

Evaluation of a new quality of life instrument for children with infantile esotropia before and after strabismus surgery

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ABSTRACT

Introduction: Infantile esotropia impacts the quality of life (QOL) of children and their families. In addition to surgical treatment, QOL assessment is an important tool for evaluating treatment success. Thus, this study aimed to assess QOL before and after strabismus surgery using the newly developed Infantile Esotropia Quality of Life Questionnaire (IEQ).

Materials and Methods: A prospective study was conducted from September 2018 to June 2019 at the Ophthalmology Clinic, Hospital Pakar Universiti Sains Malaysia. Children aged 5-17 years diagnosed with infantile esotropia were recruited. QOL and clinical examinations were measured pre- and post-strabismus surgery. The comparison of QOL scores before and after surgery was analysed using the paired t-test.

Results: A total of 126 children participated in the study: 63 aged 5-8 years and 63 aged 9-17 years. Strabismus surgery significantly improved the QOL scores in both age groups. In the younger group, scores increased from 68.00 preoperatively to 89.36 postoperatively ($P < 0.001$), while in the older group, scores increased from 78.07 to 90.21 ($P < 0.001$). No significant association was found between QOL scores and gender, angle of deviation, or stereopsis ($P > 0.05$).

Conclusion: Strabismus surgery significantly improved the quality of life in children with infantile esotropia in both age groups. The IEQ tool is a useful instrument for assessing functional and psychosocial outcomes in this population. Gender, ocular deviation, and stereopsis did not appear to influence QOL outcomes.

KEYWORDS:

Children, infantile esotropia, quality of life, strabismus surgery

INTRODUCTION

Infantile esotropia affects the functional and psychological quality of life (QOL) of children and their families.¹ It is defined as an early-onset inwards deviation of the eyes that is usually detected within the first six months of life. Studies

and populations have different rates of infantile esotropia. One of the most prevalent types of early-onset strabismus is thought to affect approximately 1 in 100 to 500 live infants.² ³ Certain demographic groups, such as those with a family history of strabismus or related neurodevelopmental disorders, frequently report higher prevalence rates.^{2,3} In addition to impairing the development of binocular vision and causing amblyopia, this disease often causes social stigma, low self-esteem, and stressed parent-child relationships because of apparent misalignment and related functional deficiencies.^{4,6}

The main treatment for restoring ocular alignment is surgical correction, which often involves bilateral medial rectus recession. The necessity of assessing surgical outcomes not only in terms of alignment success but also with a focus on psychosocial and functional QOL changes.⁷ Surgical correction provides major psychosocial advantages. For example, numerous studies have shown that children who have undergone surgery experience less social anxiety, higher self-esteem, and improved social interactions, whereas parents experience less worry and are more satisfied with their child's looks and social skills.^{4,7} Additionally, functional results such as stereopsis and binocular visual function increase, especially if surgery is performed early (before 12-24 months of age).^{3,8}

Children with strabismus have poorer QOL than visually normal children do, as demonstrated by several studies that used validated questionnaires, including the Hospital Anxiety and Depression Scale (HADS), the 25-item National Eye Institute Visual Functioning Questionnaire (NEI-VFQ-25), the Pediatric Quality of Life Inventory (PedsQL), the Intermittent Exotropia Questionnaire (IXTQ) and, more recently, the Pediatric Eye Questionnaire (PedEyeQ).⁸⁻¹⁵ However, these questionnaires were not specifically designed for children with infantile esotropia or for evaluating eye-related QOL (i.e., HADS, PedsQL). Therefore, this study aimed to assess the impact of surgery on QOL among Malaysian children with infantile esotropia by using the newly developed Infantile Esotropia Questionnaire (IEQ).¹⁶ Furthermore, the study also aimed to investigate whether sex, ocular deviation, and stereopsis have any influence on QOL.

