

## To assess knowledge and attitude of parents toward children suffering from strabismus in Indian subcontinent

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**Purpose:** Strabismus and anisometropia are the most common causes of amblyopia. It can be easily prevented or treated if detected early. With the changing socio-cultural-economic milieu of the society, the perspectives of strabismus in society are gradually changing but still adequate knowledge, awareness, and attitude of parents toward strabismus will help in preventing amblyopia and aid in the proper psychosocial adaptation of such children. This study aimed to assess knowledge and attitude of parents toward children suffering from strabismus. **Methods:** A prospective study was carried out from January 1 to February 29, 2016, through a structured questionnaire to assess the level of knowledge and attitude of parents of children suffering from strabismus. **Results:** One hundred and twenty parents of children with strabismus were interviewed through a questionnaire. Education level of 78 parents was less than graduation (60%) and of 42 parents (40%) was graduation or higher. The majority of the parents, i.e., 116 (96.67%) were bothered due to strabismus. One hundred and one (84.17%) parents felt that their child's strabismus was noticed by others during interaction. Seventy-four (61.67%) parents felt that their children will have difficulty in making friends. Ninety (75%) parents felt uncomfortable if someone asked something about their child's strabismus. One hundred and ten (91.67%) parents considered strabismus as cosmetic stigma. **Conclusion:** Some parents, especially from the lower educated segment, had poor understanding of strabismus, thus resulting in late presentation and ineffective countermeasures. The key to prevent strabismic amblyopia and its psychosocial impacts is to provide health education regarding strabismus.

**Key words:** Knowledge, psychosocial adaptation, strabismic amblyopia

Strabismus and amblyopia are common childhood ocular disabilities with prevalence ranging between 0.13%–4.7% and 0.20%–6.2%, respectively.<sup>[1,2]</sup> The manifest misalignment of the eyes often results in deficient binocular depth perception and even amblyopia. The goal in the treatment of strabismus is to realign the visual axes to eliminate diplopia, produce or restore binocular vision, improve the visual field, and/or provide a normal appearance.

Besides these functional effects, the psychosocial impact of strabismus on both the parents and children is variable but definite and depends on the socio-cultural-economic milieu. The parents based on the knowledge acquired through social environment, information technology, and local physicians seek treatment for their children. Satterfield *et al.*<sup>[1]</sup> found that patients with strabismus felt a negative impact on their lives and reported difficulty with self-image, interpersonal relationships, and school performance. The parents of such children are faced with an enormous decision of planning the course of management based on differing views in the social environment.

Recent studies indicate that despite widely held assumptions to the contrary, there is little relation between the severity of disfigurement and the amount of distress experienced by those affected—for example, by vitiligo, congenital malformation, scarring from trauma, burns, and disease.<sup>[3,4]</sup> Research indicates

that people with an esotropic strabismus are more negatively perceived by others than those with an exotropic strabismus.<sup>[5]</sup> Menon *et al.*<sup>[2]</sup> found no influence of the type of strabismus on the problems perceived by their study.

Besides the cosmetic appearance, there are a number of other short- and long-term issues for which parents become stressed about strabismus in their children. Strabismus can affect depth perception, vision, and a number of other skills. The impact of child's strabismus will be felt in every sphere of their lives; they may have trouble with their schoolwork, participating in sports, interpersonal relationship, and as a consequence may develop low self-esteem and low confidence. Surgery is one of the treatment options to correct the strabismus. However, the very thought of surgery in a child makes parents apprehensive and thus may lead to delayed presentation. These aspects of strabismus leave a negative impact on the quality of life (QOL) of parents.

Our study attempts to study the knowledge and attitude of the parents of children with strabismus in the Indian

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**Cite this article as:** Singh A, Rana V, Patyal S, Kumar S, Mishra SK, Sharma VK. To assess knowledge and attitude of parents toward children suffering from strabismus in Indian subcontinent. *Indian J Ophthalmol* 2017;65:603-6.

### Access this article online

#### Website:

www.ijo.in

#### DOI:

10.4103/ijo.IJO\_619\_16

### Quick Response Code:



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**Manuscript received:** 21.08.16; **Revision accepted:** 30.06.17

subcontinent and evaluate the current scenarios in perception for management. This study aims to give an insight into the psychosocial factors to be considered so that remedial measures may be instituted in the health education to be imparted by medical professionals while dealing with such patients and their parents. The final aim is to promote an early referral, diagnosis, and management of strabismus so that amblyopia can be avoided and effective depth perception can be achieved in the majority of cases.

