



## Full Length Article

## Understanding parental hurdles in accessing strabismus treatment

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## ABSTRACT

**Purpose:** To explore the parental factors that impede early intervention for strabismus and thus identify strategies for improving access to specialized care.**Methods:** This hospital-based cross-sectional study included 110 parents of children under 19 years with strabismus receiving treatment at the squint clinic of a tertiary health care center in north India. A pre-validated survey questionnaire was administered to the participants, that had a section about the socio-demographics of the participants, another section addressed the parental knowledge about strabismus about diagnosis, and the need for an eye examination. It also sought information about referral source, the felt need for squint examination, and reasons for not seeking treatment.**Results:** A total of 110 parents/guardians of strabismus patients (59 exotropes and 51 esotropes) were interviewed using a survey questionnaire. Parents themselves identified 80% of cases, and a substantial link ( $P < 0.0001$ ) was found between the education status of parents and the age of identification of strabismus. Fear of surgical outcomes (41.79%) was a significant barrier to timely surgery with a higher percentage of parents expressing fear of surgical outcomes ( $P = 0.025$ ). The cost of surgery (34.33%) and the non-availability of facilities (23.88%) also delayed the intervention.**Conclusions:** It is essential to educate parents about the importance of strabismus therapy at an appropriate time, stressing its reconstructive rather than merely cosmetic nature, as there are notable gaps in their knowledge. Also, we need to do away with the fear of surgical outcomes of surgical interventions for strabismus.

## 1. Introduction

Strabismus is characterized by misalignment of the eyes and is a significant public health concern due to its potential to cause functional visual impairments and psychosocial challenges for both the affected individual and their family.<sup>1</sup> The pooled estimates from epidemiological studies have found the prevalence of strabismus is 1.93% for all strabismus, 1.23% for exotropia, and 0.77% for esotropia.<sup>2</sup> According to a study, there was an average 19.9-year gap between the onset of present strabismus and surgery.<sup>3</sup> Despite the critical importance of timely intervention, the disparity in care is further exacerbated by widespread misconceptions, including the erroneous notion that treatment should be delayed until children reach a certain age.<sup>4</sup> Moreover, specialist care is hindered due to a lack of awareness, financial constraints, and geographical distance to specialized services.<sup>5</sup>

The decision to seek help for children rests with parents, highlighting

the importance of parental perspectives and the barriers they face in accessing services. To fill the gap between service demands and access, these issues must be addressed so that children receive timely and appropriate care. By identifying these, healthcare providers can develop targeted interventions to improve access to care, dispel misconceptions, and promote early strabismus therapy.

Thus, this survey aimed to explore the parental factors that impede early intervention for strabismus and thus identify strategies for improving access to specialized care.

## 2. Materials and methods

This was a hospital-based cross-sectional descriptive study conducted at the squint and orthoptic clinic of the Department of Ophthalmology in a tertiary care center in north India. Ethical approval was obtained from the Institutional Ethics Committee (AIIMS/IEC/22/314 dated May 27,

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2022), adhering to the principles of the Helsinki Declaration.

The study included 110 parents recruited from the squint and orthoptic clinic. Eligible participants were parents or guardians of children under 19 years old with strabismus receiving treatment at the ophthalmic outpatient department. Those who consented attended in-person interviews using a pre-validated survey questionnaire. Exclusions were made for parents who did not consent.

The survey questions were pre-tested to check for understandability and applicability. The data was collected by trained ophthalmology residents and supportive follow-up supervision was given throughout the process of the data collection period by a strabismus specialist. The proforma consisted of both open and closed-ended questions.

The survey had a section about socio-demographic of the participants such as age, gender, relation to child, education status, and details about birth order and siblings suffering from strabismus. Another section addressed the parental knowledge about strabismus with regard to diagnosis and the need for an eye examination. It also sought information about referral source, the felt need for squint examination, and reasons for not seeking treatment.

### 3. Statistical analyses

The data entry was done in the Microsoft excel spreadsheet and the final analysis was done with the use of Statistical Package for Social Sciences (SPSS) software, IBM manufacturer, Chicago, USA, ver 25.0. The presentation of the categorical variables was done in the form of number and percentage (%). The association of the variables which were qualitative in nature were analysed using Fisher's exact test as at least one cell had an expected value of less than 5. For statistical significance, *P* value of less than 0.05 was considered statistically significant.

