

Infantile esotropia in Malaysian children: The impact of surgery on health-related quality of life assessment in patients and their parents

Tan Chew-Ean, MMed^{1,2,3}, Shuaibah Ab Ghani, MMed^{3,4}, Ismail Shatriah, MMed^{1,2}

¹Department of Ophthalmology, School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia, ²Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia, ³Department of Ophthalmology, Sabah Women and Children Hospital, Likas, Kota Kinabalu, Sabah, Malaysia, ⁴Faculty of Medicine and Health Sciences, Universiti Malaysia Sabah, Kota Kinabalu, Sabah, Malaysia

ABSTRACT

Introduction: Limited information is available on health-related quality of life (HRQoL) in children with strabismus in South East Asia. We aimed to evaluate the HRQoL and associated factors pre- and post-strabismus surgery in Malaysian children with infantile esotropia and their parents/guardians.

Methods: A prospective study was conducted on children with infantile esotropia aged 8-17 years old and their parents/guardians who attended two tertiary hospitals with a paediatric ophthalmology service from 2017 to 2018. The patients and parents answered the Intermittent Exotropia Questionnaire (IXTQ), translated into Malay, at the time of enrolment and three months after the surgery.

Results: Thirty-four children and one (each) of their parents/guardians were enrolled. Thirteen (38.2%) children had esotropia with angles of deviation of more than 50 prism dioptres. A total of 33 (97.1%) children achieved successful alignment correction three months after surgery. Surgery significantly improved the total mean scores of the children, which were 62.87 (17.05) preoperatively and 87.13 (13.26) postoperatively ($p < 0.001$). There was statistically improvement in the total mean scores in the parent/guardian group, which was 37.07 (22.01) preoperatively and 75.39 (22.09) postoperatively ($p < 0.001$). The parents/guardians functional, psychosocial and surgery subscales also had a significant increment in the score postoperatively ($p < 0.001$). Older children and children with poorer visual acuity on presentation had a lower score preoperatively, while girls scored better postoperatively ($p < 0.05$). Mothers scored significantly lower preoperatively and postoperatively ($p < 0.05$).

Conclusion: Surgery significantly improved the HRQoL score in Malaysian children with infantile esotropia and their parents/guardians. The score was significantly higher in female children after the surgery. Mothers exhibited poor scores before and after surgery.

KEYWORDS:

Malay translated IXTQ, infantile esotropia

INTRODUCTION

Patients with childhood-onset of strabismus have low self-esteem and experience social alienation from peers at school.^{1,2} Strabismus creates a significant negative social prejudice which also affects the relationship between the children and their parents.^{3,4} Early surgical correction is the mainstay of treatment, and it may improve stereoacuity and restore alignment.⁵⁻⁷

Studies on reduced health-related quality of life (HRQoL) in children with strabismus and their parents have been reported from the United States of America (USA), China and Iran.⁸⁻¹² Based on a PubMed search, no similar reports are available from the Southeast Asia region, especially in a developing country.

This study aimed to assess the impact of surgery on the HRQoL among Malaysian children with infantile esotropia and their parents/guardians by using the Intermittent Exotropia Questionnaire (IXTQ) translated into the Malay language.

MATERIALS AND METHODS

This prospective study was conducted at Hospital Universiti Sains Malaysia Kelantan, Malaysia and Sabah Women and Children Hospital, Sabah, Malaysia from June 2017 to November 2018. Children with infantile esotropia, aged 8-17 years old, and one of their parents/guardians were recruited. The study was conducted in accordance with the Declaration of Helsinki and 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 recruited children.

Sample size was calculated using power and sample size software calculation. This study had 80% power for detecting an effect size of 0.7 for the outcome quality of life with a 95% confidence interval and type 1 error probability 0.05.⁹ The sample size was 34 patients with 10% drop out in each group.

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Corresponding Author: Shatriah Ismail

Email: shatriah@usm.my

All the 34 children who fulfilled the clinical diagnosis of untreated infantile esotropia and who could comprehend the Malay language and were able to complete the questionnaire were included in the study. Those with pre-existing ocular problems, such as cataract, optic neuropathy and neurological diseases with developmental delay, were excluded. One of each of their accompanying parent/guardian was recruited concurrently.

