REVIEW

Quality of life among caregivers of children with autism spectrum disorder: A systematic review and meta-analysis

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ABSTRACT

Background and aim: Autism spectrum disorder (ASD) imposes substantial caregiving demands, often diminishing parental quality of life (QoL). This systematic review and meta-analysis aimed to quantify parental QoL using the WHOQoL-BREF, compare outcomes by caregiver subgroup (mothers, fathers, both parents) and identify domain-specific patterns.

Methods: According to PRISMA guidelines, systematic searches in PubMed, Scopus, Web of Science, ScienceDirect and Google Scholar included cross-sectional and case–control studies using WHOQoL-BREF. Pooled means were calculated for each domain and overall QoL, with heterogeneity assessment and sensitivity analysis.

Results: Our analysis revealed an overall mean QoL score of 41.59. The analysis also showed a consistent and significant gradient in parental QoL based on caregiving arrangements. Parents sharing childcare responsibilities reported a markedly superior overall QoL (mean score: 52.51) compared to those in father-led (29.75) or mother-led (27.56) arrangements. This hierarchical pattern, in which dual-parent caregiving was associated with the highest well-being, followed by father-led and then mother-led care, was consistently observed across all four domains of quality of life. The most pronounced disparities were identified within the social and

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environmental domains (total domain scores of 36.43 and 36.59, respectively), suggesting these areas are particularly sensitive to the caregiving model.

Conclusions: Parents of children with ASD experience reduced QoL, especially in social and environmental domains. The key finding indicates that shared caregiving is a strong correlate of optimal parental QoL. Mothers are disproportionately affected, while shared caregiving appears protective. These findings support family-centered interventions and policies promoting caregiver well-being. (www.actabiomedica.it)

Key words: quality of life, autism spectrum disorder, caregivers, parents, WHOQOL-BREF, children

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that typically manifests in early childhood and is characterized by persistent deficits in social interaction and communication, alongside restricted, repetitive patterns of behavior, interests, or activities (1). In recent decades, the global burden of ASD has risen markedly, reflecting both improved diagnostic capabilities and a genuine increase in prevalence. According to global estimates from 2021, approximately 61.8 million individuals were living with ASD, corresponding to an age-standardized prevalence rate of 788.3 per 100,000 population. Prevalence was notably higher in males (1064.7 per 100,000) compared to females (508.1 per 100,000), reflecting well-established sex differences in ASD diagnosis. Moreover, ASD accounted for an estimated 11.5 million disability-adjusted life years (DALYs), underscoring its significant non-fatal disease burden, particularly among children under five years of age and populations in high-income countries (2). Raising a child with ASD imposes substantial and long-term demands on families, particularly on primary caregivers, who are typically parents or close relatives (3). While the majority of therapeutic and educational interventions focus on addressing the developmental and behavioral challenges experienced by the child, considerably less attention has been directed toward the psychological and emotional needs of caregivers themselves (4). Nevertheless, primary caregivers often endure significant stress, emotional exhaustion, and social isolation, stemming from the sustained responsibility of managing the complex and evolving needs of a child with ASD. Over time, this burden may lead to the neglect of caregivers' own physical and mental well-being, contributing to reduced QoL, elevated risk of anxiety and depression, and impaired social functioning (5). Moreover, studies consistently show that caregivers, especially mothers, of children with ASD face significantly higher levels of stress, self-stigma, anxiety, and depression than caregivers of children with typical development, leading to a lower QoL (6). Although parental stress in families raising children with ASD has been well documented, the QoLau of caregivers remains an insufficiently explored aspect. QoL is a multidimensional indicator of well-being, encompassing emotional, physical, social, and occupational domains, all of which are often compromised in long-term caregiving. Many parents, particularly mothers, often face the necessity of leaving paid employment to provide full-time care, which significantly diminishes their overall QoL. Studies show that when caregiving responsibilities fall on a single parent, QoL tends to be lower compared to families where both parents share caregiving duties and can distribute the burden more evenly. It is also important to recognize that children with ASD represent a highly heterogeneous group: not all of them become fully dependent on their caregivers. The severity of symptoms, presence of co-occurring conditions (such as intellectual disability, hyperactivity, or aggression), and the level of support required can range from mild to very high. These differences directly affect the degree of caregiver burden

and, consequently, their psychological and social well-being. Although research on ASD has expanded considerably, caregiver QoL, especially in relation to gender dynamics and caregiving roles, continues to be underexplored in the academic literature. This systematic review and meta-analysis aim to synthesize existing evidence on caregiver QoL, quantify pooled QoL estimates, and examine differences between mothers, fathers, and both parents. In doing so, it addresses a critical research gap and offers new perspectives for developing tailored support strategies for families raising children with ASD.

Materials and methods

Study registration

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (7). Eligible studies published prior to June 15, 2025, were identified and evaluated. The review protocol was prospectively registered with the International Prospective Register of Systematic Reviews (PROSPERO) under the registration number CRD420251086038, following a preliminary search to ensure that no existing or ongoing reviews addressed the same research question.

Search strategy

The comprehensive list of databases and search engines was searched: PubMed, Scopus, Web of Science, ScienceDirect, and Google Scholar. Filters applied included publication in English, publication in scholarly journals, and document types limited to articles, research articles, and early access articles. No restrictions were placed on the year of publication. The search strategy was developed after a test search in PubMed to identify relevant keywords from titles, abstracts, and MeSH terms related to parental QoL in families of children with ASD. Based on this search, the following search terms were used: parental AND "quality of life" AND "autism spectrum disorder" AND children. Further details on the search strategy are provided in Table 1.

Eligibility criteria, study selection and data collection

Table 2 presents the eligibility criteria used to select articles in accordance with the Population, Exposure, Comparator, Outcome, and Study Design (PECOS) framework. The Population included studies involving mothers, fathers, or primary caregivers of children diagnosed with ASD. Studies were excluded if they focused on caregivers of individuals and adults with ASD, with no restriction on the age

Table 1. Search strategy used for the systematic review.

Database	Search Date	Search Fields	Search query	Filters
PubMed	10.06.2025	Title, Abstract, Keywords	parental AND "quality of life" AND "autism spectrum disorder" AND children	Language: English No restriction on document type
Scopus	10.06.2025	Title, Abstract, Keywords	parental AND "quality of life" AND "autism spectrum disorder" AND children	Language: English Document Type: Articles
Web of Science	10.06.2025	Title, Abstract, Keywords	parental AND "quality of life" AND "autism spectrum disorder" AND children	Language: English Document Type: Articles and Early Access
ScienceDirect	10.06.2025	Title, Abstract, Keywords	parental AND "quality of life" AND "autism spectrum disorder" AND children	Language: English No restriction on document type
Google Scholar	10.06.2025	Title	parental AND "quality of life" AND "autism spectrum disorder" AND children	Language: English No restriction on document type

Table 2. Inclusion and exclusion criteria of study selection based on the PICOS framework.

PICOS framework	Inclusion criteria	Exclusion criteria
Population	Studies with mothers, fathers or primary caregivers of children diagnosed with ASD	Studies on adults with ASD; studies with other neurodevelopmental disorders without ASD group
Intervention/Exposure	Studies measuring parental QoL using WHOQoL-BREF with the following domains: Physical, Psychological, Social, Environmental	Studies using non-validated or other instruments; studies assessing only psychological distress
Comparator	Not applicable	Not applicable
Outcome	Studies with parental QoL across WHOQoL-BREF domains	Studies without QoL outcomes across domains; studies focused on other health outcomes
Study Design	Cross-sectional, case-control	Reviews, meta-analyses, randomized control trials, conference abstracts, case reports, editorials, non-English publications

of the individual with ASD, or included participants with other neurodevelopmental disorders without a distinct ASD group. The Exposure included studies that assessed parental QoL using the World Health Organization Quality of Life–Brief (WHOQoL-BREF) instrument, which measures four domains: physical health, psychological well-being, social relationships, and environmental factors. Studies were excluded if they used non-validated or alternative QoL tools, or focused solely on psychological distress outcomes such as anxiety, depression, or stress without assessing overall QoL. No comparator was applicable. The Outcome included the assessment of parental QoL across the four domains of the WHOQoL-BREF instrument. Studies were excluded if they did not assess QoL across domains or if they focused on unrelated health outcomes. The Study design included cross-sectional and case-control studies. Studies were excluded if they were reviews, meta-analyses, randomized controlled trials, conference abstracts, case reports, editorials, or non-English language publications.