### 4. Results

A total of 146 parents were approached but only 110 completed the interview process, rest dropped out due to reasons such as not being the primary caretakers or having insufficient information. Out of 110 children who were attending the clinic were reported to have strabismus with 59 (53.63%) having exotropia and 51 (46.36%) had esotropia.

Table 1 shows the demographic characteristics of the study subjects, including age distribution, gender, school of study, class/grade of the child, respondent relationship with the patient, education status of parents, household location, number of siblings, birth order of siblings, and presence of strabismus in other siblings. Upon analyses, it was observed that a higher proportion of males (56.36%) presented with strabismus compared to females (43.64%). The age distribution at the time of presentation to the ophthalmology clinic varied, with the majority (60%) being over 10 years old. Mothers (45.45%) are slightly more involved than fathers (37.27%) or guardians (17.27%).

The parents in our study belonged to a range of different educational backgrounds; only six (5.4%) were illiterate, while the other parents had varying degrees of education with the majority of the parents had graduated (24.55%) or obtained professional qualifications (13.64%). A substantial link (*P* < 0.0001) was found between the education status of parents and the age at which the child's squint was discovered. In particular, parents who had completed more education were more likely to identify squint in their kids at a younger age.

Sibling dynamics indicate a majority with two siblings (42.73%), most being the firstborn (57.27%). None of the parents themselves had strabismus.

Table 2 shows the parental views on the squint and eye care of the child. Parents were the primary observers of their child's squint, identifying it in 80% of cases. Lack of awareness about treatment was reported by 43.6% of parents, while 27.27% were aware but unsure of whom to approach for care. Surgical intervention was often delayed due to concerns about outcomes, with 60.9% of parents citing fear as a reason.

**Table 1**  
Distribution of demographic characteristics of study subjects.

Demographic characteristics	Frequency	Percentage
<b>Age(years)</b>		
≤1 year	7	6.36%
2–5 years	17	15.45%
6–9 years	20	18.18%
≥10 years	66	60.00%
<b>Gender</b>		
Female	48	43.64%
Male	62	56.36%
<b>School of study</b>		
Does not goes	20	18.18%
Government	25	22.73%
Private	65	59.09%
<b>Class/Grade of child</b>		
Infant	19	17.27%
Preschool	13	11.82%
High school	36	32.73%
Inter	20	18.18%
College	20	18.18%
Job	1	0.91%
Dropout	1	0.91%
<b>Relationship with the child</b>		
Mother	50	45.45%
Father	41	37.27%
Guardian	19	17.27%
<b>Educational status of the parents</b>		
Illiterate	6	5.45%
Can read and write	22	20.00%
Class 10th	21	19.09%
Class 12th	19	17.27%
Graduate	27	24.55%
Professional	15	13.64%
<b>Household</b>		
Rural	44	40.00%
Urban	66	60.00%
<b>Number of siblings of index case</b>		
1	23	20.91%
2	47	42.73%
3	22	20.00%
4 or more	18	16.36%
<b>Birth order of sibling</b>		
1	63	57.27%
2	25	22.73%
3	13	11.82%
4 or more	9	8.18%
<b>Others siblings suffer from strabismus</b>		
No	102	92.73%
Yes	8	7.27%

Additionally, cost was a significant factor, affecting 34.3% of parents, while limited access to facilities delayed surgery for 23.9%.

Despite a majority of parents (84.55%) expressing no issue with their child undergoing squint surgery, non-surgical treatment was preferred, with fear associated with surgery reported by 87.27%.

The study also found that problems during studies were reported by 29%, limitations in social interaction by 20%, and restricted outdoor activity by 13.6%.

Table 3 shows a significant association which revealed that parents with a higher educational status, tended to detect squint in their children at an earlier age more frequently, with a notable association (*P* < 0.0001) across different age groups compared to those with lower educational levels, such as illiterate or those who could only read and write.

A significant association (*P* = 0.007) was observed between the age to take a child for an eye test and the number of siblings, indicating that the timing of seeking eye care varies based on the number of siblings and birth order (Table 4).

