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Qualité de vie des parents d'enfants présentant un trouble du spectre de l'autisme : étude transversale descriptive dans un contexte marocain

Quality of Life of Parents of Children with Autism Spectrum Disorder: A Cross-Sectional Descriptive Study in a Moroccan Context

Calidad de vida de los padres de niños con trastorno del espectro autista: estudio descriptivo transversal en el contexto marroquí

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Résumé

Introduction : Le trouble du spectre de l'autisme (TSA) est un trouble neurodéveloppemental d'une prévalence croissante dont l'impact sur la qualité de vie des parents reste insuffisamment documenté dans les contextes culturels arabes et nord-africains. Cette étude avait pour objectif d'évaluer la qualité de vie des parents d'enfants présentant un TSA suivis en consultation de pédopsychiatrie à Marrakech, et d'explorer les facteurs sociodémographiques et cliniques associés.

Méthodes : Étude descriptive transversale incluant 62 parents d'enfants et d'adolescents présentant un TSA diagnostiqué selon les critères du DSM-5, recrutés à l'hôpital Ibn Nafis de Marrakech. La qualité de vie parentale a été évaluée par la version arabe du questionnaire PAR-DD-QOL (PAR-AR-QOL). L'analyse statistique comprenait une analyse descriptive et des tests de comparaison de moyennes (ANOVA), avec un seuil de significativité fixé à $p < 0,05$.

Résultats : Le score total moyen de qualité de vie parentale était de 2,88 ± 0,61, reflétant une altération modérée. L'auto-évaluation globale (item 17) montrait des niveaux majoritairement « moyenne » (30,4 %) et « peu satisfaisante » (28,6 %). La présence d'antécédents psychiatriques parentaux était le seul facteur significativement associé au score total ($p < 0,0001$).

Conclusion : Cette étude confirme une altération modérée de la qualité de vie parentale dans le contexte marocain du TSA. Les antécédents psychiatriques parentaux étaient le seul facteur significativement associé au score total de qualité de vie parentale dans notre échantillon. Ces résultats plaident pour l'intégration systématique d'un soutien psychosocial aux parents dans la prise en charge globale du TSA.

Mots-clés : trouble du spectre de l'autisme ; qualité de vie parentale ; facteurs associés

Resumen

Introducción: El trastorno del espectro autista (TEA) es un trastorno del neurodesarrollo cuya prevalencia está aumentando y cuyo impacto en la calidad de vida de los padres sigue estando insuficientemente documentado en los contextos culturales árabes y norteafricanos. El objetivo de este estudio fue evaluar la calidad de vida de los padres de niños con TEA atendidos en consultas de psiquiatría infantil en Marrakech, así como explorar los factores sociodemográficos y clínicos asociados.

Métodos: Se realizó un estudio descriptivo transversal en el que participaron 62 padres de niños y adolescentes con diagnóstico de TEA según los criterios del DSM-5, reclutados en el Hospital Ibn Nafis de Marrakech. La calidad de vida parental se evaluó mediante la versión árabe del cuestionario PAR-DD-QOL (PAR-AR-QOL). El análisis estadístico incluyó estadística descriptiva y pruebas de comparación de medias mediante ANOVA, con un umbral de significación estadística establecido en $p < 0,05$.

Resultados: La puntuación media total de calidad de vida parental fue de 2,88 ± 0,61, lo que refleja un deterioro moderado. La autoevaluación global (ítem 17) mostró que las categorías más frecuentes fueron «media» (30,4 %) y «poco satisfactoria» (28,6 %). Los antecedentes psiquiátricos de los padres fueron el único factor asociado significativamente con la puntuación total ($p < 0,0001$).

Conclusión: Este estudio pone de manifiesto un deterioro moderado de la calidad de vida parental en el contexto marroquí del TEA. Los antecedentes psiquiátricos de los padres fueron el único factor asociado significativamente con la puntuación total de calidad de vida parental en nuestra muestra. Estos resultados respaldan la integración sistemática de un apoyo psicosocial dirigido a los padres en el abordaje integral del TEA.