The eligibility assessment and data collection were conducted in accordance with the PRISMA guidelines (7). Two independent researchers performed a standardized search (M.T. and I.K.). After searching all databases, the results were combined and duplicates were removed using Mendeley reference manager (8). Only unique references were screened for relevance based on titles and abstracts. In the final stage of the eligibility assessment, full-text articles were reviewed against the predefined inclusion and exclusion criteria based on the PICOS framework. When the full text of a study was unavailable, the authors were emailed twice to request a copy. Relevant data were extracted using a standardized data collection form. The following variables were extracted from each study: the first author's last name, year of publication, country, study design, sample size, study respondents (e.g., mothers, fathers, or both), child's ASD diagnosis status, assessment setting, QoL measurement tool used to confirm the eligibility (only studies that used WHOQoL-BREF to assess the QoL were included), QoL domains assessed (physical, psychological, social, environmental), age of the respondents, age of the children with ASD, and mean and standard deviation (SD) measures across WHOQoL-BREF domains. Data extraction was performed independently by two reviewers. The two data sheets were cross-checked and merged. Any discrepancies between reviewers regarding study inclusion or data interpretation were discussed with a third author (L.Y.) until consensus was reached, and then data were combined.

Meta-analysis

The meta-analysis was conducted using RStudio (version 2024.12) (9) in R (version 4.3.2) (10). Two R packages, meta and metafor, were used to conduct the meta-analysis of proportions related to parental QoL outcomes. The pooled mean scores for each WHOQoL-BREF domain (physical, psychological,

social, and environmental) and their corresponding 95% confidence intervals (CI) were estimated using a random-effects model to account for expected heterogeneity across studies (11). Forest plots were generated to visually display the pooled estimates and the variability across studies. In addition, summary tables were prepared to present the characteristics of included studies and extracted QoL outcomes. Heterogeneity was assessed using the I^2 statistic, which quantifies the proportion of variability attributable to between-study differences rather than sampling error (12). To explore potential sources of heterogeneity, meta-regression analysis was performed using the year of publication of the study. To assess the robustness of the findings, sensitivity analyses were conducted, using the influence analysis, which helped determine if any individual study had a disproportionate impact on the overall results. Publication bias was evaluated using funnel plot asymmetry and Egger's regression test significance (11). Subgroup analyses were conducted to compare results across the respondents in the study (mother vs. father vs. both).

Risk of bias

The methodological quality of the included studies was assessed using an adapted Newcastle-Ottawa Scale (NOS) specifically modified for cross-sectional and case-control study designs (13).This instrument evaluates studies across three core domains: participant selection, group comparability, and ascertainment of outcomes or exposures. The selection of this instrument was based on its recognized capacity to evaluate key methodological dimensions, including selection, comparability, and outcome or exposure assessment, across a range of observational study designs. Furthermore, the NOS enables direct comparison of study quality across different observational designs, which was particularly relevant for this review encompassing both case-control and cross-sectional studies. For cross-sectional studies, the adapted Newcastle-Ottawa Scale (NOS) comprised six questions distributed across three domains: selection (3 items), comparability (1 item), and outcome assessment (2 items). Each item could be awarded up to one point, with a maximum of two points allocated for comparability, yielding a total possible score of 7. The selection domain assessed representativeness of the sample, sample size justification, and non-respondents. The outcome domain included assessment of outcome validity and use of appropriate statistical tests. Similarly, for case-control studies, the NOS included eight questions across three domains: selection (4 items), comparability (1 item), and exposure (3 items). The selection domain examined adequacy of case definition, representativeness of cases, selection of controls, and definition of controls. The exposure domain assessed ascertainment of exposure, use of the same method for both groups, and non-response rate. The maximum score was also 7, with comparability receiving up to 2 points, and all other items scored as 1. All studies were independently assessed for quality by two reviewers who had reached a prior agreement on the scoring procedure. Any disagreements were resolved through discussion with a third reviewer. Inter-rater agreement was calculated to ensure consistency in evaluation. Studies scoring five points or higher on both versions of the NOS were considered to be of satisfactory methodological quality and were included in the final synthesis of this systematic review (14,15).

Certainty of evidence evaluation

Adhering to the guidelines from the Cochrane Handbook for Systematic Reviews of Interventions, we assessed the certainty of evidence using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) framework (16). Furthermore, this assessment followed the procedures outlined in research notes on the evaluation of GRADE in systematic reviews (17). Certainty of evidence was calculated in RStudio, using the "GRADE" package. This framework comprises five domains: Risk of Bias, assessed using the NOS for cross-sectional and case-control studies checklists mentioned earlier; Inconsistency, assessed via the I^2 statistic; Indirectness, assessed via PICO criteria; Imprecision, assessed by determining if the 95% CI of the pooled estimate crosses the threshold of interest; and Publication Bias, assessed using Egger's test results.

Results

Study selection and characteristics of the included studies

A total of 946 records were identified through systematic searches in four electronic databases and a search engine: Scopus (n = 261), PubMed (n = 412), Web of Science (n = 220), ScienceDirect (n = 33), and Google Scholar (n = 20). After removing 330 duplicates, 616 unique records were screened based on titles and abstracts. Of these, 434 records were excluded for not meeting the inclusion criteria. The full texts of 182 potentially eligible articles were sought, but 12 could not be retrieved. Consequently, 170 full-text articles were assessed for eligibility. Following a detailed review, 157 articles were excluded for the following reasons: not using the WHOQoL-BREF instrument (n = 130) (18), incorrect article type (n = 5) (19), absence of parental QoL assessment (n = 9) (20), focus on the child's QoL rather than the parent's (n = 1), reporting only an overall QoL score without domain-specific results (n = 10), and inclusion of parents of adults (aged 18 and above) with ASD rather than parents of children with ASD, as specified in the eligibility criteria (n = 2) (21). The full study selection process is illustrated in the PRISMA 2020 flow diagram (Figure 1).

A total of 13 studies met all PICOS-based inclusion criteria and were included in the final meta-analysis. These studies were conducted across various countries. Two studies were case-control, and eleven studies were cross-sectional. Respondents' mean age ranged from 34.4 to 49.6 years. Across all studies, the children were younger than 18 years, although the exact age distribution differed by study. Further details on study characteristics and participant demographics are presented in Table 3.

Meta-analysis of parental quality of life in autism spectrum disorder

The results of the meta-analysis evaluating parental QoL across the four WHOQoL-BREF domains, stratified by caregiver subgroups (mother, father, or both parents), are summarized in Figure 2 and Figure S1. Panel A (Figure 2) shows a forest plot of pooled mean environmental QoL scores, stratified by caregiver subgroups of children with ASD. The mother subgroup included six studies and yielded a pooled mean score of 30.63 (95% CI: 11.88–49.38; I^2 = 100%). The father subgroup, based on three studies, had a pooled mean score of 33.53 (95% CI: –30.97 to 98.03; I^2 = 100%), with a wide confidence interval indicating high uncertainty. The both-parents subgroup included seven studies, with a pooled mean score of 43.03 (95% CI: 21.83–64.22; I^2 = 100%). Overall, the combined pooled mean environmental QoL score across all subgroups was 36.59 (95% CI: 25.39–47.79; I^2 = 100%). Test for subgroup differences was not significant (p=0.54). Panel B (Figure 2) presents a forest plot of pooled average scores for the social QoL scores, stratified by caregiver subgroups of children with ASD. The mother subgroup included six studies and showed a pooled mean score of 30.31 (95% CI: 13.29–47.33; I^2 = 100%). The father subgroup was based on three studies and had a pooled mean score of 31.39 (95% CI: –21.64 to 84.41; I^2 = 100%), with high variability. The both-parents subgroup included seven studies and had a pooled mean score of 43.89 (95% CI: 22.83–64.95; I^2 = 100%). Overall, the total pooled average score across all subgroups was 36.43 (95% CI: 25.75–47.10; I^2 = 100%). Test for subgroup differences was not significant (p=0.44). Panel C (Figure 2) presents a forest plot of pooled average overall QoL scores, stratified by caregiver subgroups of children with ASD. The mother subgroup included three studies and had a pooled mean score of 27.56 (95% CI: –5.16 to 60.28; I^2 = 100%), with high heterogeneity. The father subgroup included only one study, reporting a mean score of 29.75 (95% CI: 27.15–32.35). The both-parents subgroup included five studies and showed a pooled mean score of 52.51 (95% CI: 24.37–80.65; I^2 = 100%). Overall, the total pooled average score across all caregiver subgroups was 41.59 (95% CI: 25.02–58.17; I^2 = 100%). Test for subgroup differences was not significant (p=0.08).

Meta-regression by publication year

Figure 3 Panel A presents the meta-regression of effect sizes for environmental QoL scores by year of publication. A statistically significant positive trend was observed (p = 0.0192), indicating that more recent

studies tended to report higher mean scores. Panel B (Figure 3) presents the meta-regression of effect sizes for social QoL scores by year of publication, suggesting higher mean scores in recent studies, despite notable variability (p = 0.0112). Panel C (Figure 3) shows a statistically significant positive trend in overall QoL scores over publication years (p = 0.0062), suggesting that more recent studies report higher effect sizes. However, the wide confidence interval and variability among studies indicate that this trend should be interpreted with caution. Meta-regression results for physical and psychological QoL domains are presented in Figure S2.