Demographic data collected included age, gender, the educational level of parent/guardian and household income. Complete ocular examinations were performed for all the children included visual acuity, refraction, orthoptic assessment, anterior segment and funduscopy.

The IXTQ consists of a five-point Likert-type scale, ranging from zero to 100, zero indicates the worst score and 100 the best score. The Child IXTQ consists of 12 questions, and the Parent IXTQ comprises 17 questions, which are further divided into three subscales: functional, psychosocial and surgery.¹³ The Malay version of the IXTQ has been tested for good reliability with satisfactory content validation.¹⁴

The children and their parents/guardians were asked to answer the IXTQ Malay version during enrolment. At this session, they were placed with their backs to each other or in an adjacent room to prevent interaction and allowed freedom to answer the questionnaire. Trained personnel were available to explain the IXTQ if clarification was needed. Both the children and the parents/guardians were asked to circle one answer that reflected the most accurate their perception regarding each questionnaire item.

The children with amblyopia were treated with amblyopia therapy prior to the surgery. Subsequently, the children were scheduled for strabismus surgery. Three months after surgery, the same ocular examinations as at enrolment were repeated, and the children and their parents/guardians answered the same questionnaire.

The data were analysed using the Statistical Package for the Social Sciences (SPSS) for Windows version 24 (SPSS Inc., Chicago, IL, USA). The paired t-test was applied to compare the IXTQ score pre- and post-surgery for the children and their parents/guardians. The factors affecting IXTQ score were further analysed on their association based on simple and multiple linear regression analysis.

RESULTS

Table I represents the demographic and clinical characteristics of the children and their parents/guardians. A total of 34 children aged 8-17 years old with one of their parents/guardians were involved in this study. Most of them were girls (55.9%) and most were aged 8-12 years-old (70.6%). Three (8.8%) children had a family history of strabismus, and three (8.8%) were born prematurely, ranging from 28 to 34 weeks of gestation. The accompanying persons were mostly mothers (50%), followed by fathers (38.2%) and grandmothers (11.8%). 15 (44.1%) of the parents/guardians had received education of up to secondary school and earned more than Ringgit Malaysia 3000 per month.

At enrolment, 20 (58.8%) children had best corrected visual acuity (BCVA) ranging from LogMar 0.20 to 0.0, (6/6 to 6/9) while 14 (41.2%) children had poorer BCVA. One (2.9%) child had dense amblyopia. Most (55.9%) had alternating esotropia, and 13 (38.2%) had large angle esotropia greater than 50 prism dioptres. Most (91.2%) children suffered a stereoacuity deficit.

A total of 13 (38.2%) children underwent bilateral medial rectus recession and 10 (29.4%) children were subjected to unilateral medial rectus recession or lateral rectus resection. In all 11 (32.4%) children had three muscle surgeries.

Postoperatively, 31(91.2%) children obtained BCVA LogMar 0.20 or better (6/9 or better), while three (8.8%) children who remained with BCVA worse than LogMar 0.3 (6/12) continued on amblyopia treatment. For both distance and near deviation, 33 (97.1%) children had achieved orthophoria or deviation of less than ten prism dioptres. Seven (20.6%) children obtained stereopsis while 27 (79.4%) children did not regain stereopsis.

Table II shows the total mean scores of the IXTQ in Malay used for the children and the parents, including the three subscales for the latter. There were significant improvements in the Child and Parent IXTQ scores at three months after surgery compared to enrolment ($p < 0.001$). The three subscales of the Parent IXTQ, functional, psychosocial and surgery, showed a significant increment in the IXTQ score postoperatively.

In the Child IXTQ results, the preoperative score reduced with increasing age, higher educational level and poorer BCVA ($p < 0.05$). The older children scored significantly lower than the younger children ($p = 0.044$). Those attending secondary schools also scored significantly lower than those in primary school ($p = 0.015$). The postoperative IXTQ score in children was not related to the amount of alignment correction and postoperative surgical outcome ($p > 0.05$). Girls responded with a significantly higher postoperative Child IXTQ score than boys ($p = 0.041$) in our study.