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MATERIALS AND METHODS

This prospective study was conducted at Hospital Pakar Universiti Sains Malaysia (HPUSM) from September 2018 to June 2019. Children with infantile esotropia aged 5–17 years were recruited.

All registered children with infantile esotropia during the study period were screened according to the study criteria. All the children who were screened had been diagnosed with infantile esotropia greater than 40 prism dioptres from 5–17 years of age. The children were excluded from the study if they had other types of strabismus (e.g., Duane syndrome), secondary causes of esotropia (e.g., trauma and sensory), deprivation due to congenital cataracts, corneal opacity, optic atrophy, and macular scars), organic eye diseases, neurological disorders, facial, ocular or cosmetic abnormalities, syndromic or chromosomal anomalies, known intellectual disability, abducens nerve palsy or ocular surgery. Parents with known intellectual disability and psychological illnesses were also excluded. Sixty-three children with infantile esotropia aged 5–8 years and 63 children with infantile esotropia aged 9–17 years were recruited from the Ophthalmology Clinic, HPUSM.

Participants were recruited using a consecutive sampling method, whereby all children with infantile esotropia who attended the Ophthalmology Clinic, Hospital Pakar Universiti Sains Malaysia during the study period and met the inclusion criteria were invited to participate. The sample was subsequently divided into two age groups (5–8 years and 9–17 years) in accordance with the structure of the Infantile Esotropia Quality of Life Questionnaire (IEQ), which comprises age-specific validated child versions. The 5–8-year-old version contains items tailored to early childhood cognitive and emotional development, whereas the 9–17-year-old version includes psychosocial and functional items appropriate for older children and adolescents. This age-based grouping ensured that each participant completed the questionnaire aligned with their developmental stage.

Detailed demographic data, including birth history, onset of esotropia, visual performance, family history of esotropia, and history of prematurity, were obtained. The children underwent a complete clinical assessment, which involved visual acuity tests, assessments for stereopsis using Frisby Stereopsis test, cover tests, tests for extraocular motility, examinations of their pupils, and convergence tests. The children were also examined carefully for signs of anomalies in the anterior and posterior segments. An identified paediatric ophthalmologist examined all the patients who had been recruited, and a trained senior optometrist performed cycloplegic refraction assessments in all patients.

QOL was measured using the newly developed questionnaire, IEQ (Appendix I) (16). The IEQ is a valid and reliable QOL questionnaire for children with infantile esotropia and their proxy/parents. It consists of child (5–8 years old), child (9–17 years old), and proxy/parent questionnaires. The child 5–8 years old version was constructed with two subthemes: social (4 items) and emotional (6 items). The 9–17-year-old version has two subthemes: psychosocial (5 items) and functional (10 items). The proxy/parent version has four subthemes: parents' emotional problems (9 items), children's social

problems (4 items), children's emotional problems (6 items) and children's functional problems (6 items).¹⁶

All the items in the IEQ had satisfactory content evidence (scale level-content validity index, averaging method > 0.8) and good response process evidence (scale-level face validity index, averaging method >0.8). All questionnaires were found to have high internal consistency (Cronbach's alpha: 0.84–0.87 (5–8 years old), 0.83–0.86 (9–17 years old), and 0.85–0.89 (proxy/parent); acceptable intraclass correlation coefficients ($r=0.497$, $p<0.01$ (5–8 years old), $r=0.728$, $p<0.01$ (9–17 years old) and $r=0.746$, $p<0.01$ (proxy/parents); and significant correlations with the Intermittent Exotropia Questionnaire ($r=0.780$, $p<0.01$ (5–8 years old), $r=0.602$, $p<0.01$ (9–17 years old) and $r=0.444$, $p<0.01$ (proxy/parent).¹⁶

We interviewed children aged 5–8 years to answer the IEQ-5–8-year-old questionnaire on a 3-point scale. Responses for the 3-point scale included “a lot,” “sometimes,” and “not at all”. A higher score indicates a higher QOL. The maximum possible overall score was 100 (best QOL), and the minimum was 0 (QOL). For children aged 5 to 8 years, the questionnaires were administered by reading the instructions and each item to the young child word by word. The interviewer read aloud each question and the response options to the children. The children were requested to circle one response per question. A key card with three faces was used to help the child answer the questions. The intonation was kept neutral during the interview to avoid suggesting an answer to the children when the questions were read aloud.

