GEORGIAN MEDICAL NEWS

ISSN 1512-0112

NO 7-8 (364-365) Июль-Август 2025

ТБИЛИСИ - NEW YORK

ЕЖЕМЕСЯЧНЫЙ НАУЧНЫЙ ЖУРНАЛ

Медицинские новости Грузии

საქართველოს სამედიცინო სიახლენი

GEORGIAN MEDICAL NEWS

Monthly Georgia-US joint scientific journal published both in electronic and paper formats of the Agency of Medical Information of the Georgian Association of Business Press. Published since 1994. Distributed in NIS, EU and USA.

GMN: Georgian Medical News is peer-reviewed, published monthly journal committed to promoting the science and art of medicine and the betterment of public health, published by the GMN Editorial Board since 1994. GMN carries original scientific articles on medicine, biology and pharmacy, which are of experimental, theoretical and practical character; publishes original research, reviews, commentaries, editorials, essays, medical news, and correspondence in English and Russian.

GMN is indexed in MEDLINE, SCOPUS, PubMed and VINITI Russian Academy of Sciences. The full text content is available through EBSCO databases.

GMN: Медицинские новости Грузии - ежемесячный рецензируемый научный журнал, издаётся Редакционной коллегией с 1994 года на русском и английском языках в целях поддержки медицинской науки и улучшения здравоохранения. В журнале публикуются оригинальные научные статьи в области медицины, биологии и фармации, статьи обзорного характера, научные сообщения, новости медицины и здравоохранения. Журнал индексируется в MEDLINE, отражён в базе данных SCOPUS, PubMed и ВИНИТИ РАН. Полнотекстовые статьи журнала доступны через БД EBSCO.

GMN: Georgian Medical News – საქართველოს სამედიცინო სიახლენი – არის ყოველთვიური სამეცნიერო სამედიცინო რეცენზირებადი ჟურნალი, გამოიცემა 1994 წლიდან, წარმოადგენს სარედაქციო კოლეგიისა და აშშ-ის მეცნიერების, განათლების, ინდუსტრიის, ხელოვნებისა და ბუნებისმეტყველების საერთაშორისო აკადემიის ერთობლივ გამოცემას. GMN-ში რუსულ და ინგლისურ ენებზე ქვეყნდება ექსპერიმენტული, თეორიული და პრაქტიკული ხასიათის ორიგინალური სამეცნიერო სტატიები მედიცინის, ბიოლოგიისა და ფარმაციის სფეროში, მიმოხილვითი ხასიათის სტატიები.

ჟურნალი ინდექსირებულია MEDLINE-ის საერთაშორისო სისტემაში, ასახულია SCOPUS-ის, PubMed-ის და ВИНИТИ РАН-ის მონაცემთა ბაზებში. სტატიების სრული ტექსტი ხელმისაწვდომია EBSCO-ს მონაცემთა ბაზებიდან.

WEBSITE

www.geomednews.com

К СВЕДЕНИЮ АВТОРОВ!

При направлении статьи в редакцию необходимо соблюдать следующие правила:

1. Статья должна быть представлена в двух экземплярах, на русском или английском языках, напечатанная через **полтора интервала на одной стороне стандартного листа с шириной левого поля в три сантиметра**. Используемый компьютерный шрифт для текста на русском и английском языках - **Times New Roman** (**Кириллица**), для текста на грузинском языке следует использовать **AcadNusx.** Размер шрифта - **12**. К рукописи, напечатанной на компьютере, должен быть приложен CD со статьей.

2. Размер статьи должен быть не менее десяти и не более двадцати страниц машинописи, включая указатель литературы и резюме на английском, русском и грузинском языках.

3. В статье должны быть освещены актуальность данного материала, методы и результаты исследования и их обсуждение.

При представлении в печать научных экспериментальных работ авторы должны указывать вид и количество экспериментальных животных, применявшиеся методы обезболивания и усыпления (в ходе острых опытов).

4. К статье должны быть приложены краткое (на полстраницы) резюме на английском, русском и грузинском языках (включающее следующие разделы: цель исследования, материал и методы, результаты и заключение) и список ключевых слов (key words).

