

Quality of life of patients with strabismus

Qualidade de vida em pacientes estrábicos

GERALDO DE BARROS RIBEIRO¹, ANA GABRIELA ZUM BACH¹, CAMILA MAIA FARIA¹, SUZE ANASTÁSIA¹, HENDERSON CELESTINO DE ALMEIDA¹

ABSTRACT

Purpose: To evaluate the impact of strabismus on quality of life.

Methods: This cross-sectional study included 101 individuals aged 7-67 years with strabismus. They were interviewed and made to answer a questionnaire with 20 questions intended to assess the individual's interaction with their social and working environment, sensory perception, and limitations in their daily lives. There were five types of possible responses for each question: never, rarely or very few times, sometimes, frequently, and always. The questionnaire was based on the AS-20 and contained 11 questions assessing psychosocial aspects and 9 questions assessing functional aspects. Among those who were interviewed, 24.8% had undergone surgical correction of strabismus.

Results: We observed a significant impact of strabismus on the quality of life of the interviewed individuals. Feelings of sadness and inferiority because of strabismus were reported by 74.2% and 58.4% respondents, respectively. In terms of functionality, 12.1% reported difficulty in reading, 14% said they had difficulty in depth perception (stereopsis), and 17.8% frequently or always associated pain or burning sensation in the eyes to strabismus. A significant difference was detected in the quality of life scores for the psychosocial aspect among patients who had and had not undergone surgery (Wilcoxon test, 158; $p < 0.001$). Individuals who had undergone surgery had a better quality of life from the psychosocial perspective.

Conclusions: In this evaluation, we found a significant negative interference of strabismus on quality of life from both the functional and psychosocial perspectives. This demonstrated the importance of treatment for strabismus, regardless of age, because it can interfere with the functional well-being of the individual.

Keywords: Strabismus/physiopathology; Social behavior; Quality of life; Questionnaires

RESUMO

Objetivo: Avaliar a interferência do estrabismo na qualidade de vida em indivíduos estrábicos.

Métodos: Estudo transversal envolvendo 101 indivíduos estrábicos entre 7 e 67 anos. Eles foram entrevistados e responderam um questionário com 20 perguntas aplicadas pelos pesquisadores. As perguntas tinham como objetivo avaliar a interação do indivíduo com o seu meio social, de trabalho, percepção sensorial e limitações na sua vida diária, com cinco tipos de respostas para cada pergunta: nunca, raramente ou muito pouco, algumas vezes, frequentemente e sempre. O questionário foi baseado no AS-20 e contendo 11 questões avaliando aspectos psicossociais e 9 questões avaliando aspectos funcionais. Entre os indivíduos entrevistados, 24,8% haviam sido submetidos a correção cirúrgica do estrabismo.

Resultados: Observou-se impacto significativo do estrabismo sobre a qualidade de vida dos indivíduos avaliados. Sentir-se incomodado ou inferiorizado em decorrência do estrabismo foram relatados por 74,2% e 58,4% dos entrevistados respectivamente. No quesito de funcionalidade, 12,1% relataram dificuldade para ler, 14% disseram ter dificuldade na percepção de profundidade (estereopsia) e 17,8% associaram dor ou ardor nos olhos ao estrabismo frequentemente ou sempre. Diferença significativa foi detectada com respeito ao escore de qualidade de vida no aspecto psicossocial entre indivíduos que realizaram e não realizaram cirurgia (teste de Wilcoxon = 158, p -valor $< 0,001$). Indivíduos que realizaram cirurgia possuíam melhor qualidade de vida no aspecto psicossocial.

Conclusões: Nessa avaliação, percebe-se uma interferência negativa muito significativa do estrabismo na qualidade de vida, tanto funcional como psicossocial nos indivíduos pesquisados. Isso demonstra a importância do tratamento do estrabismo, independente da idade, pois ele pode interferir muito na qualidade de vida e bem estar psicossocial e funcional do indivíduo.

Descritores: Estrabismo/fisiopatologia; comportamento social; Qualidade de vida; Questionários

INTRODUCTION

Strabismus is one of the ophthalmological problems that can affect the quality of life of individuals. The quantitative assessment of the quality of life of patients with strabismus may be an important addition to clinical examination because it allows for a greater understanding of the condition and a proper assessment of the effectiveness of treatment⁽¹⁾.

