Quality of life in children with strabismus

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ABSTRACT

Purpose: To evaluate the quality of life of children with strabismus and understand their consequences in the functional and psychosocial aspects of the childhood.

Methods: A semi-structured interview adapted of Adult Strabismus-20 questionnaire was conducted with parents or the legal responsible person of children aged between 3 and 13 years old attended at the public health care. A likert-scale of five points was used to measure the impact of strabismus in childhood, from psychosocial and functional aspects.

Results: 97 children were included in the study. 61,4% of the children had esotropia (ET), while 35.9% had exotropia (XT). In each group, the magnitude of deviation was classified in smaller (<) or equal/ greater (≥) then 30 prismatic diopters. When analyzing the functional and the psychosocial scores of the groups separated by the type of strabismus and magnitude of deviation, the average score of the group with esotropia and the patients with larger deviations were worse. The correlation value between the psychosocial and functional scores was 200.656 (p <0.01).

Conclusion: Strabismus in childhood is associated with many negative effects. These consequences should be considered when deciding for surgical treatment on early ages. The strabismus treatment may change positively how these children perceive themselves, resulting in benefits on quality of life from both the functional and psychosocial perspectives.

RESUMO

Objetivo: Avaliar a qualidade de vida de crianças com estrabismo e entender suas consequências em aspectos funcionais e psicossociais da infância.

Métodos: Uma entrevista semiestruturada adaptada do questionário Adult Strabismus-20 foi realizada com os pais ou responsáveis legais das crianças entre 3 e 13 anos atendidas na rede pública de saúde. Uma escala do tipo Likert de cinco pontos foi usada para mensurar o impacto do estrabismo na infância, do ponto de vista funcional e psicossocial.

Resultados: Foram incluídas no estudo 97 crianças, sendo 61,4% com esotropia e 35,9% com exotropia. Em cada grupo, a magnitude do desvio foi classificada em menor ou maior que 30 dioptrias prismáticas. Quando analisados os escores funcionais e psicossociais de cada grupo separados por tipo e magnitude do desvio, a média do escore do grupo com esotropia e dos pacientes com maior desvio foi pior. O valor de correlação entre os escores funcionais e psicossociais foi de 0,656 (p<0,01).

Conclusão: Estrabismo na infância está associado a muitos efeitos negativos. As consequências devem ser levadas em consideração quando da decisão por tratamento cirúrgico em idades precoces. O tratamento do estrabismo pode alterar de forma positiva a percepção que a criança tem de si mesma, resultando em benefícios na qualidade de vida, tanto em aspectos funcionais quanto psicossociais.
INTRODUCTION

Strabismus is one of the ophthalmological conditions that can impact the quality of life of individuals. Historically, it has gained remarkable attention as being much more than just a noticeable attribute of appearance. Children and adults with strabismus often suffer from various psychosocial and emotional problems, such as low self-esteem, social prejudice, school bullying, increased social anxiety, fragile interpersonal relationships and issues of work opportunities. Unquestionably, strabismus is much more than just a matter of esthetics.

The literature suggests a positive impact of corrective surgery on the psychosocial functioning and well-being of patients with strabismus. However, the psychosocial effects on children have not been extensively studied, partly due to the quality-of-life methodology that turns to be more difficult to be applied in children.

Many authors criticize the use of the terms esthetic or cosmetic for the treatment of strabismus, because these terms mean “something made to improve appearance or embellish”. However, strabismus is a pathological condition associated with abnormal binocular vision that leads to modification in the normal appearance and can affect the quality of life.

Assessing quantitatively the quality of life of children with strabismus may contribute to clinical examination as it allows a better understanding of the condition and a proper evaluation of the treatment effectiveness.

In the past decades, many authors have studied the strabismus-related quality of life. There are some specific instruments for evaluation, which were developed based on interviews with patients and their relatives. Feelings and expressions have been collected and used by researchers for the improvement of more objective and efficient questionnaires to measure the impact of strabismus on the patients’ quality of life.

The Adult Strabismus-20 (AS-20) questionnaire is a 20-item questionnaire designed to assess health-related quality of life (HRQoL) in adults with strabismus. Young children end up not being included due to the difficulty in obtaining verbal information. In this case, parents become important instruments in order to demonstrate how strabismus can affect the development of the child’s perception as an individual in their environment.