5. Таблицы необходимо представлять в печатной форме. Фотокопии не принимаются. **Все цифровые, итоговые и процентные данные в таблицах должны соответствовать таковым в тексте статьи**. Таблицы и графики должны быть озаглавлены.

6. Фотографии должны быть контрастными, фотокопии с рентгенограмм - в позитивном изображении. Рисунки, чертежи и диаграммы следует озаглавить, пронумеровать и вставить в соответствующее место текста **в tiff формате**.

В подписях к микрофотографиям следует указывать степень увеличения через окуляр или объектив и метод окраски или импрегнации срезов.

7. Фамилии отечественных авторов приводятся в оригинальной транскрипции.

8. При оформлении и направлении статей в журнал МНГ просим авторов соблюдать правила, изложенные в «Единых требованиях к рукописям, представляемым в биомедицинские журналы», принятых Международным комитетом редакторов медицинских журналов - http://www.spinesurgery.ru/files/publish.pdf и http://www.nlm.nih.gov/bsd/uniform_requirements.html
В конце каждой оригинальной статьи приводится библиографический список. В список литературы включаются все материалы, на которые имеются ссылки в тексте. Список составляется в алфавитном порядке и нумеруется. Литературный источник приводится на языке оригинала. В списке литературы сначала приводятся работы, написанные знаками грузинского алфавита, затем кириллицей и латиницей. Ссылки на цитируемые работы в тексте статьи даются в квадратных скобках в виде номера, соответствующего номеру данной работы в списке литературы. Большинство цитированных источников должны быть за последние 5-7 лет.

9. Для получения права на публикацию статья должна иметь от руководителя работы или учреждения визу и сопроводительное отношение, написанные или напечатанные на бланке и заверенные подписью и печатью.

10. В конце статьи должны быть подписи всех авторов, полностью приведены их фамилии, имена и отчества, указаны служебный и домашний номера телефонов и адреса или иные координаты. Количество авторов (соавторов) не должно превышать пяти человек.

11. Редакция оставляет за собой право сокращать и исправлять статьи. Корректура авторам не высылается, вся работа и сверка проводится по авторскому оригиналу.

12. Недопустимо направление в редакцию работ, представленных к печати в иных издательствах или опубликованных в других изданиях.

При нарушении указанных правил статьи не рассматриваются.

REQUIREMENTS

Please note, materials submitted to the Editorial Office Staff are supposed to meet the following requirements:

1. Articles must be provided with a double copy, in English or Russian languages and typed or compu-ter-printed on a single side of standard typing paper, with the left margin of **3** centimeters width, and **1.5** spacing between the lines, typeface - **Times New Roman** (**Cyrillic**), print size - **12** (referring to Georgian and Russian materials). With computer-printed texts please enclose a CD carrying the same file titled with Latin symbols.

2. Size of the article, including index and resume in English, Russian and Georgian languages must be at least 10 pages and not exceed the limit of 20 pages of typed or computer-printed text.

3. Submitted material must include a coverage of a topical subject, research methods, results, and review.

Authors of the scientific-research works must indicate the number of experimental biological species drawn in, list the employed methods of anesthetization and soporific means used during acute tests.

4. Articles must have a short (half page) abstract in English, Russian and Georgian (including the following sections: aim of study, material and methods, results and conclusions) and a list of key words.

5. Tables must be presented in an original typed or computer-printed form, instead of a photocopied version. **Numbers, totals, percentile data on the tables must coincide with those in the texts of the articles.** Tables and graphs must be headed.

6. Photographs are required to be contrasted and must be submitted with doubles. Please number each photograph with a pencil on its back, indicate author's name, title of the article (short version), and mark out its top and bottom parts. Drawings must be accurate, drafts and diagrams drawn in Indian ink (or black ink). Photocopies of the X-ray photographs must be presented in a positive image in **tiff format**.

Accurately numbered subtitles for each illustration must be listed on a separate sheet of paper. In the subtitles for the microphotographs please indicate the ocular and objective lens magnification power, method of coloring or impregnation of the microscopic sections (preparations).