Older children aged 9–17 years completed the 9–17-year-old child questionnaire with the assistance of a trained interviewer. The responses for the 5-point scale Child 9–17 years old questionnaire and Proxy/parents questionnaire included “Never,” “Almost never,” “Sometimes,” “Often,” and “Almost always”. The higher the score, the greater the QOL. The maximum possible overall score was 100 (QOL), and the minimum was 0 (worst QOL).

The child should be facing away from the parent when the questionnaire is administered to the child. The question was not interpreted if the child or parent did not understand the meaning of the questions. The question was repeated verbatim. They were asked to answer this question according to their understanding. They were instructed to choose the closest response to how they felt.

To minimise interviewer-related bias, all questionnaire sessions were conducted by the same trained interviewer throughout the entire study. This approach ensured consistency in the delivery of questions, neutrality of tone, and adherence to the standardised IEQ administration protocol, thereby preventing inter-interviewer variability.

All recruited children underwent strabismus surgery at HPUSM during the study period. Three months after surgery, the children were asked to complete the same questionnaires according to their age groups. This evaluation was conducted to determine the effect of strabismus surgery on children's QOL. They were assessed for the same clinical examination as before the strabismus surgery.

Table I: Socio-demographic and clinical characteristics (N=126)

Socio-demographic and clinical data	Infantile esotropia n (%)
Age (years old)	
5 to 8	63 (50.0)
9 to 17	63 (50.0)
Gender	
Female	63 (50.0)
Male	63 (50.0)
Race	
Malay	126 (100.0)
Best corrected visual acuity	
6/6-6/15	97 (77.0)
6/18-6/60	21 (16.7)
Worse than 6/60	8 (6.3)
Stereopsis	
Present	31 (24.6)
Absent	95 (75.4)
Distant angle of deviation (Prism Diopter)	
40-50	76 (60.3)
More than 50	50 (39.7)
Near angle of deviation (Prism Diopter)	
40-50	72 (57.1)
More than 50	54 (42.9)
Refractive error (Spherical equivalent) Diopter	
Low hyperopia (Less than +2.00)	126 (100.0)

Table II: Comparison of quality of life using the Infantile Esotropia Questionnaire in children before and after surgery

Variable	Mean total score (SD)		Mean difference (95 % CI)	t-statistics (df)	p-value*
	Pre	Post			
Children aged 5 to 8 years old Mean total score	68.00 (23.19)	89.36 (11.73)	-21.36 (-28.62, -14.09)	-5.972 (34)	< 0.001
Children aged 9 to 17 years old Mean total score	78.07 (16.82)	90.21 (9.28)	-12.14 (-16.759, -7.527)	-5.346 (34)	< 0.001

**p < 0.05 is considered statistically significant (paired sample t-test)

Table III: Factors associated with quality of life in children in this study

Variables	Simple linear regression		Multiple linear regression		
	Crude ba (95% CI)	p-value	Adj. bb (95% CI)	t-stat	p-value
Child 5-8 years old					
Gender	-4.24 (-16.24, 7.75)	0.482			
Angle of deviation					
Distant	-0.37 (-0.70, 0.04)	0.028	-0.79 (-1.71, 0.13)	-1.73	0.089
Near	-0.31 (-0.66, -0.05)	0.090			
Stereopsis	-4.80 (-0.13, 0.16)	0.480			
Child 9-17 years old					
Gender	4.83 (-3.34, 13.02)	0.243			
Angle of deviation					
Distant	0.22 (-0.01, 0.45)	0.059			
Near	0.21 (-0.04, 0.46)	0.091			
Stereopsis	0.79 (-9.07, 10.64)	0.874			

a Crude regression coefficient

b Adjusted regression coefficient

R²= 7.7% (Child 5-8 years)

Stepwise, backward and forward multiple linear regression method applied.

