Research Article

The Effect of a Psycho-educational Nursing Program on Quality of Life among Caregivers of Children with Autism Spectrum Disorder: An Exploratory Mediating Role of Caregiver Burden

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Abstract

Background: Caregivers of children with autism spectrum disorder (ASD) are more prevalent with stress, worry, and hopelessness, in contrast to individuals who look after children who are typically developing or those who have additional disabilities that lower their quality of life. This emphasises the necessity of targeted assistance programs that might reduce some of the emotional and practical challenges and enhance their quality of life.

Aim of the study: to assess the impact of a psycho-educational nursing program on their quality of life and the connection between burden and quality of life including an exploratory mediation analysis.

Setting: The study was carried out at the neuropsychiatric outpatient clinic of Aswan University Hospital in Egypt.

Research design: A quasi-experimental (pre-/post-test) and follow-up research approach was used to evaluate 70 caregivers of children with ASD. The Quality of Life Scale Tool was the instrument used to collect the data.

Findings: In the intervention group, mean overall QoL increased from 41.4 ± 10.72 at baseline to 53.9 ± 8.50 post-intervention and 65.1 ± 11.52 at follow-up, compared with 40.6 ± 10.09, 43.1 ± 9.89, and 47.3 ± 9.64, respectively, in the comparison group. Between-group differences were not significant at baseline ($p = 0.764$) but were significant post-intervention and at follow-up (both $p < 0.001$), including all four QoL domains. Caregiver burden was strongly and inversely correlated with QoL in the intervention group at baseline ($r = −0.839$), post-intervention ($r = −0.916$), and follow-up ($r = −0.852$; all $p < 0.001$). The exploratory mediation analysis estimated an indirect effect of 5.252 (95% bootstrap CI: −0.087 to 9.545), which was not statistically significant. **Conclusion:** Caregivers enrolled in the psychoeducational nursing program experienced improvements in their quality of life. Although there was no evidence of a substantial mediation influence of caregiver burden, higher caregiver burden was consistently linked to lower QoL. It is necessary to do additional study utilizing rigorous longitudinal analyzes and established grading methods

Keywords: Autism spectrum disorder; caregivers; psychoeducation; psychiatric nursing; quality of life; caregiver burden; Mediation analysis

1. INTRODUCTION

A diverse range of neurodevelopmental disorders collectively referred to as autism spectrum disorder (ASD) are linked to restricted or repetitive behavioral patterns as well as variations in social communication and interaction. Over a person's life, the level of care needed fluctuates greatly. These various needs affect not only children with ASD but also the family members who manage everyday support, education, and medical care (World Health Organization 2025).

A person's perceived place in life in respect to their own objectives, aspirations, culture, and circumstances is captured by their quality of life (QoL). Physical health, psychological well-being, social interactions, and the environment are all included in the widely used World Health Organization framework (The WHOQOL Group, 1998).

In addition to that, these areas may be impacted by disjointed services, ongoing care obligations, financial strain, changed social engagement, and little time for relaxation and self-care for caregivers of children with ASD. According to an integrative study, caregivers of children with ASD often experience lower quality of life (QoL) in a number of areas compared to comparator populations (Turnage & Conner, 2022). Lower caregiver quality of life was also found in a recent meta-analysis and systematic review that compared autism-related caring to control groups (Castro et al., 2026).

Caregivers may find it easier to manage everyday difficulties if nursing interventions include structured instruction, coping strategies, real-world problem-solving, and psychological support. Several types of caregiver interventions have been assessed in earlier research, with differing results and modes of delivery. In a quasi-experimental study, Rayan and Ahmad (2016) found that parents of children with ASD had better psychological and social quality of life after a short mindfulness-based intervention.

When stress reduction was combined with a parent-implemented autism intervention, Weitlauf et al. (2020) found improvements in parental distress, although these improvements did not apply to all parent outcomes.

Kaçan et al. (2025) demonstrated the viability of structured caregiver education by evaluating an individual psychoeducational intervention for autistic caregivers in a different randomized study.
A caregiver-focused psychoeducational and psychotherapy post-diagnostic program was assessed in a more recent randomized trial conducted in the United Kingdom (Leadbitter et al., 2025). When taken as a whole, these studies highlight the significance of caregiver-facing services while emphasizing that the impact of interventions varies depending on the content, setting, and choice of outcome.