7. Please indicate last names, first and middle initials of the native authors, present names and initials of the foreign authors in the transcription of the original language, enclose in parenthesis corresponding number under which the author is listed in the reference materials.

8. Please follow guidance offered to authors by The International Committee of Medical Journal Editors guidance in its Uniform Requirements for Manuscripts Submitted to Biomedical Journals publication available online at: http://www.nlm.nih.gov/bsd/uniform_requirements.html
http://www.icmje.org/urm_full.pdf
In GMN style for each work cited in the text, a bibliographic reference is given, and this is located at the end of the article under the title "References". All references cited in the text must be listed. The list of references should be arranged alphabetically and then numbered. References are numbered in the text [numbers in square brackets] and in the reference list and numbers are repeated throughout the text as needed. The bibliographic description is given in the language of publication (citations in Georgian script are followed by Cyrillic and Latin).

9. To obtain the rights of publication articles must be accompanied by a visa from the project instructor or the establishment, where the work has been performed, and a reference letter, both written or typed on a special signed form, certified by a stamp or a seal.

10. Articles must be signed by all of the authors at the end, and they must be provided with a list of full names, office and home phone numbers and addresses or other non-office locations where the authors could be reached. The number of the authors (co-authors) must not exceed the limit of 5 people.

11. Editorial Staff reserves the rights to cut down in size and correct the articles. Proof-sheets are not sent out to the authors. The entire editorial and collation work is performed according to the author's original text.

12. Sending in the works that have already been assigned to the press by other Editorial Staffs or have been printed by other publishers is not permissible.

Articles that Fail to Meet the Aforementioned Requirements are not Assigned to be Reviewed.

ავტორთა საყურადღებოდ!

რედაქციაში სტატიის წარმოდგენისას საჭიროა დავიცვათ შემდეგი წესები:

1. სტატია უნდა წარმოადგინოთ 2 ცალად, რუსულ ან ინგლისურ ენებზე,დაბეჭდილი სტანდარტული ფურცლის 1 გვერდზე, 3 სმ სიგანის მარცხენა ველისა და სტრიქონებს შორის 1,5 ინტერვალის დაცვით. გამოყენებული კომპიუტერული შრიფტი რუსულ და ინგლისურენოვან ტექსტებში - **Times New Roman (Кириллица)**, ხოლო ქართულენოვან ტექსტში საჭიროა გამოვიყენოთ **AcadNusx.** შრიფტის ზომა – 12. სტატიას თან უნდა ახლდეს CD სტატიით.

2. სტატიის მოცულობა არ უნდა შეადგენდეს 10 გვერდზე ნაკლებს და 20 გვერდზე მეტს ლიტერატურის სიის და რეზიუმეების (ინგლისურ, რუსულ და ქართულ ენებზე) ჩათვლით.

3. სტატიაში საჭიროა გაშუქდეს: საკითხის აქტუალობა; კვლევის მიზანი; საკვლევი მასალა და გამოყენებული მეთოდები; მიღებული შედეგები და მათი განსჯა. ექსპერიმენტული ხასიათის სტატიების წარმოდგენისას ავტორებმა უნდა მიუთითონ საექსპერიმენტო ცხოველების სახეობა და რაოდენობა; გაუტკივარებისა და დაძინების მეთოდები (მწვავე ცდების პირობებში).

4. სტატიას თან უნდა ახლდეს რეზიუმე ინგლისურ, რუსულ და ქართულ ენებზე არანაკლებ ნახევარი გვერდის მოცულობისა (სათაურის, ავტორების, დაწესებულების მითითებით და უნდა შეიცავდეს შემდეგ განყოფილებებს: მიზანი, მასალა და მეთოდები, შედეგები და დასკვნები; ტექსტუალური ნაწილი არ უნდა იყოს 15 სტრიქონზე ნაკლები) და საკვანძო სიტყვების ჩამონათვალი (key words).

5. ცხრილები საჭიროა წარმოადგინოთ ნაბეჭდი სახით. ყველა ციფრული, შემაჯამებელი და პროცენტული მონაცემები უნდა შეესაბამებოდეს ტექსტში მოყვანილს.