Model assumptions are fulfilled.

There were no interactions amongst independent variables. No multicollinearity detected.

Final model equation: Mean total score = 95.46 -0.37*Distant angle of deviation (Child 5-8 years)

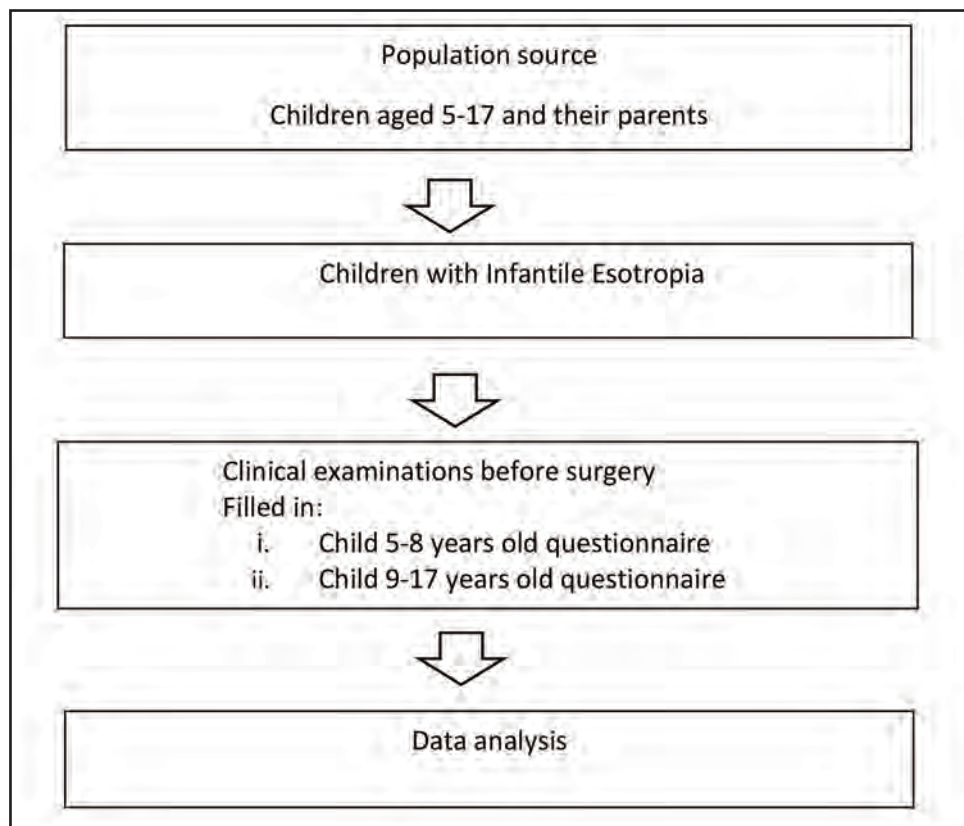


Fig. 1: Flowchart of the study – Evaluation of quality of life for children with infantile esotropia aged 5-17 years old before and after surgery

Statistical analysis and data collection

Data from case report forms were entered into the Statistical Package for the Social Sciences for Windows version 24.0 (SPSS Inc., Chicago, IL, USA). The normal distributions of the numerical variables were checked via the Kolmogorov–Smirnov test and a histogram. Descriptive statistics were used to summarize the sociodemographic characteristics of the participants. The data are presented as frequencies, means, standard deviations, and percentages. The QOL of the children with infantile esotropia before and after strabismus surgery was compared via paired t tests. The flowchart of the study is summarized in Figure 1.

Ethics approval

The study was conducted following the Declaration of Helsinki. It was approved by the Human Research Ethics Committee of Universiti Sains Malaysia (USM/JEPeM/17010070) and the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (NMRR-16-2555-32051). Written consent was obtained from the parents/guardians, and verbal assent was given by the children.