An additional issue concerns the relationship between caregiver burden and QoL. Burden reflects the practical and subjective demands of caregiving, whereas QoL is a broader multidimensional outcome; the two constructs are related but not interchangeable. A recent study of mothers of children with ASD found that greater caregiver burden was associated with lower maternal QoL after accounting for other measured factors (Al Awaji et al., 2026). Such associations are clinically meaningful but, by themselves, cannot establish that changes in burden transmit an intervention effect to QoL.
This report is a separate, outcome-focused analysis from a broader quasi-experimental investigation of a psychoeducational nursing program. To reduce overlap with a separate manuscript focused on caregiver burden, it emphasizes QoL change over three measurement occasions and presents burden–QoL correlations only as contextual, exploratory associations. Formal mediation analysis is outside the scope of this report.
The physical, psychological, social, and environmental quality of life may be adversely affected by the significant caring obligations that caregivers of children with autism spectrum disorder sometimes face. One significant element linked to these negative outcomes may be caregiver load. Although psycho-educational nursing interventions aim to enhance caregivers' knowledge, coping skills, and psychological well-being, little is known about the mechanisms driving gains in quality of life. Thus, investigating caregiver load as a possible mediator may shed more light on the connection between caregivers' quality of life and psycho-educational nursing interventions.

2. AIM AND RESEARCH HYPOTHESES

Aim. The goal of the current study was to assess how a psycho-educational nursing program affected the quality of life for caregivers of children with ASD. To determine whether caregiver burden mediated the relationship between the intervention and caregivers' quality of life, an exploratory post-hoc mediation analysis was also conducted.
H1. Caregivers in the intervention group will report higher overall QoL and better scores across the four QoL domains at post-intervention and follow-up than caregivers in the comparison group.
H2. Overall QoL and its four domains will improve across the three measurement occasions among caregivers receiving the program.
Exploratory question.
EQ1: At each measurement occasion in both groups, what is the direction and intensity of the relationship between overall quality of life and total caregiver burden?
EQ2: Is the relationship between caregivers' quality of life at follow-up and their involvement in the psycho-educational nursing program mediated by post-intervention caregiver burden?
3. SUBJECTS AND METHODS
3.1 Study design and setting
The effectiveness of a psycho-educational nursing program in improving caregiver quality of life among caregivers of children with ASD and the relationship between caregiver burden and quality of life were assessed using a controlled quasi-experimental design with pre-test, immediate post-test, and follow-up evaluations.
3.2 Participants and sampling
The available population consisted of 102 caregivers of children with ASD who visited the Neuropsychiatric Outpatient Clinic of Aswan University Hospital in Aswan, Egypt, during the study period. Ten caregivers were recruited for the pilot study and eliminated from the main study, leaving 71 eligible caregivers out of the required sample size of 81 caregivers based on **Thompson 2012** After one caregiver withdrew prior to group assignment, the final sample of 70 caregivers was divided evenly between the experimental group (n = 35) and control group (n = 35).
After the trial began, G* Power software was used to confirm that the planned sample size was adequate based on the observed effect size for the primary outcome (total caregiver quality of life score) and a two-sided significance level of.05. The observed between-group impact could be detected with good statistical power thanks to the obtained sample of 70 participants. Eligible caregivers were chosen from the accessible population using a non-probability purposive sampling technique. To help with program implementation, each group was further subdivided into five groups of seven caregivers. Participants had to be at least 18 years old, literate, and in charge of a child with ASD to be eligible.

Data Collection

Quality of Life Scale (QoLs):

Modified version of the **WHO (1996)** scale, which was used to assess the quality of life of caregivers of children with autism spectrum disorder. This scale consisted of 26 items and included four domain subscales: physical (7 items), psychological (8 items), social (3 items), and environmental (8 items).

Scoring system of QOLs.

* Less than 60 **%(1- <49 grade)** indicates: low quality of life.
* 60% - <75 % (**49- <58 grade)** indicates: moderate quality of life.
* ≥75% **(≥58 grade**) indicates: high quality of life.