Palabras clave : trastorno del espectro autista; calidad de vida parental; factores asociados.

Abstract

Background: Autism spectrum disorder (ASD) is a neurodevelopmental disorder with a growing prevalence, whose impact on parental quality of life remains insufficiently documented in Arab and North African cultural contexts. This study aimed to assess the quality of life of parents of children with ASD attending child psychiatry consultations in Marrakech and to explore associated sociodemographic and clinical factors.

Methods: A cross-sectional descriptive study was conducted involving 62 parents of children and adolescents diagnosed with ASD according to DSM-5 criteria and recruited at Ibn Nafis Hospital in Marrakech. Parental quality of life was assessed using an Arabic adaptation of the PAR-DD-QOL questionnaire (PAR-AR-QOL). Statistical analyses included descriptive statistics and comparisons of means using analysis of variance (ANOVA), with statistical significance set at $p < 0.05$.

Results: The mean total parental quality-of-life score was 2.88 ± 0.61, indicating moderate impairment. Global self-assessment (item 17) showed that the most frequently reported categories were “average” (30.4%) and “unsatisfactory” (28.6%). Parental psychiatric history was the only factor significantly associated with the total score ($p < 0.0001$).

Conclusion: This study highlights moderate impairment in parental quality of life in the Moroccan context of ASD. Parental psychiatric history was the only factor significantly associated with the total parental quality-of-life score in our sample. These findings support the systematic integration of psychosocial support for parents into comprehensive ASD care.

Keywords: autism spectrum disorder; parental quality of life; associated factors.

Introduction

Autism spectrum disorder (ASD) is one of the most complex and prevalent neurodevelopmental disorders of our time. Defined by the DSM-5 according to two main symptom domains – persistent deficits in communication and social interaction on the one hand, and restricted and repetitive behaviours, interests or activities on the other – this disorder is characterised by varying degrees of severity depending on the level of support required [1].

Epidemiological data reveal a worrying reality: whilst the World Health Organisation estimates the global prevalence at 1 in 160 children, figures in the US now stand at 1 in 59. In Morocco, the lack of official statistics and a national register must not obscure an alarming upward trend [2].

Quality of life is a multidimensional and subjective concept. The WHO defines it as an individual's perception of their place in life, within the context of the culture and value systems in which they live, in relation to their goals, expectations and concerns. It is a broad conceptual field encompassing physical health, psychological well-being, level of independence, social relationships, personal beliefs and one's relationship with the environment [3].

The quality of life of parents of children with ASD is now a major public health issue. Previous studies report a reduction in parental quality of life, influenced by various factors linked both to the characteristics of the disorder and the child's specific needs, as well as to the family and psychosocial context [4] [5]. These factors interact dynamically, making it difficult to predict parental quality of life based on a single clinical variable.

Assessing the quality of life of parents of children with ASD requires specific tools capable of capturing the unique aspects of the parental experience. With this in mind, the PAR-DD-QOL questionnaire was developed and validated in French, and subsequently adapted into an Arabic version (PAR-AR-QOL) for Arabic-speaking populations [6].

This instrument explores the emotional impact, family and social relationships, the daily burden of care, and the sense of parental competence, making it particularly well-suited to our context.

Although ASD is associated with significant family and social repercussions, its impact on parents' quality of life remains insufficiently explored within specific cultural and socio-economic contexts. To our knowledge, few studies have addressed this issue in the Moroccan context.

Aims of the study:

- To assess the quality of life of parents of children with ASD attending child and adolescent psychiatry clinics in Marrakesh.
- To explore the socio-demographic and clinical factors that may be associated with it, in order to contribute to better adaptation of clinical practices and management strategies.