In this study, we report psychosocial and functional aspects in a recent cohort of children with strabismus. The objective of this study was to evaluate the quality of life of children with strabismus and understand their consequences in the functional and psychosocial aspects of the childhood.

METHODS

This study was approved by the Institutional Review Board at Hospital de Olhos do Paraná and was performed in accordance with the principles mentioned in the Declaration of Helsinki. It was conducted at Strabismus Sector of Hospital de Olhos do Paraná.

A semi-structured interview was conducted with the parents or the legal responsible person of children aged between 3 and 13 years old after written informed consent was provided. The patients underwent identification and complete eye examination. A questionnaire assessing strabismus was filled out by the researchers. An adaptation of AS-20 questionnaire to the childhood was used, with no significant change in the content of the questions (Appendix 1).

The AS-20 was created with two distinct subscales (psychosocial and function) and has been considered reliable and valid for assessing HRQOL in adult strabismus patients. The questionnaire is self-administered and, for each question, patients choose from five Likert-type response options: “never”, “rarely”, “sometimes”, “often” and “always”.

A Likert-scale of five points was also used to measure the impact of strabismus in children, the psychosocial and functional lifestyle. Scores close to zero indicate less impact and scores close to 5 indicate more severe impact. The questions that range from one to ten are considered for the psychosocial measurement; and the questions ranging from 11 to 20, the functional measurement.

Our purpose was to assess patient interaction within social and school environments, sensory perception, and daily life limitations. This strategy aimed to simplify the understanding, make the questions’ answering easier, and allow fewer false-negative answers.

Patients’ records were analyzed for the following: gender, age, best corrected visual acuity, refractive error, use of spectacles, presence of amblyopia, treatment for amblyopia, angle of deviation in primary position, submitted or not to strabismus surgery.

Vision was assessed with Snellen test and amblyopia defined as present with two lines or more of difference, with institution of patching therapy. Refractions were performed after dilation with 1% cyclopentolate and 1% tropicamide and converted to spherical equivalent (SE).

Pre-operative alignment was measured with alternate prism-cover testing at distance (6m) and at near in all patients. The greater deviation was considered in the study.

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS) version 20. Analysis of the effect of quantitative preoperative variables was performed using Student’s t test or Analysis of Vaiance (Anova) for
independent samples or non-parametric Mann-Whitney or Kruskal-Wallis, when appropriate. The effect of association between categorical variables was analyzed using the Chi-square test. Continuous variables were verified by their normal distribution using the Shapiro-wilk test of normality. Results were reported as mean (± standard deviation) or median (minimum – maximum). Categorical variables were summarized using percentages and expressed as absolute number (% of total). P-values less than 0.05 were considered significant.

**RESULTS**

A total of 97 children were included in the study, 58.8% were female. The average age was 7.3 years old.

Two types of strabismus were included. Esotropia (ET) was present in 61.4% of the children and exotropia (XT) in 35.9% of them, no differentiation was made between constant and intermittent deviations.

Of the patients with ET, 51% had deviations of less than 30 PD and 49% had equal or more than 30 PD. Of the patients with XT, 42% had deviations of less than 30 PD, and 58% had equal or more than 30 PD.

The general characteristics stratified by type of strabismus and magnitude of deviation are summarized in table 1. There was significant difference for the following variables between the groups: age (p=0.009); magnitude of the deviations (p<0.001); psychosocial score (p=0.012); functional score (p=0.006); use of glasses (p=0.002) and SE (p=0.024) (Table 2).