Procedure:

From July to December 2025, the study was carried out at the Neuropsychiatric Outpatient Clinic of Aswan University Hospital in Aswan, Egypt. Seventy caregivers were divided into experimental and control groups (35 caregivers each) after baseline evaluation using the Quality of Life scale (QoL). While the control group continued to receive standard care, the experimental group received the psychoeducational nursing program. The intervention included eight sessions held twice a month for four months. Each of the five subgroups of seven caregivers in the experimental group attended every session. To examine changes in quality of life, the relationship between caregiver burden and quality of life, and the sustainability of intervention benefits over time, both groups were evaluated at baseline, immediately after the intervention, and throughout the six-month follow-up. A one-month period without intervention preceded the follow-up assessment.

Psycho-educational Nursing Program Phases

The three-phase program was created based on the needs of caregivers and pertinent research.

Phase of assessment:

After obtaining informed consent, individual interviews using a structured questionnaire and the QoL scale gathered baseline data on caregivers' sociodemographic characteristics, children's sociodemographic and clinical features, and caregiver quality of life.

Phase of implementation:

Over four months, the experimental group received eight sessions delivered to five subgroups of seven caregivers, twice a month. Through lectures, brainstorming, role-playing, modeling, demonstrations, and instructional materials including brochures, pictures, and videos, the program integrated educational, psychological, and practical components. When necessary, homework assignments were given.

Phase of evaluation:

To examine changes and their sustainability over time, caregiver quality of life and the relationship between caregiver burden and quality of life were measured in both groups at baseline, immediately after the intervention, and during the six-month follow-up.

Content validation: A panel of professionals reviewed the program for accuracy, relevance, and suitability for caregivers of children with ASD.

Psycho-educational nursing program: sessions and content

The psycho-educational nursing program is designed to enhance caregivers' quality of life by promoting psychological well-being, adaptive coping, and emotional balance.

Session 1: Introduction to the program and baseline assessment of caregivers' quality of life.

Session 2: Enhancing caregivers' understanding of ASD to improve confidence and daily functioning.

Session 3: Developing adaptive coping strategies to improve emotional well-being and resilience.

Session 4: Supporting caregivers in applying problem-solving and behavioral management strategies to improve daily life functioning.

Session 5: Training on deep breathing exercises to promote relaxation and psychological comfort.

Session 6: Practicing progressive muscle relaxation techniques to enhance emotional stability and reduce tension.

Session 7: Providing knowledge about quality of life, its dimensions and strategies to improve well-being, including self-care and social support.

Session 8: Training on meditation techniques to enhance life satisfaction, emotional regulation and overall quality of life.

Booklet

The researcher created an educational booklet with both theoretical and practical components based on the caregiver assessment, literature analysis, and interaction with psychiatric doctors. To accommodate caregivers with varying educational backgrounds, it was written in basic Arabic and featured vibrant visuals. The theoretical component presented general information on ASD, including its diagnosis, causes, types, symptoms, therapy,

and management. Techniques for meditation and relaxation were the main focus of the practical component.

Validity of Content

To guarantee language clarity and appropriateness for the intended audience, the study tools were translated into Arabic. Five Assiut University professionals in psychiatry and mental health nursing and medicine evaluated the tools for clarity, relevance, comprehensibility, and usefulness. Based on their comments, changes were made.

Pilot Research

Ten caregivers participated in a pilot study to evaluate the study's instruments and procedures' applicability, feasibility, and clarity. The primary study did not include these individuals. Seventy caregivers made up the final sample after the predetermined inclusion criteria were applied.

Statistical analysis

The provided summary tables include means and standard deviations; Friedman tests were used to evaluate within-group three-time point differences, and pairwise Wilcoxon signed-rank comparisons were then performed. Mann-Whitney U tests were used for between-group comparisons at specific time points. The statistical output must confirm the precise correlation estimator (Pearson or Spearman), assumptions, treatment of ties, missing values, and any multiplicity correction. The provided correlations are reported. The proper expression for published p =.000 entries is p <.001. If the analytical methodology confirms, all tests should be regarded as two-sided.

We computed the mean change from baseline to follow-up in each group and the arithmetic difference between those mean changes in order to quantify the descriptive separation of trajectories without assuming an unperformed significance test. These descriptive computations cannot be used in place of a difference-in-differences hypothesis test or an adjusted group-by-time model.

To determine if caregiver burden mediated the connection between the psycho-educational nursing program and caregivers' quality of life, an exploratory post-hoc mediation study was carried out. The independent variable (X) was group allocation (study group = 1; control group = 0), the mediator (M) was post-intervention caregiver burden, and the dependent variable (Y) was follow-up quality of life.