Sensitivity analysis

Sensitivity analyses showed that no individual study significantly influenced the pooled results, confirming the robustness of the findings, as presented in Figure 4 (Panels A-C). Influence analysis results

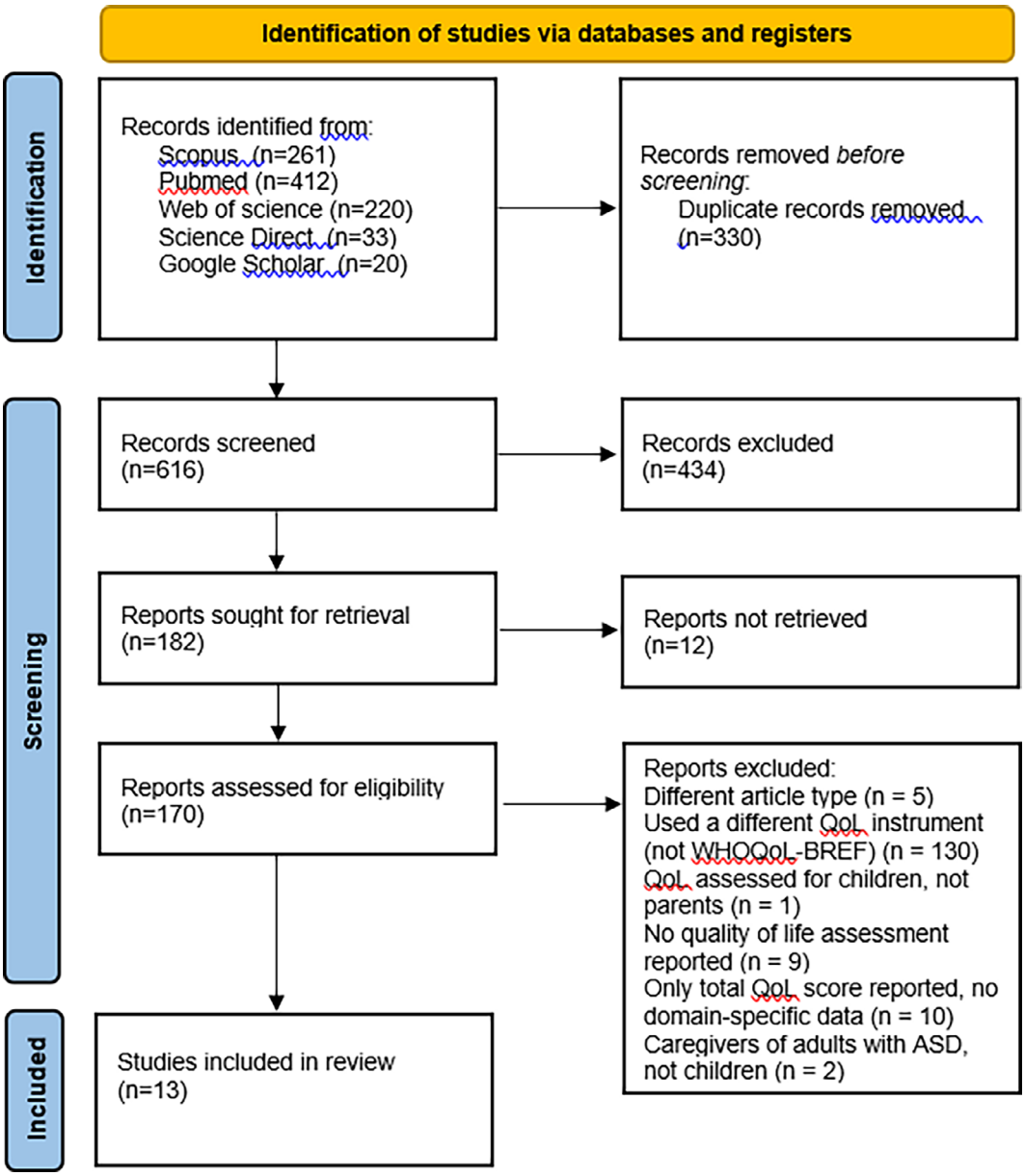


Figure 1. PRISMA flowchart of study inclusion.

Table 3. Description of the included studies.

Last name, year	Design	Country	Sample size	Respondent	Caretaker age (yrs)	Age of child with ASD (yrs)
Pisula, 2017 (24)	Cross-sectional	Poland	49	Mother Father	39.56 ± 5.50 41.87 ± 5.17	10.24 ± 3.24
McAuliffe, 2017 (25)	Cross-sectional	Ireland	51	Mother	38.41 ± 5.24	7.72 ± 2.44
Papanikolaou, 2022 (26)	Cross-sectional	Greece	56	Both parents	49.6 ± 7.8	7.3 ± 3.3
Ahmed, 2023 (27)	Cross-sectional	Jordan	100 101	Father Mother	< 35 yrs = 33.3 %; 35–45 yrs = 41.3 %; > 45 yrs = 25.4 %	18 <
AlHefdhi, 2024 (28)	Cross-sectional	Saudi Arabia	99	Both parents	NA	1–5 yrs = 62.6% 6–10 yrs = 27.3% 11–15 yrs = 8.1% 16+ = 2%
Mannion, 2023 (29)	Cross-sectional	Ireland	409	Both parents	40.34 ± 6.82	9.19 ± 3.62
Masuri, 2023 (30)	Cross-sectional	Malaysia	73	Both parents	Majority 31–40 years (68.5%); age coded mean = 2.14 ± 0.58	6.48 ± 3.00
Pondé, 2023 (31)	Cross-sectional	Brazil	108	Mother	NA	18 <
Raju, 2023 (32)	Case-control	India	30	Both parents	NA	0–5 yrs (26.7%), 6–10 yrs (50%), 11–12 yrs (23.3%)
Alenezi, 2024 (33)	Cross-sectional	Saudi Arabia	394	Both parents	39.3 ± 8.7	6–8 years (43.8%)
Dijkstra-de Neijs,2024 (34)	Cross-sectional	Netherlands	55	Mother Father	34.4 ±4.69 median age = 37.0 years, IQR = 6.0	4.6 ±1.1
Mohammadi, 2024 (35)	Case-control	Iran	70	Mother	35.97 ± 5.90	8.17 ± 2.91
Al Mansoor, 2025 (36)	Cross-sectional	Saudi Arabia	59	Both parents	39.56 ±10.00	18 <

for physical and psychological QoL domains are presented in Figure S3.

Assessment of publication bias revealed significant funnel-plot asymmetry across all QoL domains with significant Egger's regression test results: environmental QoL ($p = 0.0020$), social QoL ($p = 0.0001$), and overall QoL ($p < 0.0019$). Funnel plots are presented in the supplementary materials (Figure S4).

NOS Risk of bias evaluation and certainty of evidence assessment

According to the NOS risk-of-bias assessment, all included studies demonstrated acceptable methodological quality, each scoring at least 5 out of a possible 7 points on the respective NOS scale. Details of the assessment are provided in Table S1. Certainty of evidence assessment results are presented in Table 4 for all meta-analytic outcomes. All five pooled estimates