**Table 1.** General characteristics stratified by type of strabismus and magnitude of deviation

| Variable                        | Mean (±SD) or N (%) | Esotropia (Deviation <30) | Esotropia (Deviation ≥30) | Exotropia (Deviation <30) | Exotropia (Deviation ≥30) | P-value |
|---------------------------------|---------------------|---------------------------|---------------------------|---------------------------|---------------------------|---------|
| N total                         | 97 (100)            | 30 (30.9)                 | 29 (29.8)                 | 14 (14.4)                 | 19 (19.5)                 |         |
| Age (months)                    | 88±30.5             | 92±4±28.2                 | 95±1±37.9                 | 73±7±12.9                 | 83±2±29.0                 | 0.009   |
| Female                          | 57 (58.8)           | 11 (28.2)                 | 13 (33)                   | 6 (15.4)                  | 9 (23.1)                  |         |
| Magnitude of deviation          | 27±4±13.2           | 17±8±5.64                 | 39±5±8.06                 | 17±9±5.79                 | 36±4±8.69                 | <0.001  |
| Presence of amblyopia           | 37 (38.1)           | 12 (33.3)                 | 12 (33.3)                 | 4 (11.1)                  | 8 (22.2)                  |         |
| Visual acuity right eye         | 0.63±0.32           | 0.65±0.30                 | 0.59±0.36                 | 0.67±0.32                 | 0.59±0.35                 |         |
| Visual acuity left eye          | 0.66±0.29           | 0.65±0.26                 | 0.67±0.30                 | 0.74±0.28                 | 0.61±0.35                 |         |
| Use of glasses                  | 64 (66)             | 26 (41.9)                 | 22 (35.5)                 | 6 (9.7)                   | 8 (12.9)                  |         |
| Spherical equivalent right eye  | 1.65±0.71           | 2.86±3.24                 | 0.76±4.76                 | 1.07±0.82                 | 1.74±4.59                 |         |
| Spherical equivalent left eye   | 2.25±3.44           | 3.18±3.19                 | 1.71±2.67                 | 1.20±0.87                 | 2.43±5.59                 | 0.024   |
| Use of eye patches              | 58 (59.8)           | 18 (32.1)                 | 17 (30.4)                 | 8 (14.3)                  | 13 (23.2)                 |         |
| Strabismus surgery              | 47 (48.5%)          | 9 (20.9%)                 | 15 (24.9)                 | 7 (16.3)                  | 12 (27.9)                 |         |
| Psychosocial score              | 1.21±1.03           | 0.84±0.75                 | 1.58±0.88                 | 1.02±0.86                 | 1.35±1.14                 | 0.012   |
| Functional score                | 1.46±0.81           | 1.36±0.72                 | 1.83±0.76                 | 0.88±0.78                 | 1.47±0.87                 | 0.006   |

**Table 2.** Results of the general questionnaire stratified by type of strabismus and magnitude of deviation

| Question | Mean (±SD) | Esotropia (Deviation <30) | Esotropia (Deviation ≥30) | Exotropia (Deviation <30) | Exotropia (Deviation ≥30) | P-value |
|----------|------------|---------------------------|---------------------------|---------------------------|---------------------------|---------|
| 1        | 1.8±1.86   | 1.3±1.65                  | 2.1±2.00                  | 2.5±1.95                  | 1.5±1.87                  |         |
| 2        | 1.45±1.70  | 1.00±1.44                 | 2.45±1.68                 | 0.71±1.27                 | 1.32±1.83                 | 0.002   |
| 3        | 1.92±1.80  | 0.93±1.46                 | 2.66±1.65                 | 1.57±1.79                 | 2.37±1.86                 | 0.001   |
| 4        | 0.91±1.50  | 0.5±1.14                  | 1.38±1.63                 | 0.5±1.16                  | 1.0±1.67                  |         |
| 5        | 2.14±1.77  | 2.17±1.78                 | 2.34±1.84                 | 1.43±1.70                 | 2.32±1.83                 |         |
| 6        | 0.72±1.24  | 0.43±0.81                 | 1.0±1.34                  | 0.5±1.16                  | 1.0±1.67                  |         |
| 7        | 0.57±1.14  | 0.36±0.76                 | 0.82±1.39                 | 0.28±0.76                 | 0.78±1.32                 |         |
| 8        | 0.70±1.34  | 0.36±1.13                 | 0.79±1.40                 | 1.00±1.71                 | 0.94±1.35                 |         |
| 9        | 0.47±1.19  | 0.40±1.07                 | 0.51±1.27                 | 0.5±1.29                  | 0.63±1.38                 |         |
| 10       | 1.37±1.71  | 0.93±1.51                 | 1.72±1.87                 | 1.21±1.76                 | 1.58±1.74                 |         |
| 11       | 0.86±1.37  | 0.8±1.27                  | 1.24±1.54                 | 0.14±0.53                 | 0.94±1.39                 | 0.003   |
| 12       | 2.84±1.51  | 2.67±1.60                 | 3.34±1.11                 | 1.71±1.77                 | 2.95±1.43                 | 0.020   |
| 13       | 2.28±1.69  | 2.23±1.72                 | 2.59±1.72                 | 1.21±1.63                 | 2.58±1.61                 |         |
| 14       | 1.5±1.73   | 1.23±1.59                 | 2.10±1.86                 | 1.07±1.69                 | 1.42±1.80                 |         |
| 15       | 2.30±1.70  | 2.43±1.52                 | 2.72±1.65                 | 1.07±1.59                 | 2.21±1.84                 | 0.027   |
| 16       | 1.16±1.44  | 1.07±1.36                 | 1.24±1.64                 | 1.79±1.37                 | 0.89±1.37                 |         |
| 17       | 1.10±1.46  | 0.83±1.21                 | 1.38±1.59                 | 1.14±1.51                 | 1.26±1.69                 |         |
| 18       | 1.63±1.62  | 1.83±1.39                 | 2.03±1.84                 | 0.71±1.20                 | 1.32±1.67                 | 0.028   |
| 19       | 0.55±1.14  | 0.20±0.55                 | 1.14±1.53                 | 0                  | 0.47±1.12                 |         |
| 20       | 0.35±0.97  | 0.26±0.82                 | 0.48±1.18                 | 0                  | 0.63±1.26                 |         |

Results expressed as mean ± standard deviation. *Kruskal-Wallis.
When analyzing the quantitative variables, significant difference was observed in the functional score (p=0.028). The average score for functional quality of patients with ET (1.59±0.77) was higher than in the ones with XT (1.22±0.87).

Regarding the results of the general questionnaire stratified by the type of strabismus, a significant difference was observed in the following questions: Question 1 – “Does the child perceive that he/she has strabismus?” (p=0.05); Question 15 – “Does the child experience difficulty in perceiving depth?” (p=0.034); and Question 18 – “Does the child complain about difficulty seeing?” (p=0.012).

When considering groups separated by strabismus, we also notice that children with XT had more difficulty in perceiving themselves with the condition of strabismus. When questioned about depth of vision and difficulty in seeing, they had a higher average score, expressing a worse condition in this group.

The highest score indicates a worsening of the condition assessed by the question. When stratified by magnitude of deviation, we found significant difference for the following questions: Question 2 – “Does strabismus bother the child?” (p=0.003); Question 3 – “When you interact with other children, do you feel that they notice strabismus?” (p<0.001); Question 4 – “Does the child feel different (inferior) because of strabismus?” (p=0.029); Question 7 – “Do you feel that the child has fewer opportunities because of strabismus?” (p=0.049); Question 11 – “Do you feel that people avoid looking at the child because of strabismus” (p=0.05); Question 12 – “Does strabismus make vision difficult?” (p=0.05); and Question 13 – “Does the child have difficulty on reading because of strabismus?” (p=0.05). The group with the largest deviations (≥30) had a higher score on all these questions.

When the information on strabismus and magnitude of deviation was analyzed simultaneously, significant difference was present in the following questions: Question 2 – “Does strabismus bother the child?” (p=0.002); Question 3 – “When you interact with other children, do you feel that they notice strabismus?” (p<0.001); Question 11 – “Do you feel that people avoid looking at the child because of strabismus” (p=0.003); Question 12 – “Does strabismus make vision difficult?” (p=0.020); and Question 15 – “Does the child have difficult on reading because of strabismus?” (p=0.027); Question 18 – “Does the child complain about difficulty on seeing?” (p=0.028).

Statistical difference was observed only in the functional score, and the ET group had a higher average score than the XT group. As for psychosocial, no difference was found in the groups’ scores.

When considering the magnitude of the deviation, both scores – psychosocial and functional – showed significant worsening when we analyzed the group with large deviations (≥30); thus, showing that this group presented the worst condition for strabismus (Table 3).

To analyze the difference between the psychosocial scores of the groups separated by type of strabismus and magnitude of deviation, the tukey post-hoc test was used. We notice that the mean score of the ET group and the largest deviation showed a significant difference for ET and minor deviation (Table 4).

