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Original article

19 AMBLYOPIA AND QUALITY OF LIFE Aloe Gupta[1], Dr. Nitin V. Trivedi[2]

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Abstract

Introduction: Quality of Life is an important outcome measure in healthcare.Till today the Quality of Life of Indian amblyopic patient remains poorly understood, as there is no published study discussing them.

Method:A prospective cross sectional design of 91 amblyopic subjects between ages 3 to 12 years were conducted.Age and gender matched subject without any ocular pathology were taken as controls. The subjects underwent detailed clinical evaluation. Amblyopia and Strabismus Questionnaire was translated to Gujarati language and psychometric properties were analysed. The subjects completed the validated Gujarati questionnaire.The differences in Quality of Life among amblyopes and controls were examined, according to age, gender and clinical features.

Result: Amblyopia and Strabismus Questionnaire had an average content validity index was 0.86. The cronbach's alpha coefficient for internal consistent reliability was 0.733.The correlation coefficient analysis examining the test retest reliability was 0.914. The mean total score ofAmblyopia and Strabismus Questionnairewas 82.84 ± 18.44. The mean score for amblyopic subjects were significantly lower (82.84 vs 97.69; $p<0.05$) than controls.There were no statistical significant differences in the total score and individual domains in respect of age and gender. Amblyopic patients with strabismus scored lower in the scale of social contact and appearance in comparison to the non strabismic amblyopes($p<0.05$).

Conclusion: The revised Gujarati version of the Amblyopia and Strabismus Questionnaire appears to be a valid and reliable questionnaire in clinical setting for Indian culture for Gujarati population. The amblyopes have a poorer Quality of Life.

Key words: Amblyopia, Quality of Life, Validity, Reliability, Psychometric property.

Background: Amblyopia is defined as a "a decrease of visual acuity in one eye when caused by abnormal binocular interaction or occurring in one or both eyes as a result of pattern vision deprivation during visual immaturity, for which no cause can be detected during the physical examination of the eye(s) and which in appropriate cases is reversible by therapeutic

measures."[1]Quality of Life (QoL) is emerging as an important outcome measure for interventions designed to improve health, well-being, or both. Quality of Life differs across groups of patients as defined by disease, levels of severity, demographic features, socioeconomic status and cultural background.WHO defines quality of life (QoL) as an "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns[5]"

Till today the Quality of Life of Indian amblyopic patient remains poorly understood, as there is no published study discussing them. There are few Quality of Life questionnaires which have been developed, demonstrating good psychometric property, but the questionnaires has not been translated and validated in any Indian languages. The present study aims to validate the Gujarati version of Amblyopia and Strabismus Questionnaire and to find out the Quality of life of paediatric amblyopes.

Methodology:

Study design and Participants: The investigation used a prospective cross sectional design to study the effect of amblyopia on Quality of Life. For assessment of Quality of Life the sample population was derived from Binocular vision and Orthoptic outpatient department of a tertiary eye hospital located in Western India.

The inclusion criteria for the study were as follows: 1) age between 3 and 12 years with monocular/ binocular amblyopia with or without strabismus 2) no ocular or facial abnormalities or eye disease except strabismus 3) visual acuity of better eye 6/12 or better for monocular amblyopia 4) visual acuity > 6/24 for binocular amblyopia 5) no previous history of surgery 6) not taking any anti-anxiety or anti-depressant medication. In addition, subjects who had participated in the pilot study or for the evaluation of psychometric properties of Gujarati version of the questionnaire were excluded to avoid familiarity with the questionnaire.

Age and gender matched subject were taken as controls. Subjects with any type of amblyopia, strabismus, ocular and systemic disorder, any reported psychological problem were excluded. All the subjects and controls were native of Gujarat and preferred Gujarati as the language of communication. All the clinical examination and guidance to children or parent for filling up the questionnaire, was performed by single investigator (researcher).

For assessment of Quality of Life of amblyopic subject, Amblyopia and Strabismus Questionnaire (A&SQ) was obtained from www.retinafoundation.org/pdf/questionnaire.html. The English version of A&SQ was translated to Gujarati following a standard forward backward translation procedure to develop the Gujarati version of A&SQ. Assessment of psychometric property of the Gujarati version of A&SQ was performed.

Clinical Examination: After detailed history taking, sensory evaluation was performed with Worth Four Dot Test for distance and near. Stereopsis was measured with Titmus test (fly, animals and circles). For measurement of visual acuity Log MAR visual acuity chart was used. The angle of strabismus was measured by the simultaneous and alternating prism cover tests during fixation at distance (6 m) and at near (30 cm). Retinoscopy was performed with cycloplegia, followed by subjective refraction to obtain best corrected visual acuity. Accommodative response was evaluated using Monocular estimation method.