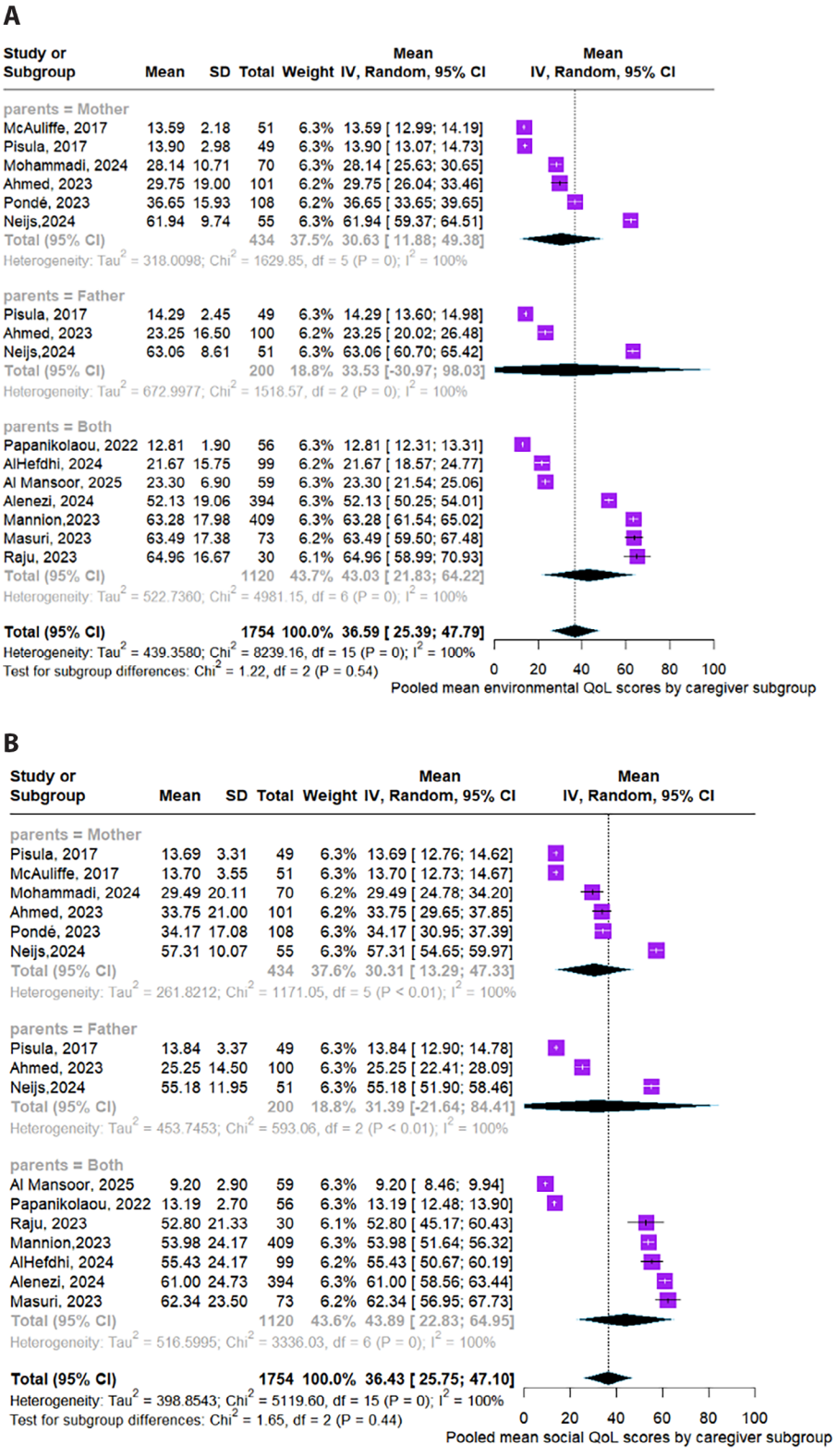
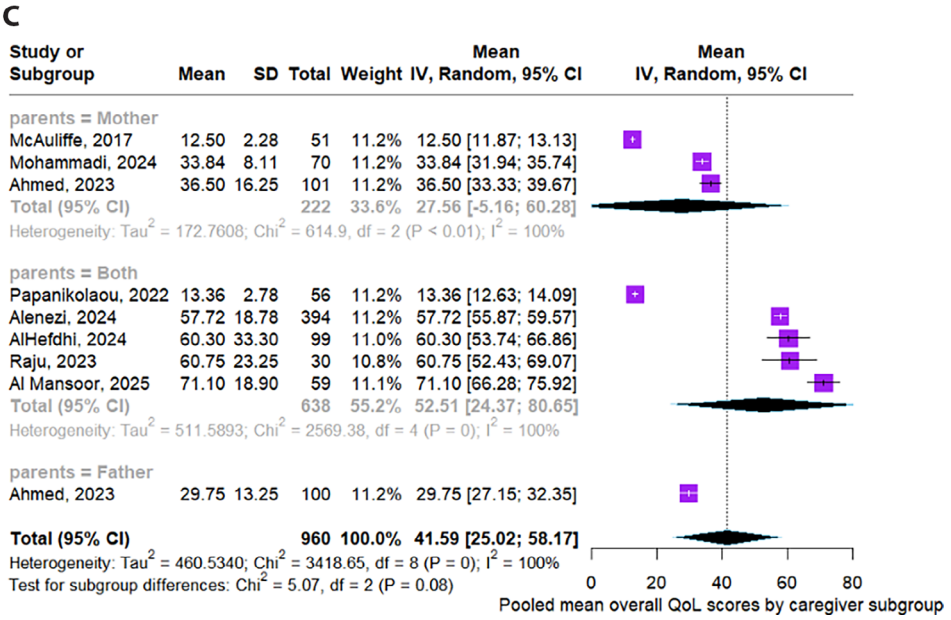


Figure 2. Pooled mean scores of different QoL domains among caregiver subgroups of children with ASD. A) Environmental QoL scores; B) Social QoL scores; C) Overall QoL scores. *Abbreviations:* CI – confidence interval; QoL – quality of life.



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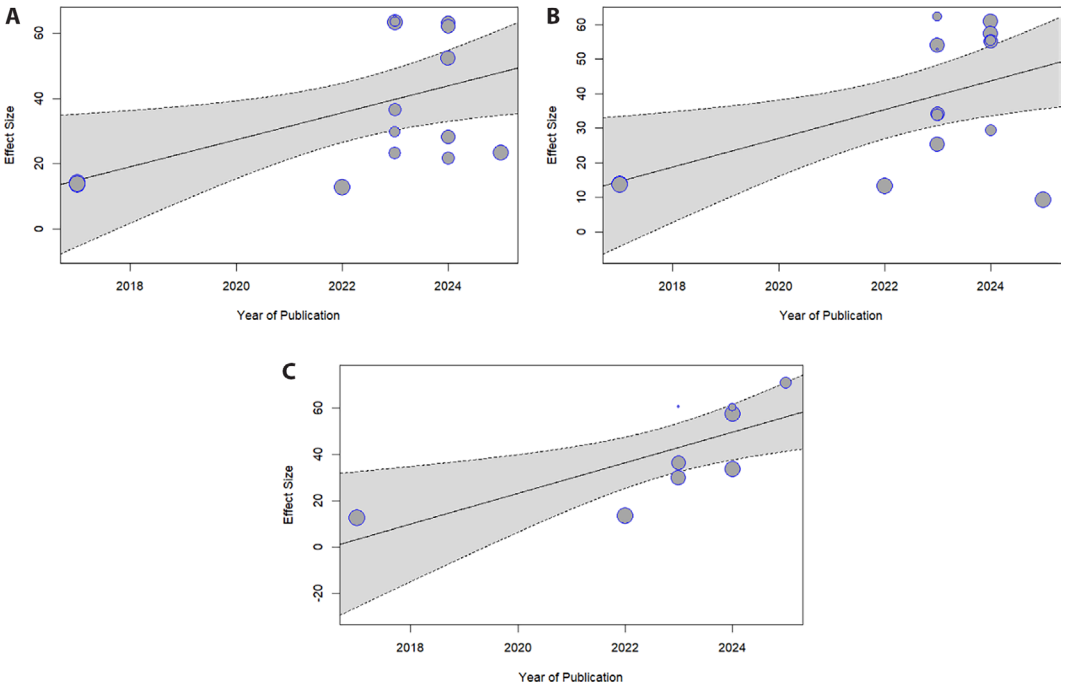

Figure 3. Meta-regression by publication year in selected QoL domains. A) Environmental QoL scores; B) Social QoL scores; C) Overall QoL scores.