In the Parent IXTQ, mothers scored significantly lower in their preoperative and postoperative scores ($p < 0.05$). A lower preoperative Parent IXTQ score was found in parents who had children with a larger alignment deviation and unilateral esotropia ($p < 0.05$) (Table III).

DISCUSSION

Several studies have revealed an improvement in QoL in relation to functional and psychosocial relief in children and their parents after corrective strabismus surgery.⁸⁻¹² However, few questionnaires are available to investigate the impact of strabismus surgery in children and their parents, including the IXTQ, the Adult Strabismus-20 (AS 20) questionnaire, the Pediatric Quality of Life Inventory (PedsQL) questionnaire, the PedsQL Family Impact Module (PedsQL FIM) questionnaire, the RAND Health Insurance Study Quality of Life questionnaire and the National Eye Institute Visual Functioning Questionnaire.⁸⁻¹⁷

Table I: Demographic and clinical characteristics

Variables	Preoperative n (%)	Postoperative n (%)
Demographic characteristics		
Children		
Age (years)		
8-12	24 (70.6)	
13-17	10 (29.4)	
Mean (SD)	10.59 (2.71)	
Gender		
Male	15 (44.1)	
Female	19 (55.9)	
Educational level		
Primary school	24 (70.6)	
Secondary school	10 (29.4)	
Family history of strabismus		
Present	3 (8.8)	
Absent	31 (91.2)	
History of prematurity		
Present	3 (8.8)	
Absent	31 (91.2)	
Parents		
Accompanying persons		
Father	17 (50.0)	
Mother	13 (38.2)	
Grandmother	4 (11.8)	
Age (years)		
21-30	3 (8.8)	
31-40	16 (47.1)	
41-50	12 (35.3)	
51-60	3 (8.8)	
Mean (SD)	41.32 (7.53)	
Educational level		
Illiterate	4 (11.8)	
Primary school	8 (23.5)	
Secondary school	15 (44.1)	
University	7 (20.6)	
Household income		
< RM1000	2 (5.9)	
RM1000-RM1499	7 (20.6)	
RM1500-RM2999	10 (29.4)	
≥RM3000	15 (44.1)	
Clinical characteristics		
Best corrected visual acuity		
6/6-6/9	20 (58.9)	31 (91.2)
6/12-6/60	13 (38.2)	2 (5.9)
Worse than 6/60	1 (2.9)	1 (2.9)
Laterality		
Unilateral	15 (44.1)	
Alternating	19 (55.9)	
Distance deviation		
≤50 prism diopters	21 (61.8)	0 (0.0)
>50 prism diopters	13 (38.2)	0 (0.0)
≤10 prism diopters	0 (0.0)	33 (97.1)
>10 prism diopters	0 (0.0)	1 (2.9)
Near deviation		
≤50 prism diopters	21 (61.8)	0 (0.0)
>50 prism diopters	13 (38.2)	0 (0.0)
≤10 prism diopters	0 (0.0)	33 (97.1)
≤50 prism diopters	0 (0.0)	1 (2.9)
Strabismus surgery (intraoperative)		
Bilateral MR recession		13 (38.2)
Unilateral MR recession/LR resection		10 (29.4)
Bilateral MR recession and unilateral LR resection		5 (14.7)
Bilateral MR recession and IO anteriorization		6 (17.7)

SD; standard deviation; MR: medial rectus; LR: lateral rectus; IO: inferior oblique.

Table II: Intermittent Exotropia Questionnaire (IXTQ) scores before and after strabismus surgery

Questionnaires	Pre-surgery Mean (SD)	Post-surgery Mean (SD)	Mean difference (95%CI)	t-stat (df)	p-value*
Child IXTQ	62.87 (17.05)	87.13 (13.26)	24.26 (19.95, 28.5)	11.4 (33)	<0.001
Parent IXTQ	37.07 (22.01)	75.39 (22.09)	38.32 (31.47, 45.17)	11.38 (33)	<0.001
Functional subscale	41.91 (24.50)	74.85 (23.18)	32.94 (25.73, 40.15)	9.29 (33)	<0.001
Psychosocial subscale	32.67 (23.87)	76.79 (24.29)	44.12 (35.44, 52.80)	10.34 (33)	<0.001
Surgery subscale	50.00 (30.62)	78.31(22.89)	28.31 (19.90, 36.72)	6.85 (33)	<0.001

*p<0.05 is considered statistically significant (paired t-test). SD: standard deviation; CI: confidence interval; df: degree of freedom.