6. ფოტოსურათები უნდა იყოს კონტრასტული; სურათები, ნახაზები, დიაგრამები - დასათაურებული, დანომრილი და სათანადო ადგილას ჩასმული. რენტგენოგრამების ფოტოასლები წარმოადგინეთ პოზიტიური გამოსახულებით **tiff** ფორმატში. მიკროფოტოსურათების წარწერებში საჭიროა მიუთითოთ ოკულარის ან ობიექტივის საშუალებით გადიდების ხარისხი, ანათალების შეღებვის ან იმპრეგნაციის მეთოდი და აღნიშნოთ სურათის ზედა და ქვედა ნაწილები.

7. სამამულო ავტორების გვარები სტატიაში აღინიშნება ინიციალების თანდართვით, უცხოურისა – უცხოური ტრანსკრიპციით.

8. სტატიას თან უნდა ახლდეს ავტორის მიერ გამოყენებული სამამულო და უცხოური შრომების ბიბლიოგრაფიული სია (ბოლო 5-8 წლის სიღრმით). ანბანური წყობით წარმოდგენილ ბიბლიოგრაფიულ სიაში მიუთითეთ ჯერ სამამულო, შემდეგ უცხოელი ავტორები (გვარი, ინიციალები, სტატიის სათაური, ჟურნალის დასახელება, გამოცემის ადგილი, წელი, ჟურნალის №, პირველი და ბოლო გვერდები). მონოგრაფიის შემთხვევაში მიუთითეთ გამოცემის წელი, ადგილი და გვერდების საერთო რაოდენობა. ტექსტში კვადრატულ ფჩხილებში უნდა მიუთითოთ ავტორის შესაბამისი N ლიტერატურის სიის მიხედვით. მიზანშეწონილია, რომ ციტირებული წყაროების უმეტესი ნაწილი იყოს 5-6 წლის სიღრმის.

9. სტატიას თან უნდა ახლდეს: ა) დაწესებულების ან სამეცნიერო ხელმძღვანელის წარდგინება, დამოწმებული ხელმოწერითა და ბეჭდით; ბ) დარგის სპეციალისტის დამოწმებული რეცენზია, რომელშიც მითითებული იქნება საკითხის აქტუალობა, მასალის საკმაობა, მეთოდის სანდოობა, შედეგების სამეცნიერო-პრაქტიკული მნიშვნელობა.

10. სტატიის ბოლოს საჭიროა ყველა ავტორის ხელმოწერა, რომელთა რაოდენობა არ უნდა აღემატებოდეს 5-ს.

11. რედაქცია იტოვებს უფლებას შეასწოროს სტატია. ტექსტზე მუშაობა და შეჯერება ხდება საავტორო ორიგინალის მიხედვით.

12. დაუშვებელია რედაქციაში ისეთი სტატიის წარდგენა, რომელიც დასაბეჭდად წარდგენილი იყო სხვა რედაქციაში ან გამოქვეყნებული იყო სხვა გამოცემებში.

აღნიშნული წესების დარღვევის შემთხვევაში სტატიები არ განიხილება.

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Содержание:

GEORGIAN MEDICAL NEWS
No 7-8 (364-365) 2025

PARENTAL QUALITY OF LIFE WHEN RAISING CHILDREN WITH AUTISM SPECTRUM DISORDER: A NARRATIVE REVIEW

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Abstract.

Background: Parents of children with autism spectrum disorder (ASD) face unique and ongoing caregiving demands that can reduce their quality of life (QoL) across physical, social, and psychological spheres.

Objectives: This narrative review consolidates existing findings concerning how caring for a child with ASD affects parental QoL and identifies actionable strategies to mitigate the burden.

Methods: We searched PubMed and Scopus for English-language studies published from January 2010 to May 2024 using terms such as "autism", "caregiver", and "quality of life". Empirical studies and systematic reviews involving parents of children (≤18 years) with ASD were included; abstract conferences were excluded.