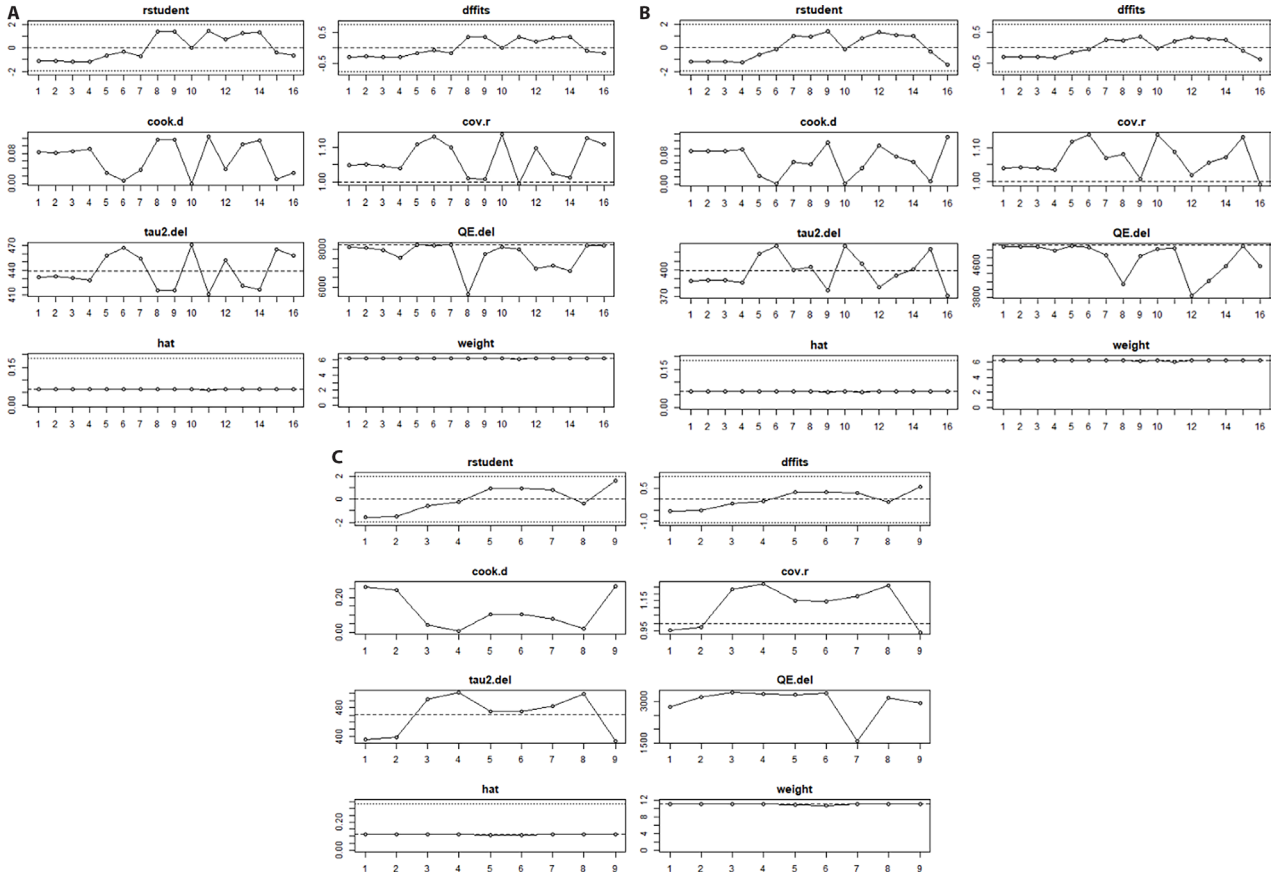

Figure 4. Influence analysis of pooled mean scores across different quality of life domains.
A) Environmental QoL B) Social QoL C) Overall QoL.

were derived from the cross-sectional and case-control studies. The risk of bias was low in all included studies. However, the inconsistency was "serious" in all five pooled estimates. Indirectness and imprecision were rated as "not serious" in all five pooled estimates. Publication bias was present in all five pooled estimates. Overall, the certainty of the evidence was judged as "low" in all meta-analytic outcomes.

Discussion

This meta-analysis synthesized data on the QoL of parents caring for children with ASD across the four domains of the WHOQoL-BREF instrument—physical, psychological, social, and environmental—as well as the overall QoL index. In all domains, the pooled mean scores were consistently low, highlighting the significant burden faced by caregivers of children with ASD. These values fall below the normative thresholds established for the general population, indicating a marked reduction in QoL within this group. These findings are consistent with previous studies that have demonstrated substantially impaired QoL among parents of children with ASD (35,36). However, the meta-analysis revealed extreme heterogeneity across studies (I^2 = 100%), which represents a major limitation. Such variability undermines the reliability of pooled estimates and restricts the generalizability of the findings. Differences in study design, sample characteristics, cultural contexts, and measurement tools likely contributed to this heterogeneity. Future

Table 4. Certainty of Evidence Results Using GRADE Framework on the Caregivers QoL Domains.

Assessment	Design of the study	Risk of bias	Inconsistency	Indirectness	Imprecision	Publication bias	Overall assessment
Pooled Physical QoL Scores	Cross-sectional and case–control	Low	Serious	Not serious	Not serious	Detected	Low
Pooled Environmental QoL Scores	Cross-sectional and case–control	Low	Serious	Not serious	Not serious	Detected	Low
Pooled Social QoL Scores	Cross-sectional and case–control	Low	Serious	Not serious	Not serious	Detected	Low
Pooled Psychological QoL Scores	Cross-sectional and case–control	Low	Serious	Not serious	Not serious	Detected	Low
Pooled Overall QoL Scores	Cross-sectional and case–control	Low	Serious	Not serious	Serious	Detected	Low

research should aim to reduce methodological inconsistencies and explore sources of variability to enhance the interpretability and applicability of QoL data in ASD caregiving. Among the domains assessed, social relationships emerged as the most adversely affected, suggesting a profound negative impact of caregiving on the social lives of parents. Limitations in social interactions, lack of support, stigma, and social withdrawal, frequently cited in prior literature, are clearly reflected in these results (39,40). Environmental quality of life was also adversely affected, likely due to financial strain, limited access to services, safety concerns, and inadequate living conditions. These factors are further intensified by the ongoing stress associated with caregiving. Psychological well-being also showed substantial impairment, consistent with elevated emotional distress, anxiety, and reduced resilience commonly reported among parents of children with ASD. Although physical health appeared relatively less affected, it remained below normative expectations, with caregivers frequently reporting fatigue, sleep disturbances, and somatic complaints (37). Across all domains, mothers consistently reported lower QoL compared to fathers, reflecting their greater involvement in daily caregiving and heightened vulnerability to stress and emotional strain. These findings are in line with a robust body of literature describing gendered disparities in caregiver well-being (38,39). Notably, mothers of children with ASD tend to experience poorer QoL than those caring for children with other neurodevelopmental conditions, underscoring the unique and multifaceted challenges associated with ASD caregiving (40). A key finding of this meta-analysis is that the highest QoL scores were observed in studies where caregiving was shared between both parents. Although subgroup differences between mothers, fathers, and both-parent caregiving did not consistently reach statistical significance, this was likely due to the limited number of studies, particularly those focusing on fathers and overall QoL. Nonetheless, the observed pattern remained consistent. This suggests a potential protective effect of shared caregiving, in which mutual support, distributed responsibilities, and cooperative parenting may buffer against the adverse impacts of caregiving. These findings underscore the importance of viewing the family as an interconnected system and highlight the need to develop interventions and support mechanisms that involve both palirents (41,42). Family QoL should be continuously monitored and supported across the lifespan of individuals with ASD, extending beyond childhood into adolescence and adulthood. This is particularly critical given the evolving support needs of individuals with ASD, which often intensify during transitional phases such as post-secondary education, employment, and independent living (43). The bidirectional relationship between family QoL and the developmental trajectory of individuals with ASD is well-established. As children with ASD mature, families must adapt to new challenges, including aging-related care and the

reduction of formal services- a phenomenon often referred to as the "services cliff" (44). Many families are ill-prepared for these transitions, which can exacerbate stress and negatively affect both caregiver well-being and individual outcomes. Regardless of the individual's level of functioning, family dynamics remain central to shaping developmental outcomes and promoting autonomy in adulthood (45,46). While impaired QoL is also observed among caregivers of children with other developmental conditions, ASD caregiving presents distinct and multifaceted challenges. For example, parents of children with Down syndrome often report better psychological and social adaptation, attributed to more predictable developmental trajectories and established support systems (47,48). In contrast, ASD caregiving is characterized by greater behavioral variability, uncertainty, and social stigma, which contribute to heightened emotional strain and reduced QoL. These unique stressors underscore the need for tailored interventions that specifically address the complexities of ASD caregiving, rather than generalizing across diagnostic categories.

Limitations and future research directions:

This meta-analysis has several limitations that warrant consideration. High heterogeneity across models (I^2 = 100%) reflects substantial variability in study methodologies, participant characteristics, and contextual factors. Key moderators - such as child age, ASD severity, and socioeconomic status—could not be examined due to inconsistent reporting. Additionally, caregiver subgroup representation was imbalanced, with limited number of studies in the QoL of fathers or both parents, reducing the robustness of comparative analyses. Evidence of publication bias suggests that studies with lower QoL scores may be overrepresented. While restricting inclusion to WHOQOL-BREF studies enhanced measurement consistency, it may have excluded relevant findings from studies using other validated QoL instruments, thereby limiting the comprehensiveness of the review. Moreover, the geographic distribution of included studies was uneven, raising concerns about the cultural generalizability of the findings. The heavy reliance on cross-sectional designs further limits causal inference and precludes examination of changes in caregiver QoL across developmental stages. Lastly, the low certainty of evidence necessitates caution in interpreting the study's findings. Future research should prioritize longitudinal designs, include diverse caregiver populations, and explore the relationship between family QoL and the development of autonomy in individuals with ASD during adulthood. Addressing these limitations is essential for generating more generalizable and actionable evidence. Understanding this linkage is essential for designing interventions that support both caregiver well-being and long-term outcomes for individuals with ASD.

Conclusion

This meta-analysis demonstrates that parents of children with ASD exhibit markedly reduced QoL across all WHOQoL-BREF domains, with consistent trends showing the lowest scores among mothers and relatively higher scores among caregiving dyads. The most severely affected domains-social and environmental-reflect the cumulative burden of social isolation, limited support networks, financial strain, and barriers to accessing essential services. These impairments appear more pronounced than those reported in caregivers of children with other developmental conditions, although the certainty of this evidence is limited by methodological variability and potential publication bias. The findings of our study underscore the need for family-centered interventions that address both clinical and psychosocial dimensions of caregiver well-being. Promoting shared caregiving and increasing paternal involvement may help redistribute caregiving burdens and improve outcomes for both parents. Given the exclusive reliance on WHOQoL-BREF and the predominance of cross-sectional designs, future research should adopt longitudinal and cross-cultural approaches to better capture the evolving nature of caregiver QoL. Exploring the relationship between family QoL and the attainment of autonomy in individuals with ASD is essential for informing policies and interventions that support lifelong well-being for both caregivers and individuals with ASD.