## Methods

This was a prospective study conducted in the Outpatient Department of Ophthalmology at a tertiary eye care center where 120 parents of children who were having strabismus were included in the study. Ethical clearance for the study was obtained from the Institutional Ethical Review Board. Written informed consent from all individuals participating in the study was taken.

A questionnaire was formulated on the basis of review of literature and socio-cultural-economic milieu to assess the knowledge and attitude of parents whose children were having strabismus. It was a structured, pilot tested and interview-based test with 16 close-ended questions. A total of 120 parents were interviewed personally during their routine visit to the strabismus clinic from January 1, 2016, to March 31, 2016. Data were collected through questionnaire and tabulated in MS-Excel. SPSS v22.0 (IBM SPSS V22.0) was used to analyze the data. Frequency distributions were drawn to study the pattern of responses of the parents. Chi-square test was used to test the significance of difference in distribution of responses. Pie charts were used to depict the data graphically.

## Results

The age of the patients was between 6 months and 5 years. A total of 120 parents were interviewed through a questionnaire

in which education level of 78 parents was less than graduation (60%) and of 42 parents (40%) was graduation or higher than that. Less than graduation was taken as less than college education as per protocol. We analyzed responses of all the questions separately as well as with education level of the parents as it was one of the major factors responsible for the knowledge and attitude of the parents regarding strabismus. The source of information for parents with higher education strata was mainly internet (81.3%) which is much more reliable as compared to the other group where source of information was mainly relatives and peer group (91.1%) which are not very knowledgeable. Thus, education level has a significant impact on knowledge and attitude of parents toward strabismus. About 36.6% of the parents noticed strabismus themselves however 63.3% of the parents noticed strabismus in their child through information by relatives or friends. Nearly, 89.3% of parents with lower education level used to think that there is no treatment for the strabismus however 10.7% parents with higher education level also used to think that there is no treatment for strabismus. This leads to late consultation of doctor which increases chances of development of strabismic amblyopia; thus, proper knowledge is very crucial.

One hundred and sixteen (96.67%) parents were bothered due to strabismus although there was variation in their knowledge level about strabismus. One hundred and one (84.17%) of the parents used to feel that other people notice their child's strabismus during interaction ( $P < 0.0001$ , significant). Ninety (75%) parents used to feel uncomfortable if someone asks something about their child's strabismus. One hundred and ten (91.67%) parents consider strabismus as cosmetic stigma [Table 1].

A total of 113 (94.17%) of the parents were having good knowledge about the facts that strabismus will hinder their child's performance and also that their child will lose on certain opportunities or professions because of this disability

**Table 1: The results of the questionnaire in tabulated form**

Questionnaire	Yes	No	Significance level
1. Did you notice your child has strabismus (crossed eyes or lazy eyes)?	99.17%	0.83%	$P < 0.0001$
2. Does your child's strabismus bother you?	96.67%	3.33%	$P < 0.0001$
3. When you interact with other people, do you feel they notice your child's strabismus?	84.17%	15.83%	$P < 0.0001$
4. Do you feel that strabismus will hinder your child's performance (at school or at work)?	94.17%	5.83%	$P < 0.0001$
5. Do you feel that your child will have few opportunities (social interaction or at work) because of strabismus?	84.17%	15.83%	$P < 0.0001$
6. Do you imagine what other people are thinking about your child's eyes?	81.67%	18.33%	$P < 0.0001$
7. Do you feel your child has more difficulty in making friends because of strabismus?	61.67%	38.33%	$P = 0.0137$
8. Do you feel uncomfortable if someone asks something about your child's abnormal eyes?	75.00%	25.00%	$P < 0.0001$
9. Do you feel that either people avoid looking at your child or stare at him/her because of strabismus?	63.33%	36.67%	$P = 0.0047$
10. Do you feel that strabismus hinders your child's vision?	93.33%	6.67%	$P < 0.0001$
11. Does your child have difficulty in reading because of strabismus?	93.33%	6.67%	$P < 0.0001$
12. Does your child have difficulty in depth perception (assess the distance of objects)?	46.67%	53.33%	$P = 0.5228$
13. Does your child close one of his eyes to read?	65.00%	35.00%	$P = 0.0014$
14. Does your child show any signs of being psychologically affected by strabismus?	36.67%	63.33%	$P = 0.0047$
15. Do you think squint is cosmetic stigma	91.67%	8.33%	$P < 0.0001$
16. Do you know that squint is treatable	76.67%	23.33%	$P < 0.0001$

( $P < 0.0001$  in both, significant). Seventy-four (61.67%) parents felt that their children will have difficulty in making friends ( $P = 0.0137$ , significant). One hundred and twelve (93.33%) were aware about the fact that strabismus can affect child's vision ( $P < 0.0001$ , significant). Only 56 patients (46.6%) were aware of the fact that strabismus impairs depth perception whereas majority 64 (54.4%) were not aware of this fact. Nearly, 36.67% of children showed signs of being psychologically affected by strabismus ( $P = 0.0047$ , significant).