Results: Twenty-four empirical studies met the inclusion criteria; eight additional sources are cited for context. Publications consistently reported lower overall and domain-specific QoL scores for parents of children with ASD versus parents of typically developing children. Increased caregiver stress, reduced social interaction, higher out-of-pocket costs, and uncoordinated support program services emerged as persistent drivers. Interventions that combined psycho-education, behavioural coaching, and sensory-adapted dental or medical environments showed moderate improvements in parental mental health and QoL metrics.

Conclusions: Multidisciplinary, family-centred programmes and policies that remove financial and accessibility barriers are critical to improving parents' QoL. Future longitudinal and culturally diverse studies must clarify which intervention components provide the most significant sustained benefit.

Key words. Autism spectrum disorder, quality of life, caregivers, psychoeducation, family-centered care.

Introduction.

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by long-term challenges in social engagement, as well as restricted, repetitive patterns of behavior, interests, or activities. Prevalence of ASD has been increasing, recent data showing that approximately one in 36 children is diagnosed with the disorder, emphasizing its significant impact on families and society [1].

Caring for a child on the autism spectrum commonly brings its own set of challenges for parents. These include managing unpredictable behaviours, coping with emotional and behavioural difficulties, and addressing the complex needs that often accompany ASD, such as comorbid mental or medical conditions. The cumulative effect of these demands can result in elevated stress levels, caregiver burden, and a reduction in overall quality of life (QoL) for parents [2].

Global studies have consistently reported that parents of children with ASD experience lower QoL compared to parents of typically developing children or those caring for children with other disabilities. A child's unstable state, the need for constant supervision, and the emotional burdens linked to navigating social and educational systems contribute to chronic stress and caregiver burnout [3]. Impact of ASD on family functioning is multifaceted; maintaining social relationships is a particular challenge, and self-harming or aggressive behaviours in children with ASD can further aggravate parental stress, adding additional challenges to caregiving [4-5].

Research has highlighted the importance of targeted interventions and support systems to mitigate the adverse effects of caregiving on parental QoL. Programmes such as TEACCH have demonstrated efficacy in enhancing parental self-efficacy, reducing stress, and increasing knowledge about ASD and effective support strategies [6]. Family-centred interventions have also been shown to improve family functioning and coping styles. At the same time, the quality of social relationships rather than their quantity emerges as a key predictor of QoL for both children with ASD and their parents [3,7]. Given these findings, holistic, context-sensitive strategies and further research are required to understand and support caregiver well-being across diverse socio-cultural settings [8-15].

Therefore, this narrative review aims to synthesise the current evidence on how caring for a child with ASD influences parental quality of life, to identify research gaps, and to outline evidence-based support strategies [16-23]. A narrative approach was selected because the available studies are methodologically heterogeneous, with diverse designs, outcome measures, cultural contexts, and intervention types precluding the pooling required for a systematic review or meta-analysis. The article first

details the search strategy and inclusion criteria, then presents results organised by QoL domains, followed by a discussion of implications and recommendations for future research [24-33].

Methods.

This article presents a narrative review. We aimed to gather, describe, and interpret the available evidence on caregiver quality of life rather than to catalogue every study exhaustively or to pool effect sizes statistically. We therefore focus on a transparent search strategy and thematic synthesis.

Searches were executed on 5 May 2024 in PubMed and Scopus for English-language literature published between January 2010 and May 2024. The identical Boolean expression was used in both sources:

("autism" OR "ASD") AND (caregiver OR parent) AND ("quality of life" OR QoL).

The search returned 256 PubMed records and 308 Scopus records. All references were imported into Zotero 6 and automatically de-duplicated, with manual verification, which removed 86 duplicates. Two reviewers independently screened the remaining 478 titles and abstracts; 72 potentially relevant articles were retrieved in full text and assessed against the inclusion criteria, with disagreements resolved by discussion. The study-selection process is summarised in Figure 1.

Twenty-four studies met the criteria and were included in the narrative synthesis; eight additional publications are cited for contextual background (e.g., prevalence statistics and instrument development).