RESULTS

A total of 126 children with infantile esotropia completed the study. Gender was equally distributed between males (50.0%,

63 children) and females (50.0%, 63 children). All the children were Malay (100.0%, 63 children). The ages were equally distributed between 5 to 7 years (50.0%, 63 children) and 9 to 17 years (50.0%, 63 children). Most children (77.0%, 97 children) had good visual acuity better than 6/18. However, most of the children had an absence of binocular vision (75.4%, 95 children). The majority of them had an angle of deviation between 40 and 50 PD at distant (60.3%, 76 children) and near (57.1%, 72 children) distances. All the children (100%, 126 children) presented with low hyperopia of less than +2.00 diopters (Table I).

The difference between the means (SDs) before and after surgery was statistically significant for children aged 5--8 years [68.00 (23.19) vs. 89.36 (11.73), $P < 0.001$] and children aged 9--17 years [78.07 (16.82) vs. 90.21 (9.28), $P < 0.001$] (Table II).

There was no significant association between the mean total scores of the infantile esotropia questionnaire and any of the factors analysed from the multiple linear regression analysis for the 5–8 year age group. For the 9–17-year-old group, there was no significant association between the mean total score and any of the factors analysed via simple linear regression. Thus, multiple linear regression analysis was not performed (Table III).

DISCUSSION

Numerous studies have consistently demonstrated that strabismus surgery significantly enhances the quality of life (QOL) of affected children and their families. Children with strabismus and their parents report fewer psychological difficulties, reduced anxiety, and improved overall well-being following successful surgical correction.¹⁷ Although children with strabismus generally have lower preoperative QOL scores compared to visually normal person, postoperative assessments reveal significant improvements in psychosocial functioning, reflecting the positive impact of surgical intervention. Patient-reported outcomes among Chinese children with intermittent exotropia further support these findings, showing significant postoperative gains in disease-specific QOL as well as reductions in anxiety and depression symptoms.¹⁸ These results highlight the crucial role of strabismus surgery in restoring not only ocular alignment but also psychological and social well-being for both children and their families.

In the present study, a significant improvement was observed in the mean total QOL scores on both versions of the IEQ following strabismus surgery ($p < 0.001$). Among children aged 5–8 years, the mean total score increased from 68.00 (95% CI: 60.03–75.97) preoperatively to 89.37 (95% CI: 85.33–93.39) postoperatively. Similarly, in children aged 9–17 years, the mean total score improved from 78.07 (95% CI: 72.30–83.85) before surgery to 90.21 (95% CI: 87.03–93.40) after surgery. These results clearly indicate that strabismus surgery led to a significant improvement in the quality of life of children with infantile esotropia across both age groups.

The findings of the present study are consistent with previous research demonstrating that strabismus surgery significantly improves the quality of life (QOL) of children with ocular misalignment. Using the Infantile Esotropia Questionnaire (IEQ), our study showed postoperative improvements across social, emotional, and functional domains, like outcomes reported in studies employing other validated instruments such as the Intermittent Exotropia Questionnaire (IXTQ). These results support the view that QOL enhancement following strabismus correction is not questionnaire-specific but reflects genuine improvements in psychosocial well-being.⁴

Comparable studies have also reported significant postoperative gains in children's QOL. Tan and Shatriah observed increased QOL scores in children aged five to eight years, and similar improvements were found in older children aged nine to seventeen years.⁴ Several other studies evaluating the general effects of strabismus surgery have reported consistent results, showing that surgical correction leads to significant improvements in both functional and psychosocial domains.^{18–22} Archer et al. also reported significant positive changes in social, emotional, and functional measures of health status following strabismus surgery in children, as assessed by the modified RAND Health Insurance Study QOL questionnaire.²¹ These findings are in agreement with our results, further confirming that surgical correction benefits multiple psychosocial dimensions in paediatric strabismus patients.