Furthermore, Table 5 shows that fear of surgical outcomes a significant barrier to timely surgery with a higher percentage of parents expressing fear of surgical outcomes (*P* = 0.025).

**Table 2**  
Parental views on the squint and eye care of the child.

Parent's awareness	Frequency	Percentage
<b>Squint examination referred by</b>		
Self noticed	88	80.00%
Teacher	11	10.00%
In clinic	9	8.18%
Relative	1	0.91%
Anganwadi worker	1	0.91%
Noticed by relatives	7	6.36%
<b>Reasons for non-utilisation of ophthalmology services</b>		
Aware	6	5.45%
Aware but not knows whom to approach	30	27.27%
Aware but could not afford treatment	4	3.64%
Sought treatment but referred	13	11.82%
Believed it will improve on its own	9	8.18%
Not aware	48	43.64%
<b>Having problem if child undergo surgery</b>		
No	93	84.55%
Yes	14	12.73%
Maybe	3	2.73%
<b>Reason of problem</b>		
Cosmesis	9	8.18%
Fear of surgery	96	87.27%
Too young	5	4.55%
<b>Limitation in activities because of squint</b>		
No	41	37.27%
Studies	32	29.09%
Social interaction	22	20.00%
Outdoor activity	15	13.64%
<b>Reason for delay in surgery</b>		
Fear of outcome	28	41.79%
Cost	23	34.33%
Nonavailability of facility	16	23.88%

**5. Discussion**

Strabismus is a challenging condition not only for the affected individual but also for the family. Early detection can improve visual acuity and binocular single vision, as well as minimize the development of amblyopia and subsequent misalignment. However, there is a heavy burden of ignored cases of strabismus that have not received timely intervention and care. The results of our study provide insights into trends and parental reasons for ignoring the timely treatment of strabismus.

**Table 3**  
Association of parental awareness with the educational status of the parents.

Parent's awareness	Illiterate(n = 6)	Can read and write(n = 22)	Class 10th(n = 21)	Class 12th(n = 19)	Graduate(n = 27)	Professional(n = 15)	Total	P value
<b>Age at which squint was noticed in the child</b>								
<6 months	1	6	6	6	4	3	26	<0.0001 <sup>a</sup>
6–11 months	0	2	2	1	4	6	15	
1–2 years	3	7	6	4	5	1	26	
3–5 years	1	3	5	6	6	3	24	
6–10 years	1	3	2	2	4	1	13	
>10 years	0	1	0	0	4	1	6	
<b>Reasons for non utilisation of ophthalmology services</b>								
Aware	0	1	0	1	2	2	6	<0.0001 <sup>a</sup>
Aware but not knows whom to approach	4	7	4	6	6	3	30	
Aware but could not afford treatment	0	1	1	1	0	1	4	
Seeked treatment but referred	0	0	2	2	5	4	13	
It will improve	1	3	1	0	3	1	9	
Not aware	1	10	13	9	11	4	48	
<b>Age to take child for an eye test</b>								
<6 months	0	1	0	0	1	2	4	<0.0001 <sup>a</sup>
6 months to 1 year	1	1	2	2	2	2	10	
2–5 years	2	7	8	10	11	8	46	
6–10 years	3	8	6	3	7	1	28	
>10 years	0	5	5	4	6	2	22	

<sup>a</sup> Fisher's exact test.

**Table 4**  
Association of age to take the child for an eye test with the number of siblings of the index case.

Age to take child for an eye test	1(n = 23)	2(n = 47)	3(n = 22)	4 or more(n = 18)	Total	P value
<6 months	1	2	1	0	4	0.007 <sup>a</sup>
6 months to 1 year	5	3	2	0	10	
2–5 years	12	22	9	3	46	
6–10 years	3	10	3	12	28	
>10 years	2	10	7	3	22	
Total	23	47	22	18	110	

<sup>a</sup> Fisher's exact test.

**Table 5**  
Association of reasons for the delay in surgery with the type of treatment advised.

Reason for delay in surgery	Surgery(n = 21)	Both {Glasses and surgery} (n = 45)	Glass and patching(n = 1)	Total	P value
Fear of outcome	14	14	0	28	0.025 <sup>a</sup>
Cost	5	17	1	23	
Nonavailability of facility	2	14	0	16	
Total	21	45	1	67	

<sup>a</sup> Fisher's exact test.

In our study population distribution of exotropes and esotropia is 53.63% and 46.36% respectively which aligns with the studies reported in India but is contrary to the global trends of more esotropes as countries with higher intensity of sunlight have exotropia as the more prevalent form of strabismus.<sup>6,7</sup>

Our study had a higher proportion of males (56.36%) presenting with strabismus compared to females (43.64%) though this difference is not statistically significant. This finding is also similar to past studies where gender-based differences in strabismus prevalence tend not to be statistically significant.<sup>8</sup> A majority (60%) of patients presenting with strabismus were over 10 years old highlighting a concerning delay in diagnosis and treatment as strabismus is typically manifested in early childhood.<sup>9</sup> The percentage of mothers who accompanied their children

to treatment was not significantly different from fathers. In today's society, both parents are equally involved in raising children,<sup>10</sup> thus it's essential to recognize the importance of involving all caregivers in the management of pediatric eye conditions to ensure comprehensive care and support for the child.

A significant association exists between parental awareness of strabismus and their educational attainment, as higher-educated parents tend to detect the condition in their children at an earlier age compared to those with lower levels of education. Moreover, there was a notable correlation ( $P < 0.0001$ ) between the age at which a child undergoes their initial eye examination and the number of siblings they have. The children with fewer siblings tend to undergo eye testing at a younger age. This trend suggests that differences in parental attention and available resources within the family may influence the timing of medical care-seeking behaviours.<sup>11</sup> This also suggests that having more siblings could potentially dilute family resources, including access to healthcare, thereby contributing to delays in seeking medical attention. According to another study, parents' ignorance has a negative impact on the age at which strabismus is presented to the specialist for treatment.<sup>12,13</sup> Thus family dynamics and resource allocation affect healthcare-seeking behaviours. Understanding these factors is crucial for addressing disparities in healthcare access and promoting timely interventions for strabismus.

Forty-one (37.2%) children were taken for eye testing only when they reported problems in reading and writing and 12 children reported to the ophthalmologist when the teacher noticed that the child was facing problems with vision. However, the majority of parents had noticed squint themselves. These observations raise some noteworthy issues. Firstly, when the child starts facing problems in reading and writing the child would have already crossed the "critical period" of visual development which is from birth to 3–5 years of age.<sup>14</sup> This is believed to be a sensitive period of development when neural circuits mature to develop depth perception accurately. Secondly, this also suggests a lack of awareness about early reporting of the condition in the educated group including teachers and even Anganwadi workers. Thus, it is reasonable to say that empowering teachers or frontline healthcare workers with knowledge about early intervention of strabismus may be a useful community health approach.<sup>15</sup>

Even after parental awareness of the condition, there is delay in undergoing surgery for squint correction. The delay is arising from multiple factors like ignorance about the condition, fear of the outcome, cost concerns, and non-availability of facilities. We found from Table 2 that 43.6% of parents were ignorant about available treatment options and 27.27% were unsure about where to seek treatment, this suggests more than half delayed surgery. This is different from a study conducted in the western province of Saudi Arabia, where a significant majority (71.5%) of parents were aware that strabismus could be treated.<sup>16</sup> Similarly, in a study conducted in Nigeria, over half (54%) of the parents surveyed were not familiar with treatments for strabismus.<sup>17</sup> This disparity between the awareness of strabismus treatment options in our study and those conducted in other countries, such as Saudi Arabia and Nigeria, is indeed notable. Such a knowledge gap suggests significant disparity in healthcare education, accessibility, and awareness programs. Understanding these potential differences can guide strategies to address the lack of awareness observed in our study. Efforts could include adapting successful awareness campaigns from other regions, tailoring educational materials to local contexts, training healthcare professionals to better communicate treatment options, and collaborating with community leaders to promote awareness.