Materials and methods

Study design and population:

This is a descriptive cross-sectional study conducted amongst parents of children and adolescents with autism spectrum disorder (ASD) attending child and adolescent psychiatry clinics at Ibn Nafis Hospital in Marrakech.

The study included 62 parents (fathers or mothers) of children and adolescents who had attended at least three child and adolescent psychiatry consultations, and for whom the ASD diagnosis had been made prior to the start of the study.

Ethical considerations:

Parents were informed of the study's objectives and its voluntary nature. Data anonymity and confidentiality were respected.

Assessment tools:

A pre-designed data collection form was used to gather socio-demographic and clinical data.

The diagnosis of ASD was made on the basis of a thorough clinical assessment by a multidisciplinary team, in accordance with NICE (2021) recommendations and the DSM-5 criteria [7]. This was supplemented by an analysis of the functional profile,

enabling the severity of ASD to be assessed and any comorbidities to be identified.
The PAR-DD-QOL is a self-administered instrument, validated in French by Raysse (2011) [8], designed to assess the impact of a child's neurodevelopmental disorders on parents' quality of life. The factor structure analysis identified three scores: an emotional score (items 1 to 6, 13 and 14), an adaptive score (items 7 to 11, 15 and 16) and a total score. Higher scores indicate a greater impairment in parental quality of life. The Arabic version (PAR-AR-QOL) exhibits highly satisfactory psychometric properties, making it suitable for use in an Arabic-speaking context [6].

Statistical analysis:

Statistical analysis was carried out using Python (version 3.10), with the data organised in Microsoft Excel. A descriptive analysis was used to characterise the study population: quantitative variables are presented as means ± standard deviations and qualitative variables as frequencies and percentages. Associations between the total score and clinical and sociodemographic variables were explored using tests for comparing means (ANOVA). Differences in means were reported with their 95% confidence intervals, and effect sizes were estimated using Cohen's d or η^2, depending on the type of comparison. The significance threshold was set at $p < 0.05$.

Results

Sociodemographic and clinical characteristics:

Table 1 presents the sociodemographic and clinical characteristics of children with ASD and their parents. The majority of children were male
(71 per cent), with a mean age of 9.85 years. Moderate and severe forms of ASD accounted for 56.5 per cent and 25.5 per cent of cases, respectively. The majority of children were non-verbal (72.6 per cent). With regard to the families, 90.4 per cent had an average or unfavourable socio-economic status and 90.3 per cent of parents were married. Among the parents, 22.6 per cent had a history of depression, 3.2 per cent of anxiety disorders and 1.6 per cent of a personality disorder.