In the next stage Slit Lamp examination was performed for evaluating any anterior segment anomaly. Detailed fundus evaluation with binocular indirect ophthalmoscopy was done to rule out any posterior segment abnormality. Glasses with full correction were prescribed followed by adaptation period of one month. Occlusion hours were determined as per the norm of Pediatric Eye Disease Investigator Group.

Data Collection and Analysis: All data were analysed by SPSS statistical package (SPSS, Version 20.0; significance $P \leq 0.05$ two tailed test). A value of $p \leq 0.05$ was considered significant. The Kolmogorov – Smirnov test was used to examine the normal distribution of the data. Content validity index was used for determining item validity. Convergent validity of the questionnaire was performed by calculating the correlations between scores of each domain and total score. Discriminative validity was evaluated by comparison of the median score of amblyopes as that of normal subject using Mann –Whitney U test. . For reliability internal consistency was estimated by Cronbach's alpha coefficient and test retest reliability was assessed by intra class correlation coefficient. The correlation (r) between the clinical parameters and the five A&SQ domains was measured by the Pearson correlation test (two-tailed). The differences in Quality of Life among amblyopes and controls were examined, according to age, gender, clinical features, using independent sample t tests.

Results:

Psychometric properties: The average content validity index was 0.86, indicating good content validity. The expert agreed that the questionnaire was culturally and conceptually adequate to measure the quality of life of amblyopic subject. AS&Q had low to moderate correlations between the score of each domain with r ranging from 0.146 to 0.509 (p<0.05), but had a high correlation between score of each domain with the total score, which ranged from r=0.378 to 0.802 (p<0.01) indicating adequate convergent validity (Table 1).

Table 1: Correlations between score for each scale and total							
		Domain1	Domain2	Domain3	Domain4	Domain5	Total
Domain1		1	.509**	.422**	.446**	.197	.802**
Domain2		.509**	1	.146	.390**	.172	.378**
Domain3		.422**	.146	1	.417**	.221*	.120
Domain4		.446**	.390**	.417**	1	.186	.628**
Domain5		.197	.172	.221*	.186	1	.639**

| Total | | | .802** | .378** | .120 | .628** | .639** | 1 |

The cronbach's alpha coefficient for internal consistent reliability was 0.733, indicating good internal consistency or homogeneity; the values for all the domains ranged from 0.605 to 0.819. The correlation coefficient analysis examining the test retest reliability for a subset of amblyopic subject who filled up the questionnaire after 15 days interval was 0.914 for overall score and 0.763- 0.975 for the domain ($p<0.05$)

Scale(items)	Test–retest reliability (n=20)	Internal consistency reliability(n=91)
Fear of losing better eye	0.975	0.696
Distance estimation	0.763	0.819
Visual disorientation	0.828	0.605
Double vision	0.924	0.803
Social contact and appearance	0.792	0.721
Total	0.914	0.733
Table 2: Reliability of A&SQ		

Participant Characteristics: A total of 108 subjects diagnosed with amblyopia, which fulfilled the inclusion criteria were enrolled in the study. The entire questionnaire was returned, but 17 were incompletely completed, leaving a total sample size of 91 subjects. Distribution of patients according to type of amblyopia is shown in figure 1. All age and gender matched visually normal subjects, taken as controls, also returned the valid questionnaire.
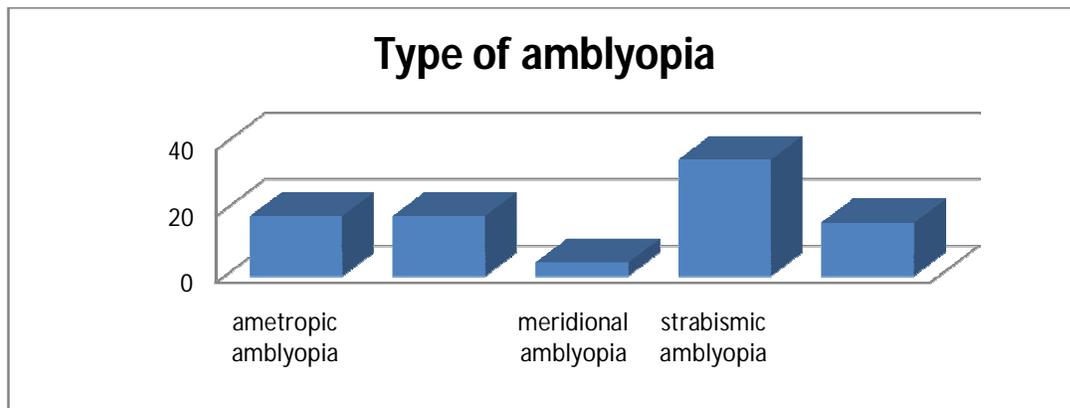
Graph 2: Distribution of subjects according to type of amblyopia