The main purpose of strabismus treatment is the alignment of the visual axes in order to achieve single binocular vision with good image fusion. Other advantages of strabismus correction include the improvement of any abnormal head posture, expansion of the visual field, restoration of stereoscopic acuity, centralization of the

visual field, elimination of diplopia, improvement in ocular motility, improvement in psychomotor development, and restoration of normal appearance⁽²⁻⁷⁾.

Both children and adults with strabismus suffer frequently from various psychosocial and emotional problems such as low self-esteem, negative social prejudice, school bullying, increased social anxiety, fragile interpersonal relations, and job opportunity issues. Strabismus is known by the lay population only as a physiognomic esthetic defect that causes damaged self-esteem and hinders relationships and psychosocial relations. Many authors condemn the use of the terms esthetic or cosmetic for the treatment of strabismus because these terms mean "something made to improve or embellish." However,

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¹ Hospital São Geraldo, Federal University of Minas Gerais (UFMG), Belo Horizonte, MG, Brazil.

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Corresponding author: Geraldo de Barros Ribeiro. Av. Silvano Brandão, 1600 - Belo Horizonte (MG) - 31015-015 - Brazil - E-mail: gbarrosribeiro@gmail.com

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strabismus is a pathological state caused by a process from an underlying disease associated with abnormal binocular vision that leads to a change in the normal appearance of an individual and can affect the quality of life⁽⁸⁻¹²⁾.

In recent years, many studies have evaluated the strabismus-related quality of life (SRQOL). There are some specific instruments for SRQOL assessment, which were elaborated on the basis of interviews with patients and their relatives. Feelings and expressions have been thus collected and used by doctors and researchers for the development of more objective and efficient questionnaires for measuring the impact of strabismus on the patients' quality of life⁽¹³⁻¹⁷⁾.

In 2009, the AS-20 questionnaire was developed for the assessment of SRQOL. It can be used in everyday clinical practice or as a research tool and can be filled out by the patient without supervision. The full version is available with no restrictions as long as it is identified by quoting its original description⁽¹³⁾. On this basis, we developed a similar questionnaire with small changes caused by cultural differences and forms of expression in our country. The questionnaire established by our department was conducted by the researchers instead of being filled out by the patient alone. With this, we could better explain the purpose of the research and the questions, making it possible for use in children aged >8 years. The purpose of this study was to assess and compare the psychosocial, emotional, and functional consequences of strabismus in a portion of the Brazilian population.

METHODS

This study was approved by the Research Ethics Committee of the Hospital das Clínicas at Universidade Federal de Minas Gerais (UFMG) on 09/28/2011. It was conducted in the Strabismus Sector of Hospital São Geraldo at UFMG. A semistructured interview was conducted with individuals aged >7 years old after their parents provided written informed consent. The patients underwent identification and complete eye examination. A questionnaire assessing

strabismus was filled out by the researchers. In addition, the patients completed a specific questionnaire with 20 questions about quality of life (Annex) that was performed specifically for the study. This questionnaire was created by the researchers on the basis of AS-20⁽¹³⁾. Its purpose was to assess patient interaction within social and working environments, sensory perception, and daily life limitations, with five types of answers for each question: never, rarely or very few times, sometimes, frequently, or always. This strategy aimed to facilitate the patient's understanding, make the answering of questions easier, and allow for fewer false-negative answers.

RESULTS

Totally, 101 individuals aged 7-67 years were interviewed. The average age of patients was 22.7 years, with the majority being ≤18 years (53.4%). With regard to the subgroups, a relative predominance of women (61.4%) was observed. With regard to the type of strabismus, 58.4% respondents had esotropia, 37.6% had exotropia, 2% had dissociated vertical deviation (DVD), 1% had left eye hypotropia, and 1% did not have any deviations because he had previously undergone corrective surgery. At the time of the study, the patients were interviewed in the strabismus outpatient department; 75.2% had not undergone strabismus correction surgery and 24.8% had already undergone surgery an average of 2.7 years before the interview. The number of answers for each question and the respective percentages are shown in table 1.