Ethic approval: Ethics approval was waived for this study as this is a systematic review of the literature.

Conflict of interest: Each author declares that he or she has no commercial associations (e.g., consultancies, stock ownership, equity interests, patent/licensing, arrangement etc-) that might pose a conflict of interest in connection with the submitted article.

Authors contribution: M.T.: Conceptualization, Methodology, Investigation, Formal Analysis, Visualization, Writing—original draft preparation, Writing—review and editing; L.Y.: Resources, Software, Data Curation, Supervision, Writing—original draft preparation, Writing—review and editing; M.K.: Validation, Writing—review and editing; Z.S.: Writing—original draft preparation, Supervision, Project Administration, Investigation; A.T.: Writing—review and editing, Project Administration; A.M.: Writing—review and editing; I.K.: Methodology, Formal Analysis, Visualization, Writing—review and editing.

Declaration on the use of AI: None.

Consent for publication: Not applicable.

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References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5-TR. Washington (DC): American Psychiatric Association Publishing; 2013.
2. Global Burden of Disease Study 2021 Collaborators. The global epidemiology and health burden of the autism spectrum: findings from the Global Burden of Disease Study 2021. Lancet Psychiatry. 2025 Feb;12(2):111–21.
3. Giovagnoli G, Postorino V, Fatta LM, et al. Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder. Res Dev Disabil. 2015 Oct–Nov;45–46:411–21. doi: 10.1016/j.ridd.2015.08.006. PMID: 26318505.
4. Cohn ES. Parent perspectives of occupational therapy using a sensory integration approach. Am J Occup Ther. 2001 May–Jun;55(3):285–94. doi: 10.5014/ajot.55.3.285. PMID: 11723969.
5. Dardas LA, Ahmad MM. Quality of life among parents of children with autistic disorder: a sample from the Arab world. Res Dev Disabil. 2014 Feb;35(2):278–87. doi: 10.1016/j.ridd.2013.10.029. PMID: 24316492.
6. Alicka Y, Gjeta A, Kotherja O, et al. The levels of stress, anxiety, and depression in parents of children with autism spectrum disorder: a review of literature. Multidiscip Rev. 2025;8(11):2025350.
7. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021 Mar 29;372:n71. doi: 10.1136/bmj.n71. PMID: 33782057; PMCID: PMC8005924.
8. Mendeley Ltd. Mendeley Desktop [software]. Version 1.19.8. London: Elsevier; 2020. Available from: https://www.mendeley.com/download-desktop
9. Posit Team. RStudio: integrated development environment for R [software]. Boston (MA): Posit Software; Available from: https://posit.co
10. R Core Team. R: a language and environment for statistical computing [software]. Vienna (Austria): R Foundation for Statistical Computing; 2023. Available from: https://www.r-project.org/
11. Harrer M, Cuijpers P, Furukawa T, Ebert D. Doing meta-analysis with R: a hands-on guide. 1st ed. Boca Raton (FL): Chapman and Hall/CRC; 2021. doi: 10.1201/9781003107347.
12. Migliavaca CB, Stein C, Colpani V, et al. Meta-analysis of prevalence: I2 statistic and how to deal with heterogeneity. Res Synth Methods. 2022 May;13(3):363–7. doi: 10.1002/jrsm.1547. PMID:
13. Wells G, Shea B, O'Connell D, et al. The Newcastle–Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses [Internet]. Ottawa: Ottawa Hospital Research Institute; Available from: https://www.ohri.ca/programs/clinical_epidemiology/oxford.asp
14. Karibayeva I, Bilibayeva G, Yerzhanova A, et al. Prevalence of vitamin D deficiency among adults in Kazakhstan: a systematic review and meta-analysis. Medicina (Kaunas). 2024 Dec;60(12):2043. doi: 10.3390/medicina60122043. PMID: 39768922; PMCID: PMC11727896.
15. Breau G, Ellis U. Risk factors associated with young-onset colorectal adenomas and cancer: a systematic review and meta-analysis of observational research. Cancer Control. 2020;27(1):1073274820976670.doi: 10.1177/1073274820976670. PMID: 33274652; PMCID: PMC8480354.
16. Schünemann HJ, Higgins JPT, Vist GE, et al. Assessing certainty in the evidence in the context of a systematic review. In: Higgins JPT, Thomas J, Chandler J, et al., editors. Cochrane Handbook for Systematic Reviews of Interventions. 2nd ed. Chichester (UK): John Wiley & Sons; 2019.
17. Brennan SE, Johnston RV. Interpreting findings of a systematic review using GRADE methods. J Physiother. 2023 Jul;69(3):198–202. doi: 10.1016/j.jphys.2023.05.012. PMID: 37277291.
18. Gardiner E, Mâsse LC, Iarocci G. A psychometric study of the Family Resilience Assessment Scale among families of children with autism spectrum disorder. Health Qual Life Outcomes. 2019 Mar 12;17(1):45. doi: 10.1186

/s12955-019-1117-x. PMID: 30866979; PMCID: PMC6417032.
19. Mavroeidi N, Sifnaios C, Ntinou A, et al. Exploring the potential impact of training on short-term quality of life and stress of parents of children with autism: the integrative parents' autism training module. Int J Environ Res Public Health. 2024 Apr 13;21(4):474. doi: 10.3390/ijerph21040474. PMID: 38673385; PMCID: PMC11050325.
20. Trew S. Made to feel different: families' perspectives on external responses to autism and the impacts on family wellbeing and relationships. Autism. 2024 Aug;28(8):2120–39. doi: 10.1177/13623613231221684. PMID: 38240288; PMCID: PMC11301965.
21. Volgyesi-Molnar M, Gyori M, Eapen V, et al. Quality of life in Hungarian parents of autistic individuals. J Autism Dev Disord. 2025 Mar;55(3):1122–37. doi: 10.1007/s10803-024-06243-3. PMID: 38280137; PMCID: PMC11828818.
22. Mohammadi A, Ghazavi Z, Moghadam MF. The effect of a happiness education program on the expressed emotion and quality of life of mothers of children with autism spectrum disorder. Iran J Nurs Midwifery Res. 2024 Jul;29(4):446–51. doi: 10.4103/ijnmr.ijnmr_20_22. PMID: 39205830; PMCID: PMC11349155.
23. Raju S, Hepsibah PEV, Niharika MK. Quality of life in parents of children with autism spectrum disorder: emphasizing challenges in the Indian context. Int J Dev Disabil. 2023;69(3):371–8. doi: 10.1080/20473869.2023.2173832. PMID: 37213591; PMCID: PMC10198003.
24. Ahmed EA, Alkhaldi SM, Alduraidi H, Albsoul RA, Alhamdan MZ. Quality of life of mothers and fathers of children with autism spectrum disorder in Jordan. Clin Pract Epidemiol Ment Health. 2023 Jun;19:e174501792304180. doi: 10.2174/17450179-v19-e230529-2022-40. PMID: 37916204; PMCID: PMC10351341.
25. Mansoor KMA. The association between intolerance of uncertainty and psychological burden among caregivers of children with autism and the impact on their quality of life. Front Psychiatry. 2025 Apr;16:1492304. doi: 10.3389/fpsyt.2025.1492304. PMID: 40352369; PMCID: PMC12061961.
26. Alenezi S, Alsewailem N, Almubaddil BA, et al. Raising hopes, facing challenges: understanding parental well-being in the midst of autism in Saudi Arabia. Behav Sci (Basel). 2024 Jun;14(7):531. doi: 10.3390/bs14070531. PMID: 39062354; PMCID: PMC11274214.
27. AlHefdhi HA, Al Zomia AS, Alshehri NM, et al. Examining the quality of life and discrimination impact on parents of children with autism spectrum disorder in the Aseer region, Saudi Arabia: a WHOQOL survey. Cureus. 2024 Feb;16(2):e53616. doi: 10.7759/cureus.53616. PMID: 38449996; PMCID: PMC10916740.
28. Dijkstra-de Neijs L, Boeke DB, van Berckelaer-Onnes IA, et al. Parental stress and quality of life in parents of young children with autism. Child Psychiatry Hum Dev. 2024 May. doi: 10.1007/s10578-024-01693-3. PMID: 38724870.
29. Mannion A, Leader G. Relationship between child sleep problems in autism spectrum disorder and parent mental health and well-being. Sleep Med. 2023;109:4–10. doi: 10.1016/j.sleep.2023.05.009.
30. Alam BP, Masuri MG, Kampus U, Alam P. Emotional states and quality of life among parents of children with autism spectrum disorder during COVID-19 in Malaysia. J Univ Malaya Med Cent. 2023;2009(6):120–32. doi: 10.22452/jummec.sp2023no2.14.
31. McAuliffe T, Cordier R, Vaz S, Thomas Y, Falkmer T. Quality of life, coping styles, stress levels, and time use in mothers of children with autism spectrum disorders: comparing single versus coupled households. J Autism Dev Disord. 2017 Oct;47(10):3189–203. doi: 10.1007/s10803-017-3240-z. PMID: 28730416.
32. Papanikolaou K, Ntre V, Gertsou IM, et al. Parenting children with autism spectrum disorder during crises: differential responses between the financial and the COVID-19 pandemic crisis. J Clin Med. 2022 Feb;11(5):1264. doi: 10.3390/jcm11051264. PMID: 35268354; PMCID: PMC8911193.
33. Pisula E, Porębowicz-Dörsmann A. 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;12(10):e0186536. doi: 10.1371/journal.pone.0186536. PMID: 29036188; PMCID: PMC5643111.
34. Pondé MP, da Silva Reis VF, Andrade e Silva NM, Siquara GM. Symptoms of anxiety and depression and quality of life in parents of children with autism during the second wave of the pandemic. Res Dev Disabil. 2023 Dec;143:104620. doi: 10.1016/j.ridd.2023.104620. PMID: 37918177.
35. Khanna R, Madhavan SS, Smith MJ, Patrick JH, Tworek C, Becker-Cottrill B. Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. J Autism Dev Disord. 2011 Sep;41(9):1214–27. doi: 10.1007/s10803-010-1140-6. PMID: 21103917.
36. Eapen V, Karlov L, John JR, et al. Quality of life in parents of autistic children: a transcultural perspective. Front Psychol. 2023 Feb;14:1022094. doi: 10.3389/fpsyg.2023.1022094. PMID: 36910746; PMCID: PMC9996029.
37. Picardi A, Gigantesco A, Tarolla E, et al. Parental burden and its correlates in families of children with autism spectrum disorder: a multicentre study with two comparison groups. Clin Pract Epidemiol Ment Health. 2018 Jul;14:143–76. doi: 10.2174/1745017901814010143. PMID: 30158998; PMCID: PMC6080067.
38. Salami S, Alhalal E. Gender differences in predictors of quality of life for parents of children with autism spectrum disorder in Saudi Arabia. J Pediatr Nurs. 2024 Jul–Aug;77:e117–24. doi: 10.1016/j.pedn.2024.03.039. PMID: 38565480.
39. Samadi SA, Ghanimi F, McConkey R. Quality of life of Iranian mothers and fathers of children with autism. Children