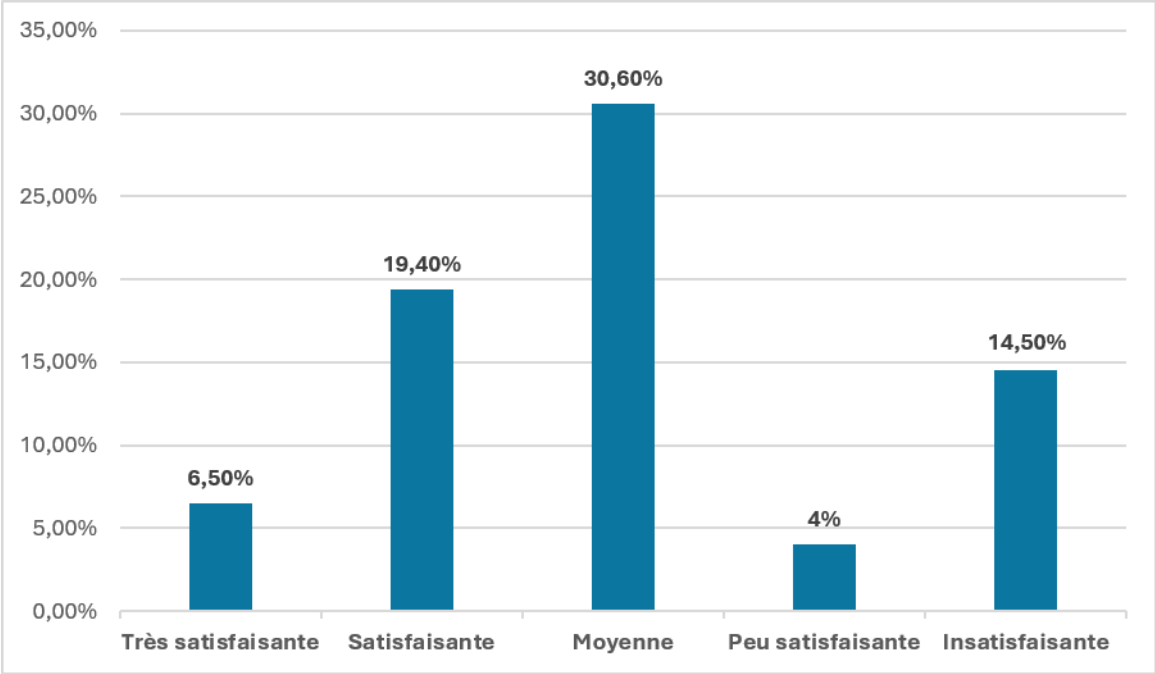
Assessment of parental quality of life:

Parental quality of life was measured using the PAR-AR-QOL scale. The mean total score was **2.88 ± 0.61**, reflecting a moderate impairment in parental quality of life in our sample.
Item 17, which provides an overall self-assessment of parental quality of life, reflects parents' subjective perception independently of the specific dimensions explored by the preceding 16 items. The distribution of responses **(Figure 1)** shows a predominance of the 'average' (30.4 per cent, n = 19) and 'somewhat unsatisfactory' (28.6 per cent, n = 18) categories, consistent with the calculated total score.

Table 1. Demographic and clinical characteristics of children with ASD and their parents.

Variable	Results
CHILDREN	
Average age	9.85 years
Gender	71 per cent boys
Birth order	18 per cent eldest; 20.7 per cent second-born; 50 per cent youngest; 6.5 per cent only child; 4.8 per cent twins
Schooling	46.7 per cent in mainstream education; 30.5 per cent not in education; 22.8 per cent in a specialised centre
Age at diagnosis	69.4 per cent diagnosed before the age of 5; 30.6 per cent after the age of 5
Language	27.4% verbal; 72.6% non-verbal
Bowel and bladder control	Achieved in 68 per cent
Behavioural difficulties	Self-harm/aggression towards others: 23.2 per cent; psychomotor instability: 34 per cent
Organic comorbidities	Epilepsy: 19.4 per cent; sensory disorders: 11.3 per cent; genetic syndrome: 11.6 per cent
Psychiatric comorbidities	Intellectual disability: 27.4 per cent; depression: 3.2 per cent
Medical history among siblings	ASD: 10 per cent; epilepsy: 5 per cent; intellectual disability: 3.2 per cent
Severity of ASD	Mild: 18 per cent; moderate: 56.5 per cent; severe: 25.5 per cent
Management	Speech and language therapy/occupational therapy: 67.7 per cent; parental guidance: 77.4 per cent; medication: 30.6 per cent
Follow-up	Regular: 68 per cent; irregular: 20 per cent; lost to follow-up: 12 per cent
PARENTS	
Average age	Mothers: 40.3 ± 8.2 years; Fathers: 49.6 ± 10.4 years
Socio-economic status	Low: 42 per cent; middle: 48.4 per cent; high: 9.6 per cent
Level of education	Illiterate: 24 per cent; secondary education: 56.5 per cent; higher education: 19.4 per cent
Employment status	Working fathers: 82.3 per cent; working mothers: 22.6 per cent
Marital status	90.3 per cent married; 9.7 per cent divorced
Marital conflicts	Reported by 25.8 per cent
History of mental health conditions	Depression: 22.6 per cent; anxiety disorders: 3.2 per cent; personality disorder: 1.6 per cent
Social support	Received by 40 per cent of parents
Substance use	Tobacco: 18 per cent; alcohol: 1.6 per cent

Figure 1. Distribution of responses to item 17 of the PAR-AR-QOL (overall self-assessment of parental quality of life, N = 62).