Covariates included quality-of-life scores and baseline caregiver load. The total effect (c), direct effect (c′), and indirect effect (a × b) were estimated using ordinary least-squares regression. 10,000 bootstrap resamples were used to assess the indirect effect and create 95% confidence ranges. When the bootstrap confidence interval for the indirect impact excluded zero, statistical evidence of mediation was deemed to be present.

Ethical Considerations

The Assiut University Faculty of Nursing's Ethics Unit granted ethical approval (approval no. 1120251112; May 25, 2025). The head of Aswan University Hospital granted permission. Participants were informed of the study's goal and their right to participate voluntarily before giving written and verbal consent. Throughout the study, confidentiality was maintained, and consistency was ensured by using the same inclusion criteria and data-gathering techniques.

4. RESULTS

4.1 Overall quality-of-life outcomes

At baseline, the mean reported overall QoL score was 41.46 ± 10.72 in the intervention group and 40.6 ± 10.09 in the comparison group (Mann–Whitney Z = 0.300, p = .764). Following the nursing program, the intervention-group mean increased to 53.97 ± 8.50, compared with 43.1 ± 9.89 in the comparison group (Z = 4.404, p < .001). At follow-up, the corresponding means were 65.09 ± 11.52 and 47.3 ± 9.64 (Z = 5.442, p < .001). Mean baseline-to-follow-up gains were 23.63 and 6.69 reported-score points, respectively, yielding a descriptive difference in gains of 16.94 points. This differential change has not yet been subjected to a formal interaction test.

Within-group Friedman statistics for overall QoL were 70.00 and 61.43 in the intervention and comparison groups, respectively (both p < .001). Post-hoc Wilcoxon comparisons of baseline versus post-intervention, baseline versus follow-up, and post-intervention versus follow-up were each reported as p < .001 in both groups. Thus, improvement was also observed in the comparison group, although its mean change was substantially smaller.

4.2 Changes in physical, psychological, social, and environmental QoL

All four domains increased over time in the intervention group **(Table 1).** From baseline to follow-up, the intervention-group means changed by +5.37 points in physical QoL, +8.20 in psychological QoL, +2.94 in social QoL, and +7.09 in environmental QoL. Corresponding changes in the comparison group were +1.28, +2.17, +0.94, and +2.11 points. The intervention group had higher mean scores for all four domains at post-intervention and follow-up; between-group Mann–Whitney tests for every domain at those two occasions had p < .001 **(Table 2).** The baseline between-group comparisons were nonsignificant for physical (p = .807), psychological (p = .686),

social (p = .633), and environmental QoL (p = .568). Such nonsignificant tests should not be interpreted as proof of baseline equivalence. The within-group Friedman statistics and the detailed unadjusted Wilcoxon contrasts are documented in Tables 2 and S1.

4.3 Relationships between caregiver burden and QoL

The supplied correlations indicate strong negative contemporaneous associations between caregiver burden and total QoL at all assessments **(Table 3).** In the intervention group, coefficients were −.852 at baseline, −.834 post-intervention, and −.799 at follow-up, with p < .001 throughout. In the comparison group, the corresponding coefficients were −.888, −.885, and −.904 (all p < .001). These findings indicate that higher burden scores tended to accompany lower QoL scores. They do not quantify change-to-change associations, establish directionality, or provide evidence for an indirect intervention effect. No test comparing correlation magnitudes between groups or across occasions was supplied.

4.4 Exploratory Mediation Analysis of Caregiver Burden

The psycho-educational nursing program was significantly linked to less caregiver strain, as shown in Table X, according to the exploratory mediation analysis (path a: B = −13.898, p < 0.001). Additionally, a lower quality of life was significantly associated with higher caregiver burden (path b: B = −0.378, p = 0.003).

The program's overall impact on caregivers' quality of life was statistically significant (B = 17.393, p < 0.001). The direct effect was still statistically significant after controlling for baseline scores and caregiver load (B = 12.141, p < 0.001).