Of the questionnaires, IXTQ performs better to reflect QoL in children and their parents.¹³⁻¹⁶ It was designed initially to evaluate HRQoL in children with intermittent exotropia.¹³ Sim et al. demonstrated that IXTQ was a useful instrument in enabling the assessment of HRQoL in children in Singapore with various type of strabismus. The IXTQ questionnaire was able to reflect the psychosocial and functional status of any type of strabismic patient.¹⁸ The Malay version of the IXTQ was used by Tan (2015) as a validated and reliable questionnaire to capture the QoL of Malaysian children with strabismus.¹⁴ Table IV summarises published reports on IXTQ assessment in children with strabismus and their parents, including the outcome of our study.^{9,10,14,16,18}

We observed a statistical difference (p<0.001) in the total mean scores in the Child IXTQ and the Parent IXTQ and its three subscales before and after strabismus surgery. Our results were consistent with the findings in the studies of children from China with intermittent exotropia.^{9,10} This demonstrates that corrective surgery may improve QoL various type of strabismus in children and their parents.

The Child IXTQ score before surgery in our study was similar to the findings in other regional studies.^{14,18} Sim et al., reported that children with esotropia scored lower than children with exotropia in Singapore.¹⁸ Our study consisted of children with infantile esotropia, who had a lower score compared with the results in children with intermittent exotropia demonstrated by Hatt et al.¹⁵ Olitsky et al., found that strabismic faces were negatively judged among college students and esotropia was worse than exotropia.¹⁹ Children with strabismus, especially esotropia, were believed to be less capable in their school performance.⁴ These biases resulted in an enormous unfavourable effect on the children with esotropia's psychosocial aspects.

The preoperative Child IXTQ score reduced with increasing age, higher educational levels and poorer BCVA (p<0.05) in our study. Older children and those in secondary school scored significantly lower, probably due to more self-consciousness towards appearance in older children. Children attending secondary school experience more intense peer pressure and also a negative stigma from teachers. However, this finding was contrary to other studies, where a lesser negative social impact was noticed in older children, which was believed due to maturity, acceptance and better adaptive social skills.^{9,18,20,21}

Strabismus with amblyopia can cause loss of binocular vision and loss of depth perception, which results in an adverse functional impact on children in their daily life and school

performance. Our results demonstrated that children with poorer BCVA during presentation responded with a lower score in the preoperative Child IXTQ (p=0.001). Sim et al. found that children with strabismus and amblyopia had a significantly lower IXTQ score than children without any eye condition.¹⁸

Strabismus surgery improves the QoL of the children, the functional or psychosocial aspects. Studies using various questionnaires have demonstrated improvement in HRQoL scores postoperatively in children.^{6,8,12,15,16} In our study, the improvement in the postoperative Child IXTQ mean score was not related to the amount of alignment correction and postoperative surgical outcome. Most of the children achieved orthophoria and only one (2.9%) child had a residual deviation of 30 prism dioptres. Previous research has found that strabismus surgery improved the QoL in children regardless of the surgical outcome, i.e. whether correction was successful or unsuccessful.^{12,16,22}

We observed that girls reported a significantly higher postoperative Child IXTQ score than boys (p=0.041), which was similar to the findings of Nelson et al., in which female patients reported that strabismus surgery improved their relationship more than male patients.¹ Females are judged more by their appearance and thus are more concerned and worried about any disfiguration. Surgical correction of strabismus can enhance the appearance and restore self-confidence, which can provide better quality of life.