When analyzing the functional score according to the type of strabismus and magnitude of deviation, there was significant difference between the average score of the ET group and the largest deviation of the XT with minor deviation.

Pearson’s correlation between the psychosocial and functional scores showed that the variables are positively and strongly correlated. This means that every time the score of one increased, the other also increased. The correlation value found was 0.656 and the p-value <0.01.

**DISCUSSION**

The psychosocial effects of strabismus in children have not been extensively studied, mainly due to the quality-of-life...
methodology that turns to be more difficult to be applied in children. (³) In this study, although the answers were obtained from the parents or legal responsible person when the children were too young to answer the questionnaire, children were always present during the interview. Older children participated in the answers, helping for a more reliable result.

Strabismus in children is much more than an esthetic condition, it is also associated with abnormal binocular vision and it can lead to amblyopia, modifying the vision functionality.

The physical appearance of strabismus can be recognized even by young children and a negative attitude towards it seems to emerge at approximately 6 years of age or less.¹¹d

This study included children aged from 3 to 13 years, with an average of 7.33 years. Despite including children under 6 years old, a negative impact was demonstrated when analyzing the perception of strabismus and the difficulty in perceiving depth and difficulty in seeing, reinforcing the evidences that even younger children already have negative responses for strabismus.

Some quality-of-life studies have demonstrated that strabismus may have a more harmful effect than other important adult ocular diseases, such as diabetic retinopathy and macular degeneration.¹¹e However, these studies consider the adult’s perception and the impact can be even more important when strabismus is present already in the early ages, modifying the quality of life of children and teenagers, as well as affecting the development of self-image and self-esteem.

When analyzing the quantitative variables, significant difference was observed in the functional score (p=0.028), where the average score for functional quality of patients with ET (1.59±0.77) was higher than in the ones with XT (1.22±0.87), indicating a worse condition of that group.

Children with XT had more difficulty in perceiving themselves with the condition of strabismus than children with ET.

When considering the magnitude of the deviation, in both scores -psychosocial and functional – the children with larger deviations presented the worst conditions.

Olitsky et al.¹¹f stated that the treatment of strabismus should not be considered cosmetic, even when there is no hope of improving binocular vision, as it may affect positively the way that others perceive the individual and also may improve their ability to socialize. Other authors reinforce this concept, as it is more difficult for children with strabismus to improve their emotional and psychiatric status. (¹⁷)

We did notice that strabismus in children was associated with many negative effects, especially in children with ET. In addition, our data suggests that the greater the deviation, the worse are the functional and psychosocial scores.

**CONCLUSION**

Strabismus in childhood is associated with many functional and psychosocial negative effects. These consequences should be considered when deciding for surgical treatment on early ages. Treating strabismus may change positively how these children perceive themselves, resulting in benefits on quality of life from both the functional and psychosocial perspectives.

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Appendix 1. Adaptation of Adult Strabismus Quality of Life Questionnaire (AS-20)

1) Does the child notice that he/she has strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

2) Does strabismus bother the child?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

3) When the child interact with other kids, does he/she feel they notice his/her strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

4) Does the child feel different (inferior) because of the strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

5) Do you feel that strabismus hinders the child’s performance at school?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

6) Do you feel that strabismus affects the relationships with other kids?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

7) Do you feel that the child have fewer opportunities because of the strabismus (social interactions)?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

8) Does the child wonder what other people think about his/her eyes?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

9) Does the child have more difficulty making friends because of the strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

10) Does the child feel uncomfortable when people ask about their eyes?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

11) Do you feel that people avoid looking at the child because of the strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

12) Does strabismus hinder the child’s vision?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

13) Does the child have difficulty in reading because of strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

14) Does the child feel more anxious because of strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

15) Does the child have more difficulty in deep perception (assessing the distance of the object)?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

16) Does the child experience any discomfort such as pain or burning in the eyes because of the strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

17) Does the child need to close one eye to read?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

18) Does the child complain of difficulty in reading?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

19) Does the child feel eye strain because of strabismus?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|

20) Does the child think about his/her strabismus so often that it hinders his/her concentration?

|       | Never | Rarely | Sometimes | Often | Always |
|-------|-------|--------|-----------|-------|--------|