well-being, their ability to cope with stress and emotions, and their physical and mental health. The study reveals that parents' anxiety is influenced by their coping skills and emotional well-being, while their mental health exhibits an inverse relationship with anxiety. These findings emphasize the need for a comprehensive approach to improving parents' quality of life, taking into account their psychological state and physical and emotional well-being. **Parental Stress and Autism:** Our study aligns with Cappe et al.'s (2012) and Cloutier and Poirier's (2023) findings, which emphasize a significant level of stress among parents of autistic children ([45]; [46]). Our observations indicate a decline in stress related to threat and loss over time, suggesting that parents adapt to the unique challenges posed by autism.

Impact of Autism on Parents' Quality of Life: Our study, based on Grimm-Astruc (2010) and Vernhet (2019) ([32]; [47]), reveals a relatively low quality of life among parents of autistic children, which contrasts with Vasilopoulou and Nisbet's (2016) findings [34]. This discrepancy highlights the impact of context and individual factors on quality of life evaluations.

Furthermore, the stability of quality of life scores observed in the research of Rattaz et al. (2016) [48] suggest a form of resilience in parents faced with their child's autism.

Parental Mental Suffering: The HADS results indicate a moderate presence of depressive and anxiety symptoms, in line with Miniarikova's (2022) findings [49]. This trend underscores the significant psychological impact of autism on parents' lives.

Improvement in the Communicative Abilities of Children with ASD: Improvement in the Communicative Abilities of Children with ASD: The observed improvement in the communicative abilities of autistic children, as a result of

specialized care, supports the effectiveness of targeted interventions for these children, as demonstrated by previous studies [32].

Repercussions on the Family: Our findings regarding parents' adjustment to life with an autistic child are consistent with Trute's (2009) observations, particularly in terms of financial stress and family life restructuring [50].

The rank in the siblings and the number of children in the siblings: The child's position as the youngest child was significantly associated with lower parental QOL. Furthermore, we found a significant negative correlation between the number of children in siblings and parents' QOL. The relationship between the number of children in siblings and the parents' QOL is controversial. For autistic cadets, the relationship would be negative due to the increase in parental burden [33]. For the latter, this relationship would be positive, explained by the extent to which siblings help the parents take care of the younger child [51].

The quality of life of parents of children with ASD is found to be lower in terms of physical and psychological health, in accordance with Turnage's (2022) literature review [52].

This study highlights the various facets of the experiences of parents of autistic children, marked by a progressive adaptation to the challenges encountered. It highlights the need for multidimensional support for these families, encompassing psychological, social and practical aspects.

Overall, the effects of Autism Spectrum Disorder (ASD) on parents in Arab countries have been examined in various studies. Research has revealed that parents of children with ASD in these countries experience significant negative consequences on their mental health and overall quality of life. They face a poorer quality of life and are at an increased risk of developing psychological disorders when compared to parents of typically developing children or those with other developmental disorders [53]. Various factors, such as financial limitations, gender, and religious coping mechanisms, can influence the impact of ASD on Arab parents[54]. These later also report high levels of parenting stress and low quality of life, particularly in physical, psychological, social, and environmental health domains [55]. These findings underscore the need for support and educational programs that address the challenges faced by Arab parents and enhance their quality of life [56].

Mothers of children with ASD in Saudi Arabia confront cognitive and lifestyle distortions, as well as difficulties in accessing professional assistance [57]. Parents of children with ASD in the region also face similar challenges, including parenting difficulties and struggles in raising their children [58]. Moreover, the COVID-19 pandemic and associated lockdowns have further intensified the challenges faced by parents of children with ASD, resulting in behavioral changes, temper tantrum, increased conflict levels, and negative impacts on health and relationships [59].

Table 1:-Features Demographic and Socio- economic of Parents

Category	Details / Percentage (%)
Gender (n=80)	Mother : 76.25%, Father : 23.75%
Age of Parents	25-35 years : 37.5%, 36-45 years : 36.25%, >45 years : 26.25%
Inbreeding	Yes : 33.75%, No: 66.25%
Number of children	1: 13.75%, 2 or 3: 61.25%, 4: 25%
Knowledge of the Disease	Yes : 78.75%, No: 21.25%
Marital status	Married : 60%, Divorced: 23.75%, Widowed : 16.25 %
Schooling	Yes : 41.25%, No: 58.75%
Status Professional	Civil servant : 36.25%, No: 63.75%
Income Couple's Monthly	<3000 DH: 53.75%, 3000 - 6000 DH: 36.25%, >6000 DH: 10%
Habitat	Urban : 63.75%, Semi- urban : 22.5%, Rural: 13.75%
Medical cover	AMO: 61.25%, CNSS: 18.75%, CNOPS: 15%, Others : 5%

Table 2: Demographic, Clinical, Functional and Therapeutic Characteristics of Children

Category	Details / Percentage (%)
Gender (n=80)	Female (F): 61.25%, Male (M): 38.75%
Age of Children	6 years: 16.25%, 07-12 years: 62.5%, 13-16 years: 21.25%
Schooling	Yes: 80%, No: 20%
Order in the Brotherhood	Eldest: 26.25%, Benjamin: 36.25%, Youngest: 37.5%
Behavior Checklist	Irritability: 88.75%, Social withdrawal: 91.25%, Stereotypical behavior: 86.25%, Hyperactivity: 95%
Psychiatric Comorbidities	Emotional problem: 86.25%, Anxiety problem: 83.75%, Attention deficit: 78.75%, Opposition problem: 96.25%, Somatic problem: 43.75%, Conduct problem: 41.25%