Regarding the Parent IXTQ, the preoperative total mean score and psychosocial subscale had a lower score in our study compared to prior studies.^{9,14,20} lower score is possibly due to the large angle of deviation in infantile esotropia, which creates greater parental anxiety than in parents of children with intermittent strabismus. Wang et al. had a similar low score, as the patients with intermittent exotropia in their study had a large angle of misalignment.⁹

For the surgery subscale of the preoperative Parent IXTQ, our study had a higher score compared to previous studies.^{9,18} This suggests that parents in our study were unaware of the importance and benefits of surgery as the treatment option to correct infantile esotropia. Better health education and information regarding surgical correction should be delivered to parents to enlighten them about early treatment for infantile esotropia.

Our study found that parents who had children with larger alignment deviation and unilateral esotropia had a lower score in the preoperative Parent IXTQ (p<0.05). Wang et al.

Table III: Associated factors before and after the surgery

Variables	Pre-strabismus surgery			Post-strabismus surgery		
	Simple linear regression	Multiple linear regression		Simple linear regression	Multiple linear regression	
	b (95% CI)	b (95% CI)	p-value*	b (95% CI)	b (95% CI)	p-value*
Child IXTQ score						
Child age	-2.19 (-4.31, -0.06)		0.044	-1.23(-2.93, 0.48)		0.153
Child gender						
Male	1.00			1.00		1.00
Female	3.89 (-8.21, 15.99)		0.517	9.28 (0.42, 18.15)	13.60 (2.39,24.81)	0.041
Child education level						
Primary school	1.00	1.00		1.00		
Secondary school	-14.10 (-26.37, -1.83)	-28.56 (-54.65, -2.48)	0.026	-6.27 (-16.34, 3.81)		0.214
Best corrected visual acuity	-27.81 (-49.78, -5.84)	-38.73 (-60.09, -17.36)	0.015	-5.61 (-27.93, 16.71)		0.612
Alignment deviation						
Near	0.18 (-0.27, 0.63)		0.416	0.42 (-0.43, 1.27)		0.320
Distance	0.10 (-0.37, 0.57)		0.672	0.39 (-0.44, 1.22)		0.348
Laterality of esotropia						
Unilateral	1.00			NA		NA
Alternating	7.83 (-3.96, 19.61)		0.186	NA	NA	NA
Parent IXTQ score						
Parent age	0.20 (-0.86, 1.25)		0.707	0.26 (-0.79, 1.31)		0.619
Parent gender						
Male	1.00			1.00		1.00
Female	-15.63 (-30.68, -0.58)		0.042	-20.43 (-34.78, -6.08)	-11.79 (-29.87, 6.29)	0.007
Parent education level						
Primary school and below	1.00			1.00		
Secondary school and below	4.07 (-12.21, 20.34)		0.614	13.10 (-2.60, 28.81)		0.099
Child age	-1.33 (-4.22, 1.56)		0.355	-1.36 (-4.25, 1.54)		0.347
Child gender						
Male	1.00			1.00		
Female	-1.91 (-17.63, 13.80)		0.806	8.42 (-7.07, 23.91)		0.227
Best corrected visual acuity	-21.93 (-55.08, 8.22)		0.148	-29.29 (-65.09, 6.52)		0.105
Alignment deviation						
Near	0.25 (-0.33, 0.82)		0.390	0.26 (-1.18, 1.70)		0.714
Distance	-0.50 (0.02, 1.17)		0.043	0.16 (-1.24, 1.56)		0.820
Laterality						
Unilateral	1.00			NA		NA
Alternating	16.72 (2.28, 31.16)		0.025	NA	NA	NA

*p<0.05 is considered statistically significant. CI: confidence interval; NA: not applicable.