The AS&Q score on total and domains: The mean total score of A&SQ was 82.84 ± 18.44. The mean score for amblyopic subjects were significantly lower (82.84 vs 97.69; $p<0.05$) than controls.The domain "fear of losing better eye" had lowest score while the domain "diplopia" had the highest score. There were no statistical significant differences in the total score and individual domains in respect of age and gender. Amblyopic patients with strabismus scored lower in the scale of social contact and appearance in comparison to the non strabismic amblyopes($p<0.05$). No significant correlation was found with the visual acuity in better seeing eye and the total score.

QoL Score	Total	Domain1	Domain 2	Domain 3	Domain4	Domain 5
Male	83.62	79.55	84.77	82.43	86.27	85.09
Female	81.94	73.33	85.34	84.21	84.44	82.36
Age: 3-7 years	83.24	77.81	84.13	82.96	86.12	85.21
Age:7-12years	82.8	77.03	84.93	83.45	85.23	83.37
Strabismic Amblyopia	82.16	77.02	84.41	81.46	86.88	81.05*
Non strabismic Amblyopia	83.57	74.63	85.75	83.70	86.49	87.3*
Total	82.84	77.08	84.44	83.13	85.55	84.01

Domain 1: Fear of losing better eye, Domain 2: Distance estimation, Domain 3: Visual Disorientation, Domain 4: Diplopia, Domain 5: Social contact and appearance*p<0.05

Discussion: The original A&SQ was developed in Dutch language, an official language of Netherland, later on the questionnaire was validated for Chinese and Italian languages for use in Chinese and Italian population. According to the constitution of India there is no national language[15]. Although Hindi and English are used for official purpose, such as parliamentary or judiciary purpose, state within India have the power and liberty to specify their own official language[16]. Hence a questionnaire common to all Indian nationals, an Indian version, could not be developed. Since the study was performed on the subjects of the state of Gujarat, a Gujarati version of the questionnaire was developed. Further translated and validated version of A&SQ in various Indian languages of the state can yield an overall picture of QoL of amblyopes in India.

The A&SQ is the self-reported questionnaire. As all the subjects belonged to the paediatric age group, there was parental involvement while answering the questions. It is difficult to state that the impact of amblyopia felt by the child is same as that thought by the adult. The parent or guardian assessment of what child perceives can be questionable. Parents can judge the child response from some real like experience such as school work, exam results or peer interactions. To overcome these difficulties parents were instructed to involve the children or to discuss with the child while answering the questionnaire. We cannot also over rule the fact that how difficult it is for the child between 3 to 7 years to fill up the questionnaire without parental involvement. Moreover subject between 7 to 12 years were also included to get more responses directly from the child and to negate the influences of parental judgement.

The overall analysis of the questionnaire showed that there was significant difference in overall scores in Quality of Life between amblyopes and controls. The findings are consistent with the findings of van de Graff et al[17], Macron et al[18] and Bian et al[19]. In the domain "social contact and appearance" female scored slightly lower than males although the differences is not statistically significant. The concept of beauty is integrated with females in Gujarati society; the males are not far behind in consciousness of appearance in day to day life. Strabismic amblyopes scored lower than non

strabismic amblyopes in the domain of "social contact and appearance". The appearance of misaligned eye may cause a feeling of inferiority and negative social attitude in strabismic amblyopes compared with non strabismic amblyopes.

There was no significant correlation between age of the amblyope and the total score. This may be attributed to the paediatric age group of the patient. Also there was no significant correlation between the score and visual acuity as well as the severity of amblyopia.

The mean A&SQ score in amblyopes was 81.72 which is higher in comparison with the findings of van de Graff et al[17], Macron et al[18] and Bian et al[19]. The differences in the score can be attributed to different population considered for the studies. There was variation in ethnicity, socio cultural life as well as the age of the population concerned. It may be hence assumed that the paediatric population with or without strabismus are less affected by their condition, which is reflected in the Quality of Life score.

Conclusion: To conclude, the revised Gujarati version of the A&SQ appears to be a valid and reliable questionnaire in clinical setting for Indian context especially for the state of Gujarat. QoL of amblyopic subject is poorer than controls. There is a significant difference in the QoL of amblyopes to that of controls. There is no difference in the overall QoL with age and gender. Lastly, the assessments of QOL through this questionnaire can be repeated at different times during therapy in order to monitor the changes in quality of life in the management of amblyopia.

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