(Basel). 2025 Mar;12(4):454. doi: 10.3390/children12040454. PMID: 40310098; PMCID: PMC12025491.
40. Abhilash V. L, Jasseer J., Quality of Life among Mothers of Children with Neurodevelopmental Disorders - Antrocom J. of Anthropology 18-2a (2022) pp. 95-102.
41. d'Orsi D, Veríssimo M, Diniz E. Father involvement and maternal stress: the mediating role of coparenting. Int J Environ Res Public Health. 2023 Apr;20(8):5457. doi: 10.3390/ijerph20085457. PMID: 37107739; PMCID: PMC10138638.
42. Jose P, Sundaram S, Varma RP. Buffering effect of spousal support on stress levels in mothers of children with a diagnosis of autism spectrum disorder in Kerala, India. J Neurosci Rural Pract. 2021 Jul;12(3):535–42. doi: 10.1055/s-0041-1727559. PMID: 34295109; PMCID: PMC8289558.
43. Garrido D, Catena A, Garcia-Retamero R. Neurodevelopmental disorders and family quality of life: emerging trends and future research directions. Pediatr Res. 2025 Jan;97(1):107–14. doi: 10.1038/s41390-024-03350-w. PMID: 38926550.
44. Wu H, Savadlou A, Paul M, et al. Psychosocial interventions and quality of life in autistic young adults: a systematic review. Rev J Autism Dev Disord. 2025. doi: 10.1007/s40489-025-00499-w.
45. Musetti A, Manari T, Dioni B, et al. Parental quality of life and involvement in intervention for children or adolescents with autism spectrum disorders: a systematic review. J Pers Med. 2021 Sep;11(9):894. doi: 10.3390/jpm11090894. PMID: 34575671; PMCID: PMC8469292.
46. Mohamad Aun NS, Zakaria SM, Ahmad Badayai AR, et al. Quality of life among mothers of high-functioning autism spectrum disorder adolescents. Int J Environ Res Public Health. 2022 May;19(11):6663. doi: 10.3390/ijerph19116663. PMID: 35682245; PMCID: PMC9180906.
47. Oliveira Ede F, Limongi SC. Quality of life of parents/caregivers of children and adolescents with Down syndrome. J Soc Bras Fonoaudiol. 2011 Dec;23(4):321–7. doi: 10.1590/S2179-64912011000400006. PMID: 22231052.
48. AlAhmari FS, Alageel AF, Aldosari MA, Bagha MY. The quality of life of parents of children with Down syndrome in a tertiary care hospital: a qualitative research study in Saudi Arabia. Ann Med Surg (Lond). 2022 Sep;81:104428. doi: 10.1016/j.amsu.2022.104428. PMID: 36147136; PMCID: PMC9486666.

Annex

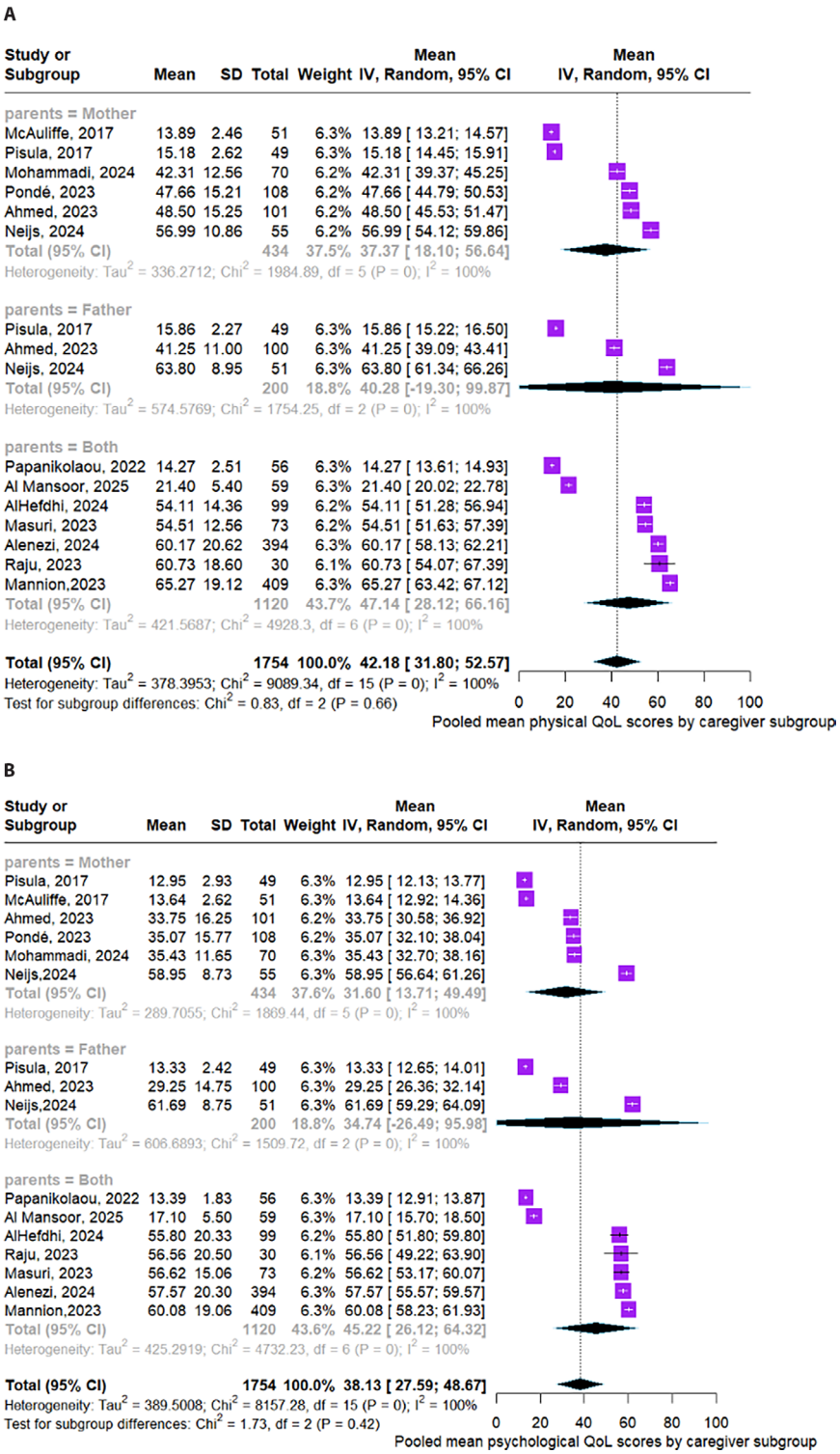

Figure S1. Pooled mean scores of different QoL domains among caregiver subgroups of children with ASD. A) Physical QoL scores; B) Psychological QoL scores.