Fear of surgery outcomes influenced 28 (41.79%) cases, while cost impacted 23 cases (34.33%), and nonavailability of facilities affected 16 (23.88%) cases as shown in Table 2. These findings emphasize that fear, both of surgical outcomes and associated costs, emerges as another set of barriers to timely intervention. Despite the majority being ready for squint surgery for their child, fear remains a prevalent factor, leading to a preference for non-surgical options. This is in line with previous studies

that have highlighted the importance of providing information to both parents and children before undergoing surgery to reduce anxiety.<sup>18</sup>

Moreover, parents who expressed fear of surgical outcomes were less likely to choose timely surgical intervention contributing to treatment delays. Hence, health workers should acknowledge and also address apprehensions of parents at the earliest contact.<sup>19</sup>

Children's ability to achieve the best potential in terms of health depends upon their parents' understanding of health issues which also includes the timely correction of visual impairments such as strabismus.<sup>20</sup> While previous studies have explored parental attitudes towards strabismus<sup>12,16,21</sup> our research aimed to identify actionable solutions at the public health level by investigating the underlying reasons behind parental perspectives.

We observed significant information gaps in the initial diagnosis and also an understanding of long-term implications of compromised stereopsis and binocularity due to delayed strabismus correction similar to previous studies.<sup>12,13,16,17,21</sup> We thus highlight the need for parental awareness in the early detection and treatment of strabismus, uncovering common barriers such as lack of knowledge, fear of surgery, and financial concerns.

It should be understood that healthcare providers play a vital role in emphasizing the importance of prompt treatment. It is concerning that despite possessing adequate knowledge, many parents do not prioritize addressing strabismus in their children, possibly due to financial constraints or surgical anxieties.

To address these obstacles, comprehensive public education initiatives, pre-surgery consultations, and improved healthcare access, including financial support for strabismus surgery are essential. We advocate for community-wide awareness campaigns, school screenings, and accessible early detection programs to overcome these challenges.

One major limitation that was inherent to our study was a hospital-based collection of data which led to the selection bias. However, we should also acknowledge that hospital-based studies are valuable by letting us understand the health concerns at the initial stages. Directly going into the community may not serve the purpose and sometimes research tends to lose the direction to reach meaningful conclusions.

There are some notable limitations when involving parents. Since we are relying on data from a specific population who are already seeking medical care leading underrepresentation of broader community experiences. Moreover, parents who visit hospitals may have higher literacy status about health or even about access to healthcare resources. Thus, this population has a relatively greater awareness of health issues or may have a significantly different socioeconomic status as compared to the general population. Consequently, our findings from hospital-based data might not accurately reflect the factors and this skew can result in an overestimation of awareness and timely intervention rates, masking the challenges faced by underserved populations.

To overcome these limitations, a few strategies can be considered in future. Firstly, expanding the study design to community and field studies for a more comprehensive understanding of health barriers to strabismus care. The second approach can be collaborating with schools, community centers, and local health organizations to facilitate broader outreach. These partnerships can help gather data offering a more accurate reflection of community health issues. Lastly, employing mixed-method approaches that combine reaching out to teachers, and community health workers who can be focus groups to enrich the understanding of parental perspectives and challenges. All these can ultimately lead to better-informed interventions and policies.

Through this survey, we conclude that there are significant gaps in parental awareness and thus it's imperative to educate parents about the necessity of strabismus therapy, emphasizing its reconstructive nature rather than just cosmetic. Highlighting how treatment can improve the patient's visual experience across multiple levels is significant. Also, we should initiate appropriate measures to eliminate the fear associated with surgical outcomes.

## Study approval

The authors confirm that any component of the work reported in this publication that involved human patients or animals was conducted with the ethical permission of all appropriate bodies, and the study was performed under the Declaration of Helsinki. The study protocol was approved by the Institutional Ethics Committee (AIIMS/IEC/22/314 dated May 27, 2022).

## Author contributions

The authors confirm contribution to the paper as follows: Conception and design of study: OC, AS, BK; Data collection: AS, HP, SS, MK, PK; Analysis and interpretation of results: OC, AS, HP, SKM, BK; Drafting the manuscript: OC, AS, HP, MK, SS, PK; All authors reviewed the results and approved the final version of the manuscript.

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## Declaration of competing interest

The authors declare that none of the work reported in this study could have been influenced by any known competing financial interests or personal relationships.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aopr.2024.08.004>.

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