In addition to visual and functional improvements, several studies have highlighted the psychological benefits of strabismus surgery. Nelson et al. found that surgical correction enhanced patients' self-confidence, self-esteem, and perceived intelligence.²³ Such findings align with our observation that ocular realignment contributes positively to self-image and social interaction among children. A similar conclusion was reported by Wang et al., who found significant increases in Child IXTQ scores following corrective surgery for intermittent exotropia.²⁴ When compared with adults, as reported by Glasman et al., children in our cohort demonstrated higher preoperative QOL scores.²² This difference may reflect age-related variations in emotional awareness and perception of social stigma.

Despite the overall improvement in QOL among children following strabismus surgery, our study found no significant association between the mean total IEQ scores and several clinical or demographic factors, namely gender, angle of deviation, and stereopsis, in both child age groups (5–8 years and 9–17 years). These results differ from those of previous studies that identified specific factors influencing postoperative QOL among strabismus patients.

No significant association was found between QOL and gender ($p > 0.05$). This finding contrasts with that of Durnian et al., who reported that female strabismic patients had significantly lower QOL scores on the Adult Strabismus Questionnaire (AS-20).²⁵ Similarly, Chew-Ean et al. and Nelson et al. observed greater psychosocial improvement among female patients following surgery.^{19,26} The lack of gender-related differences in our cohort may be explained by the younger age of our participants, as younger children may be less socially self-conscious and therefore less affected by gender-related differences in appearance or peer perception. At this developmental stage, psychosocial responses may be more influenced by family support and visual function than by gender norms.

We also found no significant relationship between QOL and the angle of deviation ($p > 0.05$). This contrasts with findings by Nelson et al., who reported that patients with larger angles of deviation experienced greater negative psychosocial effects due to more noticeable misalignment.²⁶ In our study, the absence of this relationship could be attributed to children's limited awareness of cosmetic differences compared to adults, as well as the possibility that parents' perceptions and support may lessen the psychosocial effects of larger deviations. Consistent with our findings, Van de Graaf et al. and Ritchie et al. also reported no correlation between angle of deviation and QOL scores, suggesting that psychosocial adaptation may play a greater role than deviation magnitude in determining subjective well-being.^{27–28}

Similarly, no significant association was observed between stereopsis and QOL ($p > 0.05$). One possible explanation lies in the structure of the IEQ itself. The child 5–8-year-old version does not include items assessing depth or distance perception, as these were excluded during the questionnaire's development phase following factor analysis. For the older group, although one item addressed depth perception, most respondents (65.1%) selected "not at all," suggesting that

stereopsis was not perceived as a major concern affecting daily life. Therefore, while stereopsis is an important clinical measure of binocular function, it may not directly influence perceived QOL in children, who are less aware of subtle depth-related visual limitations. In contrast, Dickmann et al. reported a positive association between improved stereopsis and QOL in adults, possibly reflecting the greater functional and occupational importance of binocular vision in older populations.²⁹

Our findings on factors affecting QOL differed from those reported in Western studies.^{25-26,29} In our study, gender, angle of deviation, and stereopsis did not influence QOL in children with infantile esotropia. One possible explanation may lie in cultural and perceptual differences between populations. Children in our cohort appeared less concerned about cosmetic appearance or functional limitations such as depth perception. For instance, comments gathered informally during questionnaire administration suggested that some children felt satisfied with their appearance and did not perceive difficulties in everyday tasks such as walking, playing, or pouring water. These informal remarks do not represent structured qualitative data but may reflect a general trend of reduced self-consciousness about appearance among younger Malaysian children.

Although our study did not formally assess cultural attitudes, previous research has shown that sociocultural context can influence perceptions of strabismus. Alzuhairy et al. reported that 70.4% of Arab parents in Saudi Arabia expressed positive attitudes towards strabismus, highlighting how cultural norms and beliefs shape perceptions of the condition.³⁰ However, this and similar studies primarily focused on parental attitudes rather than children's self-perceived QOL.