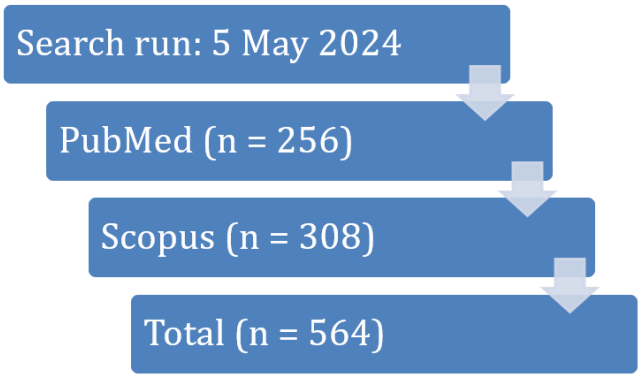

Figure 1. *PRISMA-style flow of study selection.*

Eligibility criteria:

- **Population:** parents or primary caregivers of children ≤ 18 years with a clinical diagnosis of Autism Spectrum Disorder.
- **Study designs:** quantitative, qualitative, or mixed-methods empirical studies and systematic reviews.
- **Outcome:** any caregiver-reported quality-of-life measure (generic or ASD-specific).
- **Exclusions:** commentaries, editorials, conference abstracts without full text, theses, and papers reporting QoL solely from the child's perspective.

Data extraction and synthesis:

Key characteristics (author, year, country, design, sample size, child age, QoL instrument, and main caregiver-focused findings) were charted in a structured spreadsheet. Findings were grouped under the four World Health Organization QoL domains (physical, psychological, social, environmental) and woven into an interpretive thematic narrative highlighting convergent evidence, methodological gaps, and directions for future research.

All material synthesised was previously published and in the public domain; therefore, **no ethical approval was required.**

Results and Discussion.

Twenty-four empirical studies met all inclusion criteria and were synthesised thematically. Table 1 summarises ten illustrative examples; the remaining fourteen appear in Supplementary Table S1.

Psychological burden and stress:

Caregivers showed elevated stress, anxiety and depressive symptoms across studies [3,5]. Unmet service needs and persistent stress were the strongest global drivers of low QoL [3]. Person-centred early-childhood services reduced parental strain [2]. In a Malaysian cross-sectional study, child-specific behavioural difficulties were the strongest predictors of lower parental QoL.

Financial strain:

Out-of-pocket costs, reduced work hours, and unemployment correlated with poorer QoL [3,13,18,19]. Psychological support partly reduced the impact of economic stress in Jordan [13].

Social isolation and stigma:

Brazilian caregivers described profound isolation and stigma [17]. Peer networks and practical help improved well-being [18].

Child-related factors:

Greater symptom severity and psychiatric comorbidity predicted lower caregiver QoL [4,19]. Conversely, multidisciplinary parent-training programmes increased family functioning and QoL [2,24]. Multidisciplinary early-intervention programmes improved overall family functioning in ≥ 70 % of cases [33].

Gender differences:

One controlled study found that mothers experience more depressive distress than fathers, whereas fathers emphasised financial pressure [5]. No study isolated paternal QoL—an evident gap.

Health- and service-system factors:

High-quality, co-ordinated services—often nurse- or paediatric-led—were linked to higher QoL [2,3,19]. Fragmented or delayed care compounded stress and economic burden [3].

Cultural context and measurement issues:

Caregiver QoL scores were generally lower in emerging-economy settings (Jordan, Brazil) than in Western Europe/North America [13,14,17,18]. Contributing factors include (i) extended-family role expectations, (ii) higher stigma discouraging community participation, and (iii) fee-for-service health systems that shift costs to families. Measurement nuance also matters: WHOQOL-Bref covers broad domains but may miss autism-specific stressors; Family-QoL scales emphasise household functioning; EQ-5D

Table 1. *Illustrative studies (10 of 24) on caregiver quality of life in Autism Spectrum Disorder (ASD).*

Ref.	Author (year)	Country/setting	Design & sample	QoL/HRQoL tool(s)	Key QoL driver(s)	Main caregiver finding
[3]	Turnage 2022	USA – integrative review	30 studies, parents ≤ 18 y	SF-36; WHOQOL-Bref; FQoL; PedsQL	Stress · service gaps	Global QoL ↓; unmet services & chronic stress dominate
[2]	Dijkstra-de Neijs 2024	Netherlands – cohort	189 families, child < 6 y	PSI-SF; WHOQOL-Bref	Service quality	Person-centred early care ↑ maternal QoL
[4]	Ten Hoopen 2020	Netherlands – multicentre	224 dyads	PedsQL; CarerQoL	Child comorbidity	Comorbidities ↓ HRQoL in child & parent
[13]	Kasem 2023	Jordan – comparative	100 ASD vs 100 controls	WHOQOL-Bref	Financial strain · depression	Psychosocial QoL ↓; counselling mitigates depression
[14]	Souza 2024	Brazil – community	245 parents (6–18 y)	OHIP-14	Low SES · health burden	Oral-health QoL ↓ with severity & poverty
[17]	Procopio 2024	Brazil – qualitative	22 caregivers	Thematic interviews	Isolation · stigma	Peer learning ↓ burden; isolation persists
[18]	Borilli 2022	Brazil – survey	60 families (mild ASD + ID)	Family-QoL Scale	Community networks	Practical help ↑ family QoL
[5]	Baker-Ericzén 2005	USA – case-control	98 parents (toddlers)	Parenting-Stress Index	Stress · gender effect	Mothers > fathers on depressive stress
[19]	Beadle-Brown 2016	UK – observational	74 families (complex needs)	PAS-ADD; QoS	Service quality	Higher support quality ↑ family QoL
[24]	Abid 2024	Tunisia – RCT	72 parents (preschoolers)	WHOQOL-Bref	Training intervention	Parent-training ↑ QoL vs control

Table S1. *Additional sources cited for context, methodology, or adult-QoL gaps (not part of the 10 illustrative studies in Table 1).*

Ref.	Author (year)	Country / setting	Design & sample	QoL / HRQoL tool(s)	Key QoL driver(s)	Main caregiver finding
1	Maenner 2023	USA – surveillance	Registry prevalence (background)	—	—	Service-demand backdrop
6	Schopler 2005	USA – book	Conceptual framework	—	Service model	TEACCH person-centred principles
7	Eapen 2023	Australia / UAE	258 parents	WHOQOL-Bref	Culture · stigma	QoL ↓ where stigma ↑
10	Tedla 2024	Saudi Arabia	154 caregivers	WHOQOL-Bref	Child severity	Severity ↑ → QoL ↓
11	Fante 2024	Italy – mixed	84 parents	FQoL; interviews	Self-efficacy	Parent self-efficacy mediates QoL
12	Epstein 2019	Australia – qualitative	64 parents	Thematic	Stress themes	Four QoL domains identified
15	Ikeda 2014	NZ – review	47 studies	Instrument audit	Measurement	Maps QoL-scale gaps
16	Arias 2018	Spain – cross-sectional	92 families	PedsQL-Family	ID comorbidity	ID + ASD ↓ family QoL
20	Buwade 2018	India – survey	120 parents	WHOQOL-Bref	Economic strain	Lower QoL with low income
21	Deguchi 2024	Japan – mixed	35 partners	WHOQOL-Bref; interviews	Partner stress	Spousal support predicts QoL
22	Pfeiffer 2017	USA – conceptual	Delphi study	—	Outcomes	Defines caregiver outcomes
23	Balbin 2022	Philippines – scoping	27 adult-ASD studies	Various	Adult QoL	Lack of adult-caregiver data
26	Gómez 2020	Spain – narrative	18 studies	Family-QoL	Family function	Integrates ID & ASD issues

(used once) focuses on health utility and can underestimate psychosocial burden. Studies using CarerQoL captured larger stress effects linked to comorbidity [4].

Recent studies show that oral health, although often underestimated, significantly affects the quality of life of people with autism spectrum disorder (ASD). Children with high-functioning autism feel the greatest gap precisely in their social lives; communication difficulties and high sensory sensitivity make it difficult for them to cooperate at the dentist and make them avoid public activities such as eating, talking, or smiling [27]. As a result, daily oral health appointments provide a unique lens on social participation and strongly influence how parents judge the success of the intervention.

Oral health and participation:

Spanish work has already argued that quality of life instruments should broaden their focus from strictly individual measurements to factors at the family and environmental levels; Notably, many of the 68 indicators derived from Delphi relate to self-care, food textures, and community involvement—areas that directly intersect with oral health and mealtime participation [28]. Incorporating such indicators into dental records would allow clinicians to document whether improvements in oral hygiene translate into broader benefits in participation for the child and reduced caregiver burden for the family.

Complementing these findings, an Italian nested case–control survey showed that children with ASD who followed a structured preventive dental regimen had significantly better OHRQoL scores and their parents reported lower emotional distress and family conflict compared with both un-enrolled ASD peers and neurotypical controls, underscoring oral health as a gateway to broader social participation [29]. Positioning the dental clinic as a low-pressure, high-frequency point of contact thus offers dual benefits – promoting preventive oral care while simultaneously expanding the gateway to participation in specialist services. Taken together, these findings suggest that future HRQoL frameworks should treat oral health not as a peripheral biomedical outcome, but as a socially embedded node of participation, monitored simultaneously at the child and family levels.

Future Directions.

· Longitudinal multi-country cohorts: enrol >1 000 parents at diagnosis; 5-year follow-up with stress biomarkers (salivary cortisol, actigraphy) and quarterly WHOQOL-Bref + FQoL.

· Father-inclusive designs: quota ≥ 40 % fathers; add qualitative focus-groups on gendered coping **[5].**

· Diagnosis-timing analysis: link registry age-at-diagnosis to parental QoL at 2 & 5 years.

· Culturally adapted instruments: Delphi panels in SE Asia & E Europe; validated with Rasch analysis.

· Studies in patients with dental appliances should be considered due to the potential impact of these appliances on local and systemic conditions [30-32].

· Family-centred RCTs: multisite 12-week parent-training + peer-support package; outcomes = FQoL change & cortisol slope.

· Economic evaluations: embed cost-utility (EQ-5D) alongside service-quality trials.

· Meta-research on QoL vs HRQoL: network meta-synthesis comparing WHOQOL-Bref, EQ-5D, CarerQoL, PedsQL-Family Impact.

· Advances in technology, including artificial intelligence, could show promise in the detection of children with ASD [33].

Implications for Service Providers & Policymakers.

· Expand tailored, person-centred services, especially during transitions [2,13].

· Draft culturally responsive policy using transcultural data [7,8].

· Strengthen financial supports—subsidies, respite, flexible work—to ease burden [13,18].

· Standardise service quality nationally to reduce regional disparities [2].

· Embed subjective QoL metrics in routine planning (WHOQOL-Bref, FQoL) [11].

· Promote peer-led networks to combat isolation [17,18].

Sustain research funding so policy remains evidence-based [24].

Conclusion.

Parents of children with Autism Spectrum Disorder (ASD) experience significantly lower quality of life across all domains, including psychological and economic. Comorbid conditions, severity of symptoms, and major development transitions intensify the stress of caregiving, while incoherent services as well as cultural and socioeconomic barriers compound the challenges. On average, parents' QoL scores are lower than the population average, highlighting the need for specific supportive interventions.

Strong evidence suggests that multidisciplinary, family-focused interventions implemented early and coordinated across health, education, and social sectors can yield clinically meaningful improvement.

Digital and telehealth platforms expand reach when designed with accessibility, linguistic, and cultural appropriateness. Strengthening informal networks, addressing parental mental health, and supporting flexible caregiving roles further improve outcomes.

Policy must shift from isolated and reactive assistance to flexible, lifelong-oriented systems that integrate financial assistance, respite, and mental health services. Future research should refine culturally sensitive QoL instruments, expand sampling beyond WEIRD populations (Western, Educated, Industrialised, Rich and Democratic), and test scalable interventions that include caregiver well-being. Improving child outcomes and caregiver well-being are inseparable goals; addressing them together is the only sustainable path to better lives for families living with ASD.

Abbreviations.

ASD: Autism Spectrum Disorder
QoL: Quality of Life

Acknowledgments.

The authors received no funding for this research from public, commercial, or not-for-profit agencies.

Conflict of Interest.

The authors declare no conflict of interest.

Data-Access Statement.

No new data were generated or analyzed in this study.

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