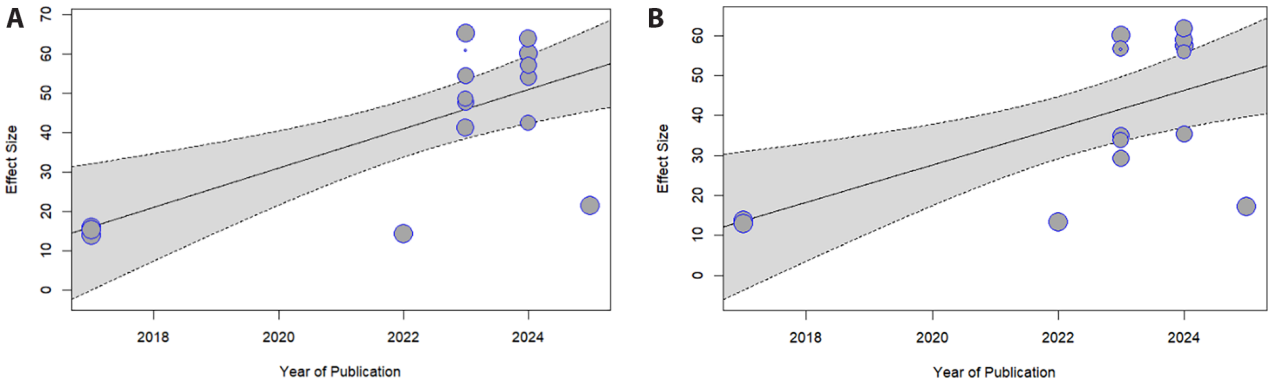

Figure S2. Meta-regression by publication year in selected QoL domains. A**)** Physical QoL scores; B) Psychological QoL scores.

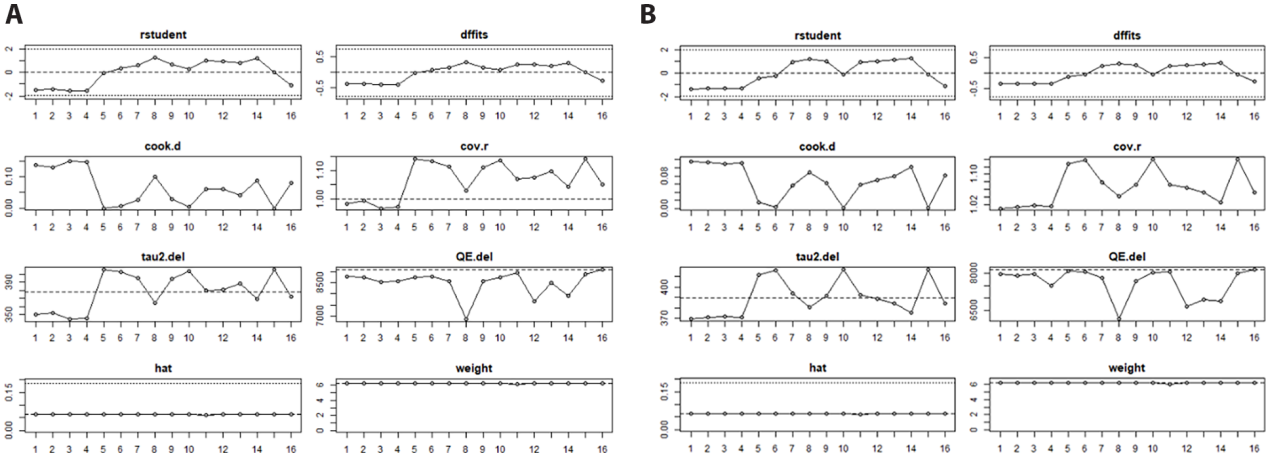

Figure S3. Influence analysis of pooled mean scores across different quality of life domains. A) physical QoL; B) psychological QoL.

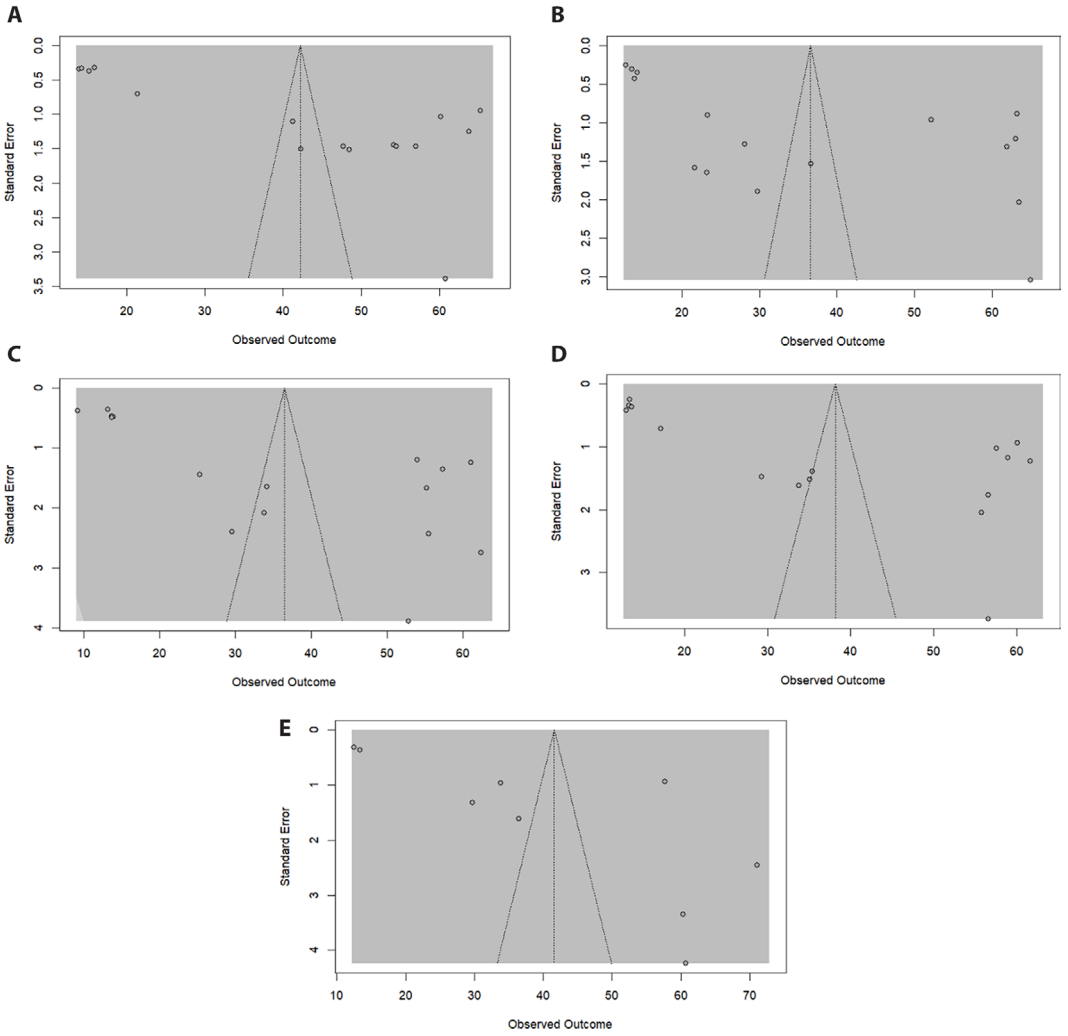

Figure S4. Assessment of publication bias across pooled studies of different quality of life domains. A) physical QoL; B) Environmental QoL; C) Social QoL; D) Psychological QoL; E) Overall QoL.

Table S1. Risk of bias (quality) assessment according to the Newcastle–Ottawa Scale (case-control and cross-sectional studies).

Study	**Criteria 1**	**Criteria 2**	**Criteria 3**	**Result**
Case-control studies				
Author, year	Selection (max?)	Comparability (max?)	Exposure (max?)	Total (max?)
Mohammadi,2024 (22)	3	1	2	6
Raju, 2023 (23)	3	1	2	6
Cross-sectional studies				
Author, year	Selection (max 3)	Comparability (max 2)	Outcome (max 2)	Total(max 7)
Ahmed, 2023 (24)	2	1	2	5
Al Mansoor, 2025 (25)	2	1	2	5
Alenezi, 2024 (26)	3	1	2	6
AlHefdhi, 2024 (27)	2	1	2	5
Dijkstra-de Neijs, 2024 (28)	3	1	2	6
Mannion, 2023 (29)	2	1	2	5
Masuri, 2023 (30)	3	2	2	7
McAuliffe, 2019 (31)	2	1	2	5
Papanikolaou, 2022 (32)	3	1	2	6
Pisula, 2017 (33)	2	1	2	5
Pondé, 2023 (34)	3	1	2	6