For the first question in the quality of life questionnaire, 68.3% patients always noticed that they had strabismus, and when added together with the answers of "frequently" and "sometimes", this number increased to 83.1%. When asked how frequently strabismus bothered them, 49.5% reported that it always did, and when combined together with the answers "frequently" and "sometimes", this percentage increased to 74.2%. The majority of the patients (54.4%) thought that people were always staring at their eyes, and only 15.8% thought that people never noticed their strabismus. When asked if they felt

Annex. Questionnaire on the impact of strabismus on patient quality of life

Questions	Never	Rarely or very few times	Sometimes	Frequently	Always
1- Do you notice you have strabismus (crossed eyes or lazy eyes)?					
2- Does strabismus bother you?					
3- When you interact with other people, do you feel they notice your strabismus?					
4- Do you feel different (inferior) because of strabismus?					
5- Do you feel that strabismus hinders your performance (at school or at work)?					
6- Do you feel that strabismus affects your relations with other people?					
7- Do you feel that your opportunities (social interaction or at work) are fewer because of strabismus?					
8- Do you imagine what other people are thinking about your eyes?					
9- Do you have more difficulty in making friends because of strabismus?					
10- Do you feel uncomfortable if someone asks something about your eyes?					
11- Do you feel that people avoid looking at you because of strabismus?					
12- Does strabismus hinder your vision?					
13- Do you have difficulty in reading because of strabismus?					
14- Do you feel more stressed out (anxious) because of strabismus?					
15- Do you have difficulty in depth perception (assess the distance of objects)?					
16- Do you feel any discomfort such as pain or burning sensation in the eyes because of strabismus?					
17- Do you have to close one of your eyes to read?					
18- Do you have diplopia (double vision)?					
19- Do you feel eye strain because of strabismus?					
20- Do you think about your strabismus so frequently that it hinders your concentration?					

inferior because of the strabismus, 41.5% reported that they always did. If we considered the answers "sometimes" and "frequently", this percentage increased to 58.4%. Of all the interviewed patients, 22.7% felt that strabismus affected their performance at school or work.

In terms of their relationships with other people, 53% patients felt that strabismus affected their interpersonal relationships at some point in their lives. Of those patients, 22% felt that this was a constant problem. They were asked if social interaction and job opportunities were diminished because of strabismus, and 44.5% answered that it always, frequently, or sometimes happened in their lives.

The majority of patients (71.2%) imagined what other people thought about their eyes, and 34.6% observed the same. The majority of the patients (62.3%) answered that strabismus never prevented them from making friends, but 16.8% felt that it always interfered. The majority of patients (62.3%) always, frequently, or sometimes felt upset when somebody asked them about their eyes, and 16.8% felt that people frequently or always avoided looking at them.

When asked if strabismus hindered their vision, 22.7% answered that they were frequently or always impaired by their problem, and 12.1% said that they had difficulty in reading because of strabismus. With regard to an increase in anxiety related to strabismus, 27.7% were always or frequently anxious. When asked about their assessment of depth perception or the evaluation of the distance between objects, 11% patients reported that they always faced this difficulty. Pain or burning sensation in the eyes was also associated with strabismus; 57.4% patients felt some kind of discomfort. Of all the patients interviewed, 84% reported that they never had to close one eye while reading. The majority of patients (82.1%) did not complain of double vision, but this always happened to 4.9%. Many patients related eye strain with strabismus, 26.7% sometimes felt eye strain, and 18.8% always or frequently felt eye strain. In addition, many patients reported attention deficits related to the problem: 19.8% always experienced them and 26.7% sometimes or frequently experienced them.

A significant difference was detected in quality of life scores for the psychosocial aspect between patients who had and had not undergone surgery (Wilcoxon test, 158; $p < 0.001$). Individuals who

underwent surgery had a better quality of life from the psychosocial aspect (the median value for individuals who did not undergo surgery was -0.467, while that for those who underwent surgery was 1.095). The same difference was detected for the total quality of life score (Wilcoxon test, 169; $p < 0.001$). Individuals who underwent surgery had a better total quality of life (the median value for individuals who did not undergo surgery was -0.475, while that for individuals who underwent surgery was 1.21). No significant difference was detected at the 5% level in the functional aspect of the quality of life score between individuals who had and had not undergone surgery.