Cultural and religious values may also influence perceptions of illness and healthcare-seeking behaviour. Glover et al. suggested that sociocultural background and religious orientation shape individuals' attitudes towards health conditions and their willingness to pursue treatment.³¹ In our study, it is possible that similar cultural or religious perspectives influenced how families perceived strabismus and its psychosocial impact. For instance, both Malaysian and Middle Eastern societies share certain values and family-oriented beliefs that may encourage parental acceptance of visible conditions such as strabismus, reducing the stigma experienced by affected children. However, this interpretation remains speculative, as our study did not directly examine religious or cultural determinants of healthcare behaviour. Alzuhairy et al. also reported that cultural norms and traditions may foster understanding and support for children with strabismus.³⁰ Nonetheless, their study focused on parental attitudes rather than children's self-perceived QOL. Hence, while cultural and religious contexts may help explain variations in psychosocial responses between populations, such conclusions should be drawn cautiously. Future qualitative and cross-cultural studies are recommended to explore in greater depth how beliefs, social norms, and community perceptions influence QOL and healthcare-seeking behaviour in paediatric strabismus.

This study has several limitations that should be considered when interpreting the findings. One major challenge involved the reliability of responses among younger participants, particularly those aged eight years and below. Younger children often required additional explanation, prompting, or parental assistance to understand the questionnaire items. Some were shy, silent, or hesitant to engage with unfamiliar researchers, which may have affected the accuracy of self-reported QOL data. To minimise these challenges, we used age-appropriate IEQ versions; The 5–8-year-old version with simplified language and visual cues, and the 9–17-year-old version with more abstract concepts to improve comprehension and engagement. The research team also used rapport-building strategies and small tokens such as coloured pencils or stickers to enhance cooperation.

Another limitation concerns the single-centre sampling approach. As the study was conducted at a tertiary centre in Kelantan, Malaysia, the majority of participants were of Malay ethnicity. This relatively homogeneous demographic composition limits the generalisability of the results to other ethnic groups and cultural contexts. Cultural norms, parental attitudes, and societal perceptions of strabismus are known to influence QOL outcomes and may differ across populations. Therefore, future multicentre studies involving more diverse and multi-ethnic samples are warranted to enhance external validity and allow for broader comparisons.

Furthermore, the absence of a control group restricts the ability to differentiate between the effects of surgery and other contributing factors, such as natural psychosocial adaptation or parental reassurance over time. Including a non-surgical or observational control group in future research would help strengthen causal inferences regarding the impact of surgery on QOL.

Finally, the relatively short postoperative follow-up period of three months provides only a snapshot of early outcomes. Although significant QOL improvements were observed during this time, these results may not reflect longer-term psychosocial or functional adjustments. As children's adaptation and binocular development continue over time, longitudinal studies with extended follow-up periods (e.g., six to twelve months) are necessary to determine the durability and stability of postoperative QOL gains.

CONCLUSION

In summary, this study demonstrated that strabismus surgery significantly improves the quality of life of children with infantile esotropia across social, emotional, and functional domains. The absence of associations between QOL and factors such as gender, stereopsis, and angle of deviation suggests that postoperative well-being is influenced more by psychosocial adaptation, parental reassurance, and perceived cosmetic improvement than by clinical parameters alone. Cultural and familial contexts may also play a role in shaping children's perceptions and experiences, although further qualitative and multicentre research is needed to confirm these influences.

While the study was limited by challenges in questionnaire reliability among very young participants, single-centre sampling, and a relatively short follow-up duration, the results nonetheless provide valuable insight into the broader psychosocial impact of strabismus correction. Future longitudinal, multicentre studies involving diverse populations and extended follow-up periods are recommended to evaluate the long-term stability of QOL improvements and to better understand the interplay between visual, functional, and cultural factors in paediatric strabismus outcomes.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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