Factors associated with parental quality of life:

Of all the variables studied (Table 2), only a history of parental psychiatric disorders was significantly associated with the total parental quality of life score ($p < 0.0001$). Parents with a history of psychiatric disorders had a mean score of 3.45 ± 0.54, compared with 2.67 ± 0.54 for those without such a history, representing a difference of 0.77 points (95% CI: [0.46; 1.08]), with a large effect size (Cohen's d = 1.43).

Table 2. Association between the total parental quality of life score and the variables studied. Significance threshold: $p < 0.05$.

Variable studied	p-value	95% CI	Cohen's d	η^2
Socio-economic status	0.25	[0.00; 0.22]	-	0.05
Parental psychiatric history	**< 0.0001**	**[0.46; 1.08]**	**1.43**	**-**
Parents' educational attainment	0.74	[0.01; 0.19]	-	0.02
Medical history among siblings	0.20	[-0.17; 0.79]	0.49	-
Child's language level	0.38	[-0.20; 0.51]	0.24	-
Child's psychiatric comorbidities	0.09	[-0.04; 0.67]	0.50	-
Severity of ASD	0.16	[0.01; 0.22]	-	0.06

Note: The 95% CI corresponds to the CI for the difference in means for variables with two groups and to the CI for η^2 for variables with more than two groups.

Discussion:

The socio-demographic and clinical characteristics of our population are consistent with the data reported in the international and regional literature. The mean age of the children (9.85 years) is similar to that reported in a multicentre Mediterranean study, where the mean age of the children was around 9 years [9], and higher than that in a Tunisian series (6.5 years) [10]. The predominance of males (71 per cent, sex ratio 2.4:1) is consistent with data from the literature [11]. The mean age at diagnosis—before the age of 5 for 69.4 per cent of the children—is consistent with the Tunisian data (mean age at first consultation of 3.8 years) [10] and the Saudi results [12], where the majority of children underwent intervention between the ages of 3 and 5. These results are consistent with data from the French ELENA cohort, which reports a mean age at diagnosis of 4.9 years, influenced primarily by clinical severity, the presence of a comorbid intellectual disability and the level of language skills [13].

The proportion of marital conflicts (25.8 per cent) is close to the figures observed in comparative studies, highlighting the cross-cutting impact of ASD on family dynamics regardless of geographical context. This finding is consistent with the international literature, which highlights that the emotional, organisational and financial burden associated with ASD can undermine marital stability, particularly where support resources are limited [14].

Finally, regarding the severity of ASD, the predominance of moderate to severe forms in our study is consistent with the Tunisian findings, where a majority of children had high CARS scores, as well as with Saudi and international data, which report a similar distribution of severity levels. This convergence suggests that populations monitored in specialist hospital settings tend to include comparable clinical profiles, characterised by symptoms severe enough to warrant prolonged specialist care [7].

The mean total parental quality of life score of 2.88 ± 0.61 reflects a moderate impairment, consistent with the findings of Baghdadli et al. [15] and Mallek et al. [16] using the same PAR-DD-QOL scale. This consistency suggests that the impact of ASD on parental quality of life is significant but of moderate intensity. Studies using other instruments reach similar conclusions: the Cameroonian study by Mbassi et al. [17] using the SF-36 and studies using the WHOQOL [18] report a significant reduction in quality of life across the physical, mental and social dimensions.

The impairment in parental quality of life observed in our study may be explained by the overall and ongoing burden associated with the child's daily care. Repeated care, constant vigilance and ongoing adaptation to specific needs require a far greater investment than that required by a typical family dynamic. This burden is often compounded by difficulties in interaction. Parents may experience frustration stemming from the difficulty in understanding their child's needs, intentions or emotions, as well as from the fear of not being understood by their child. Behavioural difficulties (aggression, stereotyped behaviours), which are often unpredictable, expose the family to stigma and encourage withdrawal and isolation [16]. The organisational overload resulting from frequent appointments significantly disrupts the family's daily routine and leads to chronic fatigue, irritability and even depressive symptoms in parents, which in turn affects their ability to be there for their other children and impacts the couple's relationship [19].

A history of parental psychiatric disorders is the only factor significantly associated with a reduced quality of life ($p < 0.0001$). Among the parents included in the study, 22.6 per cent had a depressive disorder, 3.2 per cent an anxiety disorder and 1.6 per cent a personality disorder. This finding is consistent with the literature highlighting the central role of parental mental health [20]. Zablotsky et al. [21] notably reported an association between the severity of autistic symptoms, the child's psychiatric comorbidities and the risk of maternal depression. These findings suggest that ASD may act as an aggravating factor, placing a strain on psychological resources

already weakened by a pre-existing psychiatric condition.
The literature has also highlighted the existence of a bidirectional association between parents' mental health and the psychological difficulties of their children with ASD. Indeed, a longitudinal study involving 188 families of children and adolescents with ASD found that parental depressive symptoms predicted greater internalising difficulties in young people with ASD 12 months later [22]. However, the complexity of the interactions between parental mental health and the psychological difficulties of children with ASD, as well as the cross-sectional nature of our study, do not allow us to establish a causal link between these variables.
An association between the severity of autistic symptoms, language limitations and increased parental stress has been reported in the literature [23]. Nevertheless, in our study, no statistically significant association was found between the total parental quality of life score and the severity of ASD ($p = 0.16$) or the child's language level ($p = 0.38$). These results should be interpreted with caution, particularly given the small sample size and the complex interaction between parental factors and the child's characteristics.
Receiving a diagnosis is a particularly vulnerable time, which may be accompanied by parental anxiety, feelings of self-blame, a sometimes incomplete understanding of the disorder and, finally, the grieving process for the child they had imagined; hence the importance of early identification and support for parental psychological distress as part of the overall management of ASD [17].
Our results should not be interpreted in a deterministic manner. Recent literature highlights the existence of protective factors: parental resilience is a key factor associated with a better quality of life, regardless of the severity of the disorder [24][25][26]. It is fostered by positive coping strategies, social support, a sense of parental self-efficacy and certain cultural resources such as spirituality [27]. Social integration and the reduction of stigma limit isolation and improve the perception of quality of life [25]. Parental quality of life in the context of ASD therefore results from a dynamic balance between risk factors and protective factors.
These findings highlight the value of interventions that incorporate not only care for the child but also the strengthening of parental and family resources. Comprehensive management of ASD must include the early identification of parental psychological distress, the systematic strengthening of parenting skills relating to stress management, coping strategies and problem-solving, as well as the provision of appropriate psychosocial support, particularly for parents with pre-existing psychiatric vulnerability. These findings open up avenues for future research into the mechanisms of resilience and the evaluation of the effectiveness of support interventions within the Moroccan cultural context.

Conclusion:

Several limitations should be noted. The cross-sectional nature of the study does not allow for the establishment of causal relationships. The sample size ($n = 62$) may limit the ability to identify certain statistically significant associations. Recruitment from a specialist hospital setting introduces a selection bias towards more severe clinical profiles. The absence of a control group means that quality of life cannot be compared with that of neurotypical parents. These limitations call for caution when generalising the results and argue for larger-scale studies in the Moroccan context.

Conflicts of interest:

The authors declare that they have no conflicts of interest.

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