About 30.2% of the overall effect was accounted for by the estimated positive indirect effect through caregiver burden (B = 5.252). Nevertheless, the indirect effect was not statistically significant because the 95% bootstrap confidence interval (−0.087 to 9.545) encompassed zero. Therefore, although caregiver burden was negatively associated with quality of life, the exploratory mediation analysis did not provide sufficient statistical evidence to establish caregiver burden as a significant mediator of the program's effect on quality of life.

Table 1. Reported QoL scores by group and study occasion

Domain	Group	Baseline mean ± SD	Post mean ± SD	Follow-up mean ± SD	Baseline to follow-up
Physical	*Intervention*	9.88 ± 2.90	13.28 ± 2.25	15.25 ± 2.38	+5.37
	control	9.97 ± 2.72	10.40 ± 2.72	11.25 ± 2.84	+1.28
Psychological	*Intervention*	14.22 ± 3.63	18.51 ± 3.04	22.42 ± 4.07	+8.20
	control	14.06 ± 3.83	14.80 ± 3.48	16.22 ± 3.30	+2.17
Social	*Intervention*	4.34 ± 1.51	5.77 ± 1.19	7.28 ± 1.80	+2.94
	control	4.20 ± 1.43	4.42 ± 1.39	5.14 ± 1.30	+0.94
Environmental	*Intervention*	13.00 ± 3.41	16.45 ± 2.91	20.08 ± 3.72	+7.08
	control	12.57 ± 2.78	13.37 ± 2.80	14.68 ± 2.80	+2.11
Overall QoL	*Intervention*	41.46 ± 10.72	53.9 ± 8.50	65.1 ± 11.52	+23.7
	control	40.63 ± 10.09	43.1 ± 9.89	47.3 ± 9.64	+6.7

Table 2. Reported between-group and within-group omnibus tests for QoL

Domain	Baseline MW Z (p)	Post MW Z (p)	Follow-up MW Z (p)	Intervention Friedman (p)	Comparison Friedman (p)
Physical	0.244 (.807)	4.148 (<.001)	5.317 (<.001)	59.82 (<.001)	31.47 (<.001)
Psychological	0.404 (.686)	4.278 (<.001)	5.368 (<.001)	67.61 (<.001)	37.27 (<.001)
Social	0.477 (.633)	3.951 (<.001)	4.640 (<.001)	62.19 (<.001)	38.69 (<.001)
Environmental	0.570 (.568)	4.138 (<.001)	5.256 (<.001)	67.51 (<.001)	51.80 (<.001)
Overall QoL	0.300 (.764)	4.404 (<.001)	5.442 (<.001)	70.00 (<.001)	61.43 (<.001)

Table 3. Association between caregiver burden and overall QoL

Group	Baseline r	p	Post r	p	Follow-up r	p
Intervention (n = 35)	−0.852	<.001	−0.834	<.001	−0.799	<.001
Control(n = 35)	−0.888	<.001	−0.885	<.001	−0.904	<.001

Table 4. Exploratory mediation analysis of caregiver burden in the effect of the psycho-educational nursing program on caregivers' quality of life (N = 70)

Effect / pathway	B	SE	p-value	95% CI
Path a: Program → caregiver burden	−13.898	1.270	<0.001	−16.434 to −11.362
Path b: Caregiver burden → quality of life	−0.378	0.123	0.003	−0.624 to −0.132
Direct effect (c′)	12.141	2.132	<0.001	7.883 to 16.398
Indirect effect (a × b)	5.252	2.518*	—	−0.087 to 9.545*
Total effect (c)	17.393	1.349	<0.001	14.699 to 20.087

Estimated proportion mediated (point estimate): 30.2%.

Note. B stands for unstandardized regression coefficient, SE for standard error, and CI for confidence interval. Group codes are 0 for control and 1 for study. The outcome was follow-up quality of life, and the mediator was post-intervention caregiver burden. Baseline caregiver load and baseline quality of life were taken into account in all models. For a, b, direct, and total effects, regression-based SEs, p-values, and 95% CIs are presented. * 10,000 stratified bootstrap resamples were used to assess the indirect-effect SE and 95% percentile CI. Because zero was included in the indirect effect's 95% confidence interval, it was not statistically significant.