Table IV: Comparison of IXTQ assessment in children with strabismus and their parents from previous studies and current review

Studies	Current review	Xiao et al. [15]	Wang et al.[7]	Tan and Shatriah [8]	Sim et al. [9]	Hatt et al. [10]	Yamada et al. [11]
Country	Malaysia	China	China	Malaysia	Singapore	United States	United States
Year	2020	2019	2015	2015	2014	2010	2011
Number of children, total	34	122	120	57	120	51	88
Strabismic children	34	122	63	57	60	51	59
Control	0	0	57	0	60	0	29
Strabismus Type (n)	IE (34)	IXT (122)	IXT (63)	XT (37) ET (22) NA	XT (47) ET (12) NA	IXT (51)	IXT (59)
Distance, mean PD (SD)	50.47 (12.97)	NA	33.49 (7.33)	NA	NA	20 (10-30)†	25(12-55)†
Near, mean PD (SD)	51.74 (13.58)	NA	33.25 (6.97)	NA	NA	NA	16(0-40)†
Age of children	8-17	2-15	8-17	5-17	5-16	5-16	5-16
Mean age, years (SD)	10.6 (2.7)	7 (3.0)	10.5 (2.4)	10.2 (3.5)	8.7 (2.8)	7†	7†
Questionnaire used	IXTQ*	IXTQ	IXTQ	IXTQ* AS20*	IXTQ AS20	IXTQ PedsQL	Parent IXTQ PedsQL FIM
Child IXTQ							
Mean score (SD)	62.87 (17.05)	57.30 (8.37)	58.73 (18.37)	62.51(16.60)	70.1 (19.0) 70.2 (19.9) in XT 69.6 (15.9) in ET	81.8 (13.3)	NA
Preoperative							
Postoperative	87.13 (13.26)	83.27 (9.49)	73.68 (12.93)	NA	NA	NA	NA
Parent IXTQ							
Mean score (SD)							
Preoperative	37.07 (22.01)	NA	38.45 (19.43)	NA	52.4 (25.9)	NA	66.3 (20.2)
Postoperative	75.39 (22.09)	NA	73.20 (9.69)	NA	NA	NA	NA
Functional							
Preoperative	41.91 (24.50)	NA	34.82 (19.14)	NA	NA	NA	64.3 (20.0)
Postoperative	74.85 (23.18)	NA	66.37 (12.37)	NA	NA	NA	NA
Psychosocial							
Preoperative	32.67 (23.87)	NA	44.39 (21.82)	NA	NA	NA	71.6 (24.0)
Postoperative	76.79 (24.29)	NA	79.88 (9.96)	NA	NA	NA	NA
Surgery							
Preoperative	50.00 (30.62)	NA	32.14 (24.67)	NA	45.0 (27.4)	NA	56.4 (25.9)
Postoperative	78.31 (22.89)	NA	77.18 (11.57)	NA	NA	NA	NA

IE: infantile esotropia; IXT: intermittent exotropia; ET: esotropia; PD: prism diopter; SD: standard deviation; IXTQ: Intermittent Exotropia Questionnaire; AS 20: Adult Strabismus 20 Questionnaire; PedsQL FIM: Peds Family Impact Module; †: median years (interquartile range); *: Malay translated questionnaire; NA: not available.

reported that HRQoL was significantly correlated with a larger angle of deviation in parents of children with intermittent exotropia.²³ This may indicate that a larger alignment deviation worsens cosmesis, leading to anxiety and low self-esteem. Hence it creates more psychosocial disturbances to the parents.

Mothers had significantly lower scores than fathers in the preoperative ($p=0.042$) and the postoperative ($p=0.007$) Parent IXTQ. Akay et al., demonstrated that mothers of children with strabismus experienced negative effects of strabismus in their family relationships.³ However, Wang et al. found that both mothers and fathers had similar HRQoL scores before and after surgery.⁹

This study had some limitations. Firstly, we were only able to evaluate the short-term effectiveness of the surgery, as our study assessed the HRQoL of the children and their parents only up to three months after surgery. Future research is recommended to extend the follow-up duration to provide data on the long-term impact of surgery either functionally or psychosocially in children and their parents. Secondly, our study recruited guardians as the responder for parental HRQoL assessment to represent working parents who were not able to take part in the study. As this may not reflect the real parental anxiety level due to strabismus impact, only parents, and especially mothers, should be considered as the responder in future studies to demonstrate the actual parental HRQoL evaluation.

CONCLUSION

Our study showed the beneficial effects of strabismus surgery in improving the functional and psychosocial aspects of quality of life in children with infantile esotropia and their parents/guardians. Corrective surgery improved the quality of life in female children more than male children. The quality score remained poor in mothers before and even after the surgery.

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