DISCUSSION

Some quality of life studies have demonstrated that strabismus may have a more harmful effect than diabetic retinopathy, macular degeneration, or a mild cerebrovascular accident⁽¹⁸⁾. This study demonstrated that strabismus in adults was associated not only with functional effects but also with psychosocial negative effects; both can have a great influence on all aspects of the patient's life.

Reports of the psychosocial negative effects of strabismus in adults were published in 1993; the patients said that every aspect of their lives was affected by strabismus, such as self-esteem, employment prospects, interpersonal relationships, education, and playing sports⁽¹⁹⁾. More severe manifestations have been observed, including an increase in the occurrence of psychiatric disorders in young adults with strabismus, particularly exotropia. A study determined that 41.3% patients with strabismus developed mental health problems compared with 30.7% from the control group^(20,21).

In order to assess the quality of life, it is necessary to focus on the problems associated with the disease of interest. Therefore, it is important to develop specific assessment tools. Previous studies have quantified the negative effects of strabismus using a variety of generic questionnaires that were nonspecific for strabismus, such as the Time Trade-Off (TTO) (how much time of their life they would use to achieve perfect vision) or the Standard Gamble (SG: what would they risk in order to achieve perfect vision). According to the former, there was a 3.7% decrease in quality of life^(20,22,23).

Table 1. Answers for the 20 questions (Q1 to Q20) with absolute numbers and the percentage for each one of them in brackets

	Never	Rarely or very few times	Sometimes	Frequently	Always
Q1	16 (15.84)	1 (0.99)	12 (11.88)	3 (2.97)	69 (68.32)
Q2	18 (17.82)	8 (7.92)	21 (20.79)	4 (3.96)	50 (49.50)
Q3	16 (15.84)	4 (3.96)	20 (19.80)	6 (5.94)	55 (54.46)
Q4	38 (37.62)	4 (3.96)	14 (13.86)	3 (2.97)	42 (41.58)
Q5	52 (51.49)	7 (6.93)	14 (13.86)	5 (4.95)	23 (22.77)
Q6	48 (47.52)	10 (9.90)	18 (17.82)	3 (2.97)	22 (21.78)
Q7	52 (51.49)	4 (3.96)	19 (18.81)	7 (6.93)	19 (18.81)
Q8	29 (28.71)	5 (4.95)	26 (25.74)	6 (5.94)	35 (34.65)
Q9	63 (62.38)	2 (1.98)	17 (16.83)	2 (1.98)	17 (16.83)
Q10	36 (35.64)	2 (1.98)	27 (26.73)	3 (2.97)	33 (32.67)
Q11	59 (58.42)	7 (6.93)	18 (17.82)	2 (1.98)	15 (14.85)
Q12	58 (57.43)	8 (7.92)	12 (11.88)	5 (4.95)	18 (17.82)
Q13	69 (68.31)	5 (4.95)	15 (14.85)	3 (2.97)	9 (8.91)
Q14	52 (51.49)	5 (4.95)	16 (15.84)	7 (6.93)	21 (20.79)
Q15	69 (69.00)	5 (5.00)	12 (12.00)	3 (3.00)	11 (11.00)
Q16	43 (42.57)	8 (7.92)	32 (31.68)	6 (5.94)	12 (11.88)
Q17	84 (83.16)	2 (1.98)	9 (8.91)	0 (0.00)	6 (5.94)
Q18	83 (82.18)	3 (2.97)	9 (8.91)	1 (0.99)	5 (4.95)
Q19	52 (51.49)	3 (2.97)	27 (26.73)	6 (5.94)	13 (12.87)
Q20	52 (51.49)	2 (1.98)	18 (17.82)	9 (8.91)	20 (19.80)

CONCLUSIONS

In our study, we managed to capture the perception of younger individuals aged >7 years, which is the age at which a child can recognize the interference of strabismus with the functional and psychosocial aspects of his or her life. Our study demonstrated that strabismus interfered with patient quality of life. A significant variation was observed in the psychosocial aspect of quality of life between patients who had and had not undergone surgical treatment. With this information, new studies can be conducted for the assessment of quality of life before and after surgical treatment in patients with strabismus.

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