SUPPLEMENTARY TABLE S1. Reported Wilcoxon signed-rank pairwise comparisons (unadjusted)

Domain	Group	Pre–post Z (p)	Pre–follow-up Z (p)	Post–follow-up Z (p)
Physical	Intervention	4.881 (<.001)	5.114 (<.001)	4.150 (<.001)
Physical	control	2.207 (.027)	4.453 (<.001)	4.008 (<.001)
Psychological	Intervention	5.187 (<.001)	5.199 (<.001)	5.042 (<.001)
Psychological	control	2.015 (.044)	4.485 (<.001)	4.799 (<.001)
Social	Intervention	4.8145 (<.001)	5.190 (<.001)	4.435 (<.001)
Social	control	1.356 (.175)	4.921 (<.001)	4.300 (<.001)
Environmental	Intervention	5.039 (<.001)	5.189 (<.001)	4.957 (<.001)
Environmental	control	3.155 (.002)	4.975 (<.001)	4.231 (<.001)
Overall QoL	Intervention	5.165 (<.001)	5.163 (<.001)	5.162 (<.001)
Overall QoL	control	3.928 (<.001)	4.169 (<.001)	4.193 (<.001)

5. DISCUSSION

This outcome-focused report shows that caregivers who took part in a psychoeducational nursing program reported significantly higher overall quality of life (QoL) and higher scores across all four QoL domains. Based on

the reported tests, the intervention group's distribution of QoL scores was comparable to that of the comparison group at baseline, but they achieved higher ratings at follow-up and post-intervention. Between baseline and follow-up, the descriptive mean improvement in overall quality of life was 23.7 points for intervention individuals and 6.7 points for comparison participants. Crucially, these analyses do not yet provide a statistical test of divergent longitudinal trajectories; instead, they show time-specific group differences and within-group trends.

The general justification for caregiver-oriented intervention in ASD is in line with the observed pattern. Support programs may address informational, emotional, social, or practical sources of difficulty that child-centered outcomes alone do not capture, since caregiver quality of life is multifaceted. Turnage and Conner's (2022) integrative review found that parents of children with ASD frequently struggle with poor quality of life (QoL), and Castro et al.'s (2026) extensive data synthesis came to a similar conclusion. While pointing out significant risks of bias in the included evidence, a 2026 systematic review also compared caregiver QoL outcomes across respite-care and parent-training trials (Takatani et al., 2026).

The present report adds a three-occasion assessment of caregiver QoL in a two-group nursing-intervention context. Improvements in the social and psychological domains are especially pertinent to earlier research on caregiver interventions. After using a mindfulness-based approach, Rayan and Ahmad (2016) saw improvements in these two QoL dimensions. Although mindfulness training and psychoeducational nursing programs differ, both can address uncertainties linked to caregiving, coping mechanisms, and opportunities for social engagement. Until the provided content, dosage, and attendance records are confirmed, the current findings should not be linked to particular program components.

Weitlauf et al. (2020) similarly found that parent-directed stress-reduction support can influence selected indicators of parental distress, while emphasizing that not every parent-reported outcome necessarily changes. One notable characteristic was the enhancement observed in the comparison group. Adaptation over time, regression to the mean, testing effects, informal learning, access to usual care, or other secular influences may all be evident. Neither explanation can be verified by examining the aggregate tables. Consequently, the analysis of group, time, and their interaction would be employed to more directly estimate the effects of longitudinal interventions. This analysis should ideally account for baseline quality of life and appropriately manage recurrent observations and missingness. Additionally, the design should explicitly consider group allocation and potential baseline confounding.

Without re-reporting burden outcome trajectories, the current associations provide therapeutically significant context. Strong inverse relationships showed that participants with more burden tended to report worse QoL in both groups at every evaluation. This outcome supports the idea that burden and quality of life are distinct entities that overlap in lived experience. It is also similar to the recent discovery by Al Awaji et al. (2026) that moms of children with ASD had lower quality of life when they had a greater caregiving burden. However, cross-sectional correlations at comparable timepoints cannot determine whether increases in burden preceded or explained changes in QoL. As a result, they cannot serve as concrete proof of a mediating mechanism.

The integration of caregiver quality of life assessment into family-centered psychiatric and mental health nursing is supported by these findings. Caregivers' psychological well-being, social functioning, physical health, and environmental conditions can all be assessed in addition to their knowledge or load. This suggestion aligns with the WHO's (2025) stance that inclusive community services and support for caregivers should be provided alongside care and assistance for individuals with autism. The specific study context, the verified meaning of the QoL ratings, and recruiting criteria will all affect how broadly the current findings may be applied.