## Discussion

The study was carried out to assess the knowledge and attitude of parents toward children suffering from strabismus in Indian population. In majority of the cases, strabismus is a treatable condition that requires identification and treatment at early age. However, whether the treatment is given in a timely manner depends on parents' knowledge and attitude. Lack of knowledge and information among parents adversely affects the age of presentation and management of strabismus. Parents in our study were segregated into two groups, namely, the ones with a graduate or equivalent degree while the others comparatively were less educated.

Most of the parents in the lower educated strata were unaware of the possible treatments for the condition hence did not seek proper medical advice and timely treatment. This led to the delayed presentation of patients, resulting in higher susceptibility to strabismic amblyopia. Furthermore, their information was primarily sourced from relatives and friends, rather than from more reliable sources such as the internet or other electronic media. This further resulted in a passive approach to identification and treatment of the condition. Parents' knowledge regarding strabismus is very essential to prevent strabismic amblyopia since once amblyopia sets in, it leads to a diminution of vision and loss of binocularity, reducing of vision at a later date, and thus, hampering job opportunities.<sup>[1-3,6]</sup> Proper knowledge can be acquired through health education, internet, or seeking early consultation of doctor.

The other stratum, comprising of parents with graduate or higher level of education, was seen to be more optimistic about their children's condition because of higher levels of awareness. These parents had access to the internet which is a more reliable and comprehensive source of information, as against the parents in the lower educated stratum, who had received incomplete and often misleading information from their peers.

Although in our study, 36.67% of children showed signs of part of the children suffering from strabismus, it is not only cosmetic concern but also it had more implications. It has adverse effects on their self-esteem, self-confidence, ability to obtain work, and interpersonal relationship. These children face ridicule at school and work which severely impairs their socialization, symptoms of which are lower aspiration level and remoteness from social groups - both primary and secondary. Correction of strabismus offers improvement in psychosocial functioning.<sup>[6,7-20]</sup> In a study by Menon *et al.*,<sup>[21]</sup> 95% of participants reported positive changes in appearance, self-confidence, self-esteem, and relationship with friends after being treated for strabismus. However, they found no influence of the type of strabismus on the problems perceived

by their study participants. In our study, we found that most of the parents used to feel that their child will have difficulty in making friends, will have few opportunities in terms of job, strabismus will hinder their child's performance, and also few of them noticed psychological changes due to strabismus in their children. Moss and Robinson *et al.* have summarized the literature relating to the visibility and severity of a disfigurement and psychological distress.<sup>[22,23]</sup> Both concluded that there is no clear relation between the objective severity of a "visible difference" and adjustment. Preoperatively, psychological QOL including apprehensions about strabismus was not apparent postoperatively. Thus, knowledge and attitude of the parents toward early presentation and getting timely management of strabismus is most critical in avoiding the adverse psychological, social, and medical ramifications of this disability. Ozer *et al.* in a study aimed to study QOL in children with autism found that there was significant improvements after management in functional limitations ( $P < 0.01$ ) and psychosocial interactions ( $P < 0.01$ )<sup>[24]</sup> which correlated to our study even though no children with autism was included. Our findings are also supported by a study by Ziaei *et al.* published in 2016, who used a modified version of the RAND Health Insurance Study QOL questionnaire which included changes in anxiety, depression, and social relations as an assessment criteria and found that strabismus surgery positively impacts physical and psychosocial function in children.<sup>[25]</sup>

In our study, we noticed that most of parents were also under constant stress because of the views expressed by others about their child's condition and the sense of discomfort experienced when they were asked about their child's "abnormal" eyes. However, the stress experienced was higher among parents from the lower educated stratum and with lower levels of knowledge about the condition. On the contrary, parents from the higher educated stratum, probably because of their awareness about the possibility of treatment, were less stressed but still misinformed or misguided about the effective management.

## Conclusion

Our study exposes the direct and strong link of the stress, both psychological and social, faced by children suffering from strabismus and their parents with the education and awareness levels of the parents. While more educated parents are not severely impacted by the social stigma of their children being strabismic, they also tend to sometimes delay the management as they are not aware of the vision and stereoscopic disability imposed by strabismus. The key to prevent strabismic amblyopia and its allied psychosocial impacts is to provide health education regarding strabismus and its effects at grass root level.

## Acknowledgments

The authors would like to thank all the participants who consented to participate in this study.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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