Table 3: Impact of the child's pathology on the couple and the family

Measure	Father (\pm standard deviation)	Mother (\pm standard deviation)	P-Value
HADS Anxiety	9.78 \pm 2.45	12.02 \pm 2.63	<0.01
HADS Depression	11.13 \pm 1.13	12.95 \pm 1.68	<0.01
SF12PCS	48.03 \pm 8.57	59.80 \pm 14.94	<0.01
SF12 MCS	41.1 \pm 6.2	39.95 \pm 12.65	<0.01
PAR-QoL-ES	3.21 \pm 0.71	3.53 \pm 0.98	NS
PAR-QoL-AS	3.15 \pm 0.68	3.47 \pm 0.47	NS
Total Score	3.19 \pm 0.39	3.68 \pm 0.51	NS

Legend: NS: not significant; PCS: SF12 physical component score; MCS: SF12 mental component score; PAR-QoL-SE: Score of the emotional component of PAR- Qol ; PAR-QoL-AS: Adaptive component score of PAR- Qol ; HADS: hospital anxiety and depression scale.

Table 4: Impact of the child 's pathology on the family in depending on the number of children

Measure	Parents (one child)	Parents (3 children)	P-Value
HADS Anxiety	10.41	11.89	< 0.01
HADS Depression	10.01	12.55	< 0.01
SF12PCS	54.71	41.54	< 0.01
SF12 MCS	57.96	38.65	< 0.01
PAR-QOL ES	3.36	3.11	NS
PAR-QOL AS	3.48	3.2	NS

Legend: NS: not significant ; PCS: SF12 physical component score; MCS: component score mental from SF12; PAR-QOL: Parental quality of life; HADS: hospital anxiety and depression scale.

Table 5: Comparative study of HADS, SF12 and PAR-QOL scores according to parental monthly income

Category	< 3000 DH	> 6000 DH	P-Value
Anxiety – Mother (HADS)	12.36	9.00	< 0.05
Anxiety – Father (HADS)	10.16	7.50	< 0.01
Depression - Mother (HADS)	11.36	9.00	< 0.05
Depression - Father (HADS)	10.20	5.50	< 0.01
SF 12 PCS - Mother	38.12	54.83	< 0.01
SF 12 PCS - Father	41.56	58.56	< 0.05
SF 12 MCS - Mother	40.96	51.93	< 0.05
SF 12 MCS - Father	41.85	55.61	< 0.01
PAR QoL ES - Mother	3.36	2.83	NS
PAR QoL ES - Father	3.55	3.10	NS
PAR QoL AS - Mother	3.48	2.63	NS
PAR QoL AS - Father	3.88	3.05	NS

Legend: NS: not significant; PCS: SF12 physical component score; MCS: SF12 mental component score; PAR QoL-ES: Score of the emotional component of PAR- Qol ; PAR QoL-AS: Adaptive component score of PAR- Qol ; HADS: hospital anxiety and depression scale

Table 6: Correlation between anxiety/depression and adaptive , emotional, physical and mental scores experienced by parents of children with ASD.

		HADS Anxiety		HADS Depression	
		r	p-value	r	p-value
PAR QoL	Adaptive Score (AS)	0.305	0.01	0.165	0.01
	Emotional Score(ES)	0.436	0.05	-0.07	0.05
SF12	MCS	0.386	0.05	0.073	0.05
	PCS	-0.412	0.05	0.012	0.05

Legend: r = Pearson Correlation Coefficient, PAR QoL SA = Adaptive Component Score of Parental Quality of Life, SE = Emotional Component Score. SF 12 PCS/MCS = Short Form 12 Physical/Mental Component Summary. HADS = Hospital Anxiety and Depression Scale.

4. Conclusions

This study provides insights into the impact of autism on parents' quality of life, highlighting emotional disturbances, changes in daily routines, and effects on overall health. Despite these challenges, strong family ties persist, possibly due to strong social and cultural values. The study also indicates that families with multiple children and those with lower incomes face increased difficulties. Based on these findings, psycho-educational support for parents is recommended, focusing on stress and emotion management, problem-solving, and improving their ability to care for their autistic child while handling the associated challenges. However, the study has some limitations, such as the use of quantitative data, which highlights the need for

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complementary qualitative analyses. More in-depth analysis of parental perceptions of autism and comparison with a control group would also be beneficial. In the future, it is crucial to evaluate the effectiveness of psychological supports and financial support policies. Improved communication between healthcare professionals and families is also necessary for effective care. In summary, this study sheds light on the multifaceted challenges faced by families of children with autism, emphasizing the need for a comprehensive and multidisciplinary approach to enhance parents' quality of life. Future research should focus on devising integrated strategies that take into account socioeconomic factors, such as the number of children and family income as well as the need for comprehensive support

services, social support, and appropriate coping skills for parents of children with ASD in Morocco to improve their well-being and enable them to better navigate the unique challenges they encounter.

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