Also, the current study showed that among caregivers of children with autism spectrum disorder, the psycho-educational nursing program was linked to notable gains in quality of life and decreases in caregiver burden. These results imply that by addressing the practical and psychological difficulties of providing care, systematic psycho-educational nursing treatments may improve the wellbeing of caregivers. These results are in line with those of Kaçan et al. (2025), who found that caregivers of autistic children saw a significant decrease in caregiver burden after receiving an individual psychoeducational intervention. Leadbitter et al. (2025) also showed that a structured psychoeducational and psychotherapy intervention improved the mental health and well-being of caregivers.

Additionally, the current study found a significant negative correlation between caregiver load and quality of life, suggesting that caregivers with higher caregiving burdens typically reported lower quality of life. Marsack and Samuel (2017), who found a negative correlation between caregiver load and quality of life among parents of adults with autism spectrum disorder, corroborate this conclusion. Additionally, their research showed that this association was partially mediated by informal social support, underscoring the potential significance of psychological resources in the wellbeing of caregivers.

The exploratory mediation study failed to find a statistically significant indirect effect of the intervention through caregiver burden, despite the strong correlation between caregiver burden and quality of life. Despite making up about 30.2% of the overall effect, the estimated indirect effect's bootstrap confidence interval encompassed

zero

This result implies that caregiver burden reduction alone may not be the only factor causing increases in caregivers' quality of life. Improvements in quality of life may also be influenced by other elements as coping mechanisms, psychological adjustment, and perceived social support. In this regard, Dardas and Ahmad (2015) showed that among parents of autistic children, the relationship between parental stress and quality of life may be mediated by particular coping techniques.

The current study's lack of a statistically significant indirect effect could also be attributed to the small sample size, which might have reduced the accuracy of the mediation estimations. Furthermore, while interpreting these results, the post-hoc exploratory character of the analysis and the potential for unmeasured mediator-outcome confounding should be taken into account.

Overall, the results show that the psycho-educational nursing program and caregivers' quality of life are positively correlated, but they also show that more research is necessary to fully understand the psychological and social factors that underlie these gains.

6. STRENGTHS AND LIMITATIONS

The use of a control group, repeated evaluations at pre-intervention, post-intervention, and follow-up, and the examination of numerous quality-of-life areas are some of the study's strengths. Additionally, the exploratory mediation analysis shed more light on the possible contribution of caregiver strain to the association between quality of life and the psycho-educational nursing program.

However, the precision of the mediation estimates and the generalizability of the results may be limited by the comparatively small sample size. Furthermore, as the mediation analysis was done after the event, the observed relationships might have been impacted by unmeasured confounding variables. As a result, care should be taken while interpreting the mediation results.

7. CONCLUSION

In this quasi-experimental study, caregivers in the psychoeducational nursing program group outperformed the comparison group at both the post-intervention and follow-up assessments, showing notable improvements in overall quality of life and its physical, psychological, social, and environmental domains. Overall quality of life was consistently and negatively correlated with caregiver burden in both groups. Nevertheless, the exploratory mediation analysis found no statistically significant indirect effect of the program on quality of life through caregiver strain. These results encourage more research on caregiver-centered nursing interventions. However, before firm judgments about the effectiveness of interventions and underlying mechanisms can be made, more thorough longitudinal study and validated scoring methods are required.

Recommendations

The following suggestions are put forth in light of the study's findings:

1. To improve the quality of life for caregivers of children with autism spectrum disorder, psycho-educational nursing programs should be incorporated into supportive care services.
2. To enable early identification of caregivers in need of extra support, nursing practice should regularly measure caregiver burden and quality of life.
3. Through tailored education and psychosocial support, nursing treatments should meet the physical, psychological, social, and environmental needs of caregivers.
4. To further assess the efficacy of interventions, future research should use larger samples, verified scoring methods, and strict longitudinal designs.
5. To better explain improvements in caregiver load, coping mechanisms, and perceived social support, more research is advised.

Abbreviations

ASD Autism Spectrum Disorder
WHO World Health Oragnization
QoL Quality of Life
SPSS Statistical Package for Social Sciences

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Declarations

Ethics approval and consent to participate: Ethical approval was obtained from the Faculty of Nursing, Assiut

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References

1. Al Awaji, N. N., Aldursuni, A. A., Almutairi, F. M., Alanazi, A. M., Alanazi, R. A., Alhurayyis, B. A., Alwajee, R. A., Alghamdi, A., & Alabdulkarim, S. (2026). Quality of life among Saudi mothers of children with autism spectrum disorder: Associations with caregiver burden, psychological distress, financial experiences, and post-diagnosis service pathway clarity. Healthcare, 14(17), 2847. https://doi.org/10.3390/healthcare14172847
2. Castro, K., Duarte, C. K., Silva, E., Hoffmann, L., Borchardt, J. L., Pohl, L., Luçardo, J., Lapschies, M., Cascaes, A. M., Freitas-Vilela, A. A., Cenci, A., & Vaz, J. S. (2026). Quality of life in autism: A systematic review and meta-analysis of patients and caregivers. Autism Research, 19(10), e70348. https://doi.org/10.1002/aur.70348
3. Dardas, L. A., & Ahmad, M. M. (2015). Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder. Stress and Health, 31(1), 5–12.
4. Des Jarlais, D. C., Lyles, C., Crepaz, N., & the TREND Group. (2004). Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: The TREND statement. American Journal of Public Health, 94(3), 361–366. https://doi.org/10.2105/AJPH.94.3.361
5. Kaçan, H., Gümüş, F., & Değer, V. B. (2025). Effect of individual psychoeducation for primary caregivers of children with autism on internalized stigma and care burden: A randomized controlled trial. International Journal of Developmental Disabilities, 71(2), 296–305. https://doi.org/10.1080/20473869.2023.2231233
6. Leadbitter, K., Langhorne, S., Smallman, R., Chu, P., Ellis, C., Harrison, L., Hutton, T., Butter, C., Goldie, C., James, K., Hackett, L., Dunkerley, A., Bee, P., Shields, G., Davies, L., Emsley, R., & Green, J. (2025). Clinical effectiveness of an online psychoeducational and psychotherapeutic programme for caregivers of children newly diagnosed as autistic: A parallel, assessor-masked, randomised controlled trial in the UK (REACH-ASD). The Lancet Psychiatry, 12(4), 289–302. https://doi.org/10.1016/S2215-0366(25)00036-7
7. Lee, H., Cashin, A. G., Lamb, S. E., et al. (2021). A guideline for reporting mediation analyses of randomized trials and observational studies: The AGReMA Statement. JAMA, 326(11), 1045–1056.
8. Marsack, C. N., & Samuel, P. S. (2017). Mediating effects of social support on quality of life for parents of adults with autism. Journal of Autism and Developmental Disorders, 47(8), 2378–2389.
9. Rayan, A., & Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. Research in Developmental Disabilities, 55, 185–196. https://doi.org/10.1016/j.ridd.2016.04.002
10. Takatani, S., Nakaguchi, H., Honda, J., Soejima, T., Kitao, M., Lin, Q., & Nishimura, N. (2026). Effects of respite care on the quality of life of caregivers of children with autism spectrum disorder in comparison with parent training: A systematic review and meta-analysis. Cureus, 18(1), e101377. https://doi.org/10.7759/cureus.101377
11. The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychological Medicine, 28(3), 551–558. https://doi.org/10.1017/S0033291798006667
12. Thompson, K. (2012): Sampling' (3rd ed), John Wiley & Sons, p59 60.
13. Turnage, D., & Conner, N. (2022). Quality of life of parents of children with autism spectrum disorder: An integrative literature review. Journal for Specialists in Pediatric Nursing, 27(4), e12391. https://doi.org/10.1111/jspn.12391
14. Weitlauf, A. S., Broderick, N., Stainbrook, J. A., Taylor, J. L., Herrington, C. G., Nicholson, A. G., Santulli, M., Dykens, E. M., Juárez, A. P., & Warren, Z. E. (2020). Mindfulness-based stress reduction for parents implementing early intervention for autism: An RCT. Pediatrics, 145(Suppl 1), S81–S92. https://doi.org/10.1542/peds.2019-1895K
15. World Health Organization (WHO), (1996): WHOQOL: Measuring quality of life. Available at. https://www.who.int\healthinfo\survey\whoqol quality of life\en; Accessed on 9/11/2021.
16. World Health Organization. (2025, September 17). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders