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The Key Informant Strategy to Determine the Prevalence and Causes of Functional Low Vision among Children in South India

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Abstract

Purpose—To report the prevalence and causes of functional low vision (FLV) in school-age children in Coimbatore District, Tamil Nadu, India and to report our experience using the key informant (KI) method in this setting.

Methods—Children suspected of having low vision were identified by KIs or Aravind Eye Hospital personnel in Coimbatore District. All identified children underwent a cycloplegic refraction and full eye exam. A primary cause of decreased vision was determined for each child. The prevalence of FLV was calculated for children 6–14 years old. Spectacles and low vision devices were provided free of charge.

Results—345 children age 6–14 years were referred and 231 had FLV. The positive-predictive value of KI referrals was 64.5%. The prevalence of FLV was 0.071% (7.1 per 10,000; 95% CI 0.062–0.080%) and ranged from 0.026%–0.141% across the district's blocks. Older children (age 11–14 years; OR 1.41; 95% CI 1.09–1.82) and males (OR 1.52; 95% CI 1.16–1.98) had greater odds of being diagnosed with FLV. The most common causes of FLV were retinal disorders (30.0%) and amblyopia (25.5%). Low vision devices were provided to 169 children who had a mean near and distance visual acuity improvement of 0.31 and 0.63 logMAR, respectively ($p < 0.001$).

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Conclusion—This study reports a moderate prevalence of FLV and demonstrates the ability of KIs to identify school-age children with FLV in south India. The provision of basic low vision services can improve visual outcomes in this population.

INTRODUCTION

There are relatively little data on the causes and prevalence of low vision among children in the developing world. However, the World Health Organization (WHO) has noted that 19 million children age 15 years and under are visually impaired worldwide and that 90% live in developing countries.¹ Community-based strategies can be an effective means to obtain local epidemiological data to assess the need for low vision services and plan appropriate public health interventions targeted to specific populations.²

The WHO's International Classification of Diseases (ICD-10) defines low vision based on presenting visual acuity (VA) and therefore includes correctable conditions such as refractive error.³ In contrast, a 1993 WHO working group defined the term *functional low vision* (FLV) as: "...one who has impairment of visual functioning even after treatment and/or standard refractive correction, and has a VA of less than 6/18 to light perception, or a visual field less than 10° from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of tasks."⁴ This definition is clinically rigorous and reproducible, distinguishes low vision from correctable visual impairment, and accounts for visual field loss, which is absent from some other definitions.

Aravind Eye Hospital (AEH) is the only tertiary eye care hospital and the only low vision rehabilitation center in Coimbatore District, Tamil Nadu, India, an area with a total population of more than 3 million people,⁵ nearly 400,000 of whom are school aged children 6–14 years old.⁶ Because low vision is a relatively rare condition among children,⁷ a population-based survey may not always be the most practical method to detect cases.² Therefore, we employed the key informant (KI) strategy, which is a well-described method^{2,8} that relies on community members who are trained to identify and refer children suspected of having low vision. KIs are able to leverage their local knowledge and position in their communities to identify children with a condition of interest at a lower cost and sometimes more efficiently than trained health workers.² The purpose of this study was to estimate the prevalence and causes of childhood FLV in Coimbatore District and to determine the viability of the KI method in this region.

METHODS

This study was approved by the PSG Institute of Medical Sciences Research Human Ethics Committee and adhered to all tenets of the Declaration of Helsinki. We have followed STROBE guidelines in presenting this study.⁹

Setting and Participants

In the 2011 census, Coimbatore District had a population of 3,458,045.⁵ The district is subdivided into 12 administrative blocks; we excluded the block of Sultanapet and the Valparai region of Anamalai from this study since their location or challenging terrain made

it difficult for field workers to reach children. Additionally, we collected and reported data separately for Coimbatore City because of its large population. Thus, after we excluded the 25,278 children in Sultanapet and Valparai, our sampling frame included a total of 325,434 children aged 6–14 years old.⁶ Data were collected from December 2014–December 2016. This study was part of a larger outreach project funded by the United States Agency for International Development to identify all children with low vision in Coimbatore District and provide spectacles and low vision aids to those in need.

Data Sources

We adopted a similar approach to past KI studies, employing multiple referral sources,¹⁰ including referral by KIs; identification by AEH personnel; and referral by allied healthcare workers in Coimbatore City. All participating referral sources were taught how to measure visual acuity (VA) with a Snellen chart and to administer our low vision screening questionnaire (Supplemental Material 1) that asked about basic medical history, timing of onset and type of visual symptoms, and family background. A child was referred for screening VA <6/18 in either eye.

The KIs were community members, most of whom were school teachers (66%), while the rest were “Aganwadi workers” from mother and child care centers. The KIs were underwent a one-day training session led by three of the authors of this study (SJ, JN, SS) and an AECS refractionist. The training included didactic instruction on basic anatomy and physiology of the eye; common pediatric eye diseases; refractive error and low vision; visual behaviors of children with low vision; visual acuity assessment; conducting an interview; and data entry. Practical sessions were then conducted to evaluate and remediate interviewing and VA testing skills until KIs were able to accurately and consistently obtain data. After they completed training, KIs spent 3–4 weeks visiting each village and school (including schools for the blind, special education schools, and standard primary schools) in their respective communities. We regularly assessed the accuracy of each KI’s VA testing and referrals and provided additional remediation for individual KIs as needed. KIs used a structured form to interview community members in order to identify and locate affected children (Supplemental Material 2). After covering their assigned territory, KIs turned in lists of children suspected of having low vision.

AEH personnel were also a source of referrals. AEH operates three satellite vision centers in Coimbatore District. The vision centers are staffed by technicians trained to perform a full eye exam and refraction, prescribe basic medications, and refer to the base hospital in Coimbatore City and/or obtain a telemedicine consultation as needed. Technicians at each vision center underwent structured training at the base hospital to augment their knowledge of pediatric eye disease and learn the screening protocol for this study. In Coimbatore City, our study team also coordinated with special schools and medical professionals, including physiotherapists, occupational therapists, speech therapists, developmental pediatricians, and neurologists to obtain referrals. This referral source was not engaged elsewhere in the district since these medical services were not widely available elsewhere.

Each child suspected of having FLV and one parent were provided free meals and transportation to attend an examination at a low vision camp held near their home or at the AEH hospital in Coimbatore City.

Variables

Sociodemographic data collected from each child included: age, sex, location of residence, parental income, and grade in school. All children underwent a cycloplegic refraction by a refractionist, a comprehensive eye exam by an ophthalmologist, and, when indicated, a low vision assessment by a rehabilitation therapist. Best-corrected VA (BCVA) was measured separately for each eye using a logMAR chart at 6m with standard overhead lighting; the testing distance was varied for those unable to read at 6m. Based on the exam, a primary ocular diagnosis was determined for each child. These are reported using the WHO Eye Examination Record for Children.¹¹ Amblyopia was recorded as the primary diagnosis if no structural abnormality was detected and the child had anisometropia, nystagmus, or strabismus. Cortical visual impairment was assigned as the primary diagnosis if no ocular cause was identified and there was a history or suspicion of a corresponding central nervous system abnormality. All children with treatable ocular problems were referred to AEH in Coimbatore City for further evaluation and treatment.

Children were considered to have FLV if the primary cause of their vision loss was not correctable and they had BCVA < logMAR 0.48 (6/18) and perception of light (PL) in their better-seeing eye.⁴ The population of 6–14 year olds in each block was determined from data provided by the Indian Ministry of Human Resource Development.⁶ The rural and urban population of the District was determined from the 2011 Indian Census.⁵

Provision of Spectacles and Devices

If new spectacles were needed, they were provided to children free-of-charge the same day. If an eye care provider recommended a magnifier or telescope, near (for magnifiers) or distance (for telescopes) vision was measured with and without use of the device. Low vision devices were dispensed on the same day without charge if the child experienced an improvement of 2 lines on the eye chart beyond what was achieved with prescription spectacles. Some children with visual difficulty related to lighting also received reading lamps.

Statistical Methods

We calculated the positive predictive value (PPV) of referral sources as the number of true FLV cases referred divided by the total number of referrals. Point estimates and 95% confidence intervals (CIs) for the prevalence of FLV were calculated using a binomial rather than normal distribution since the number of affected individuals was low. Logistic regression was used to estimate the odds of a child in Coimbatore District being referred and diagnosed with FLV as a function of their age and sex. The one sample test of proportions was used to compare the proportion of children in our sample from rural areas with the general population. A paired t-test was used to analyze changes in near and distance vision after prescription of low vision aids. Statistical analyses were performed using SAS

software, (SAS Institute; Cary, NC), and for all analyses $P \leq 0.05$ was considered statistically significant.

RESULTS

345 children were referred for examination and 231 were confirmed to have FLV (67.0%). The PPV of referrals did not differ between referral sources (64.5% for KIs and 68.9% at AEH; $p=0.38$). None of the children identified at AEH were also referred by KIs. Baseline characteristics of our study sample are presented in Table 1. Among children with FLV, the mean (SD) age was 10.2 (2.7) years; 61.9% were male; 24.7% lived in rural locations; 72.3% had parents with an annual income $<72,000$ Rupees (approximately US\$1,096); 35.5% attended a school for the blind; and the mean BCVA in the better-seeing eye was 1.03 (0.50) logMAR (approximately 6/60). The proportion of children with FLV was not significantly different between those living in urban and rural areas of the district ($p=0.89$) or between those with parental annual incomes above or below 72,000 Rupees ($p=0.36$).

The overall prevalence of FLV in Coimbatore District was 0.071% (7.1 cases per 10,000; 95% CI 0.062–0.080%) and prevalence estimates ranged from 0.026%–0.141% across the blocks (Table 2). The likelihood of a child being referred and receiving a diagnosis of FLV was significantly greater if they were older (age 11–14 compared to 6–10 years; OR 1.41; 95% CI 1.09–1.82) or male (OR 1.52; 95% CI 1.16–1.98). Table 3 presents the frequencies of various anatomic sites of FLV. The two most common anatomic sites/etiologies of FLV were retina (including myopic fundus, retinal degeneration, retinal detachment, retinopathy of prematurity) and amblyopia, which together accounted for more than 55% of all FLV in our sample.

A total of 169 children received at least one low vision device (magnifier, telescope, or reading lamp). Among the 164 children who received a magnifier and the 65 who received a telescope, near and distance VA improved an average of 0.31 (95% CI 0.26–0.35; $p<0.001$) and 0.63 (95% CI 0.59–0.68; $p<0.001$) logMAR, respectively.

DISCUSSION

In this study, we determined that the prevalence of FLV in Coimbatore District was 0.071%. Most cases of FLV were due to either retinal disease or amblyopia. Nearly three-quarters of the children with FLV received at least one low vision device, which resulted in a significant mean VA improvement.

Several other studies^{12–16} have examined the prevalence of FLV among Indian children, which has ranged from 0.06% in Pune¹⁶ to 0.3% in Andhra Pradesh (Table 4).⁷ In the current study, we detected a lower prevalence of FLV compared to some investigations, suggesting either under-ascertainment of cases or that there is less childhood FLV in this region. Although the prevalence detected in this study was low compared to population-based surveys in India, it was comparable to rates detected by KIs in Pune, India¹⁶ and to population-based surveys in other developing countries including China,^{20,21} Malaysia,²² and South Africa,²³ where the prevalence of FLV ranged from 0.065–0.085%. Studies comparing the sensitivity of KIs to systematic household surveys have shown mixed results,

with some suggesting that the two methods are comparable¹⁷ and others noting that KIs may underestimate true population prevalence.^{18,19}

The prevalence of FLV in this study ranged from 0.026%–0.141% across the district's blocks. Several of the higher prevalence blocks (e.g. Coimbatore City, Sulur, and Periyanaayakkanpalayam) are located close to educational or medical services for children with low vision. It is possible that families of children with FLV may choose to reside near low vision services or that ascertainment of cases was easier in these areas. It is also possible that under-ascertainment could have occurred in some of the lower prevalence blocks since this study was not a population-based survey like some prior studies in India.^{12–15}

Interestingly, we found that boys in Coimbatore District were more likely than girls to be diagnosed with FLV, though the reasons for this are not clear. Other studies have either not reported whether prevalence varied by gender, or have not found an association.^{10,12–14} While schools were an important site for identification of affected children, we do not believe that our finding is related to differences in the rate of school attendance between boys and girls. In fact, 91% of girls and 90% of boys attend primary school in Tamil Nadu, which has the highest school attendance rates of any state in India.²⁴ A second possibility is that boys with vision problems were more likely to be brought to Aravind facilities, one location where children were identified. Finally, it is possible that boys in this region suffer from a higher prevalence of FLV. Though we did not obtain data to examine the inheritance patterns of prevalent genetic eye diseases, doing so could help to clarify this question.

A majority of FLV cases in our study were caused by either retinal disease or amblyopia. These were also found to be the most common causes of FLV in other regions of India.^{12,13} Notably, however, we detected a lower prevalence of FLV due to corneal pathology than prior studies. The reason that we detected less corneal disease may be explained by the epidemiologic transition in childhood low vision and blindness that Gilbert and colleagues have described.²⁵ They showed that in locations with higher socioeconomic status, corneal etiologies are less prevalent and a greater proportion of low vision and blindness is attributable to amblyopia, cortical visual impairment, and retinal causes. Compared to most other states in India, Tamil Nadu ranks higher on socioeconomic development indicators,²⁶ and this may in part explain the relatively low prevalence of corneal FLV.

We found that KIs were able to successfully identify school-aged children with FLV in this study. Referrals from KIs had a PPV of 64.5%, which was higher than in some other comparable investigations.^{27,28} Though the reasons for this are not known, it is possible that teachers may be particularly effective KIs due to their relatively high educational attainment or their experience working with children. An important advantage to the KI strategy was that all children believed to have FLV in Coimbatore District were personally identified, and thus we were able to provide low vision aids to all who would benefit from them.

More than 70% of children diagnosed with FLV in our study received a low vision device, which resulted in significant improvement in near and distance VA. These results validate the importance of screening efforts to refer children suspected of having FLV and to provide

appropriate interventions when indicated, as doing so may have the potential to improve quality of life, productivity, and day-to-day functioning.²⁹

Limitations

There were several limitations to our study. First, we may not have enumerated all children with FLV in Coimbatore District, as KIs may have failed to identify some children. One reason this could have occurred is if teachers were less to identify children outside of schools, especially if children with vision problems were less likely to attend school. We did not survey Sultanapet or the Valparai region of Anamalai. These areas were difficult to reach and therefore may experience decreased access to eye care and could have a relatively high prevalence of FLV that would have led to an underestimation of the overall prevalence in the district. Like prior KI investigations that used multiple referral sources,^{10,27} we also did not employ a pure KI strategy. Children identified at AEH vision centers and at the Coimbatore hospital were included. No children identified at AEH were also referred by KIs, though we did not determine if this was because KIs or families chose not to screen those who were already AEH patients. Also, due to the difficulty of detecting and quantifying peripheral field loss in a community-based setting, we did not include children with constricted visual fields and preserved acuity. Thus, we may have underestimated of the prevalence of FLV due to causes such as retinal degenerations or glaucoma. The current study focused on one district in northern Tamil Nadu and its results are not necessarily generalizable to other regions of India.

Future work should examine data from population-based surveys to determine whether the rate of FLV varied by sex in other Indian samples, as this may help to explain whether this finding is a biological or cultural phenomenon, or due to this study's ascertainment methodology. Additionally, work could be done to identify the occupational and sociodemographic characteristics associated with optimal referral patterns among KIs in India and elsewhere, as well as to rigorously validate a standardized KI methodology, as this could enhance confidence in the results of future studies.

Conclusions

In summary, there was a moderate prevalence of FLV among children in Coimbatore District and the most common causes were retinal disease and amblyopia. A majority of children with FLV experienced considerable improvement in their near and/or distance VA with the use of a low vision device. This study also demonstrates both the feasibility of using KIs to identify school-aged children with low vision in south India, as well as the potential for basic low vision services to substantially improve visual outcomes in this population. Future work could provide furtherer justification for investment in pediatric low vision care by documenting the functional and economic benefits of low vision outreach and services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Baseline characteristics of children referred for suspicion of functional low vision.

	All Referred Children (N=345)		Functional Low Vision (N=231)	
	Mean	SD	Mean	SD
Age, years	10.1	2.7	10.2	2.7
	Frequency	Proportion (%)	Frequency	Proportion (%)
Sex, male	199	57.7	143	61.9
Rural residence	84	24.4	57	24.7
Annual parental income, Indian Rupees [/]				
<72,000	244	70.7	167	72.3
72,000	101	29.3	64	27.7
Better Eye logMAR BCVA (Snellen)				
0.48 (6/18)	88	25.5	0	0.0
< 0.48 (6/18) and 1.00 (6/60)	124	35.9	124	53.7
< 1.00 (6/60) and 1.30(3/60)	25	7.2	25	10.8
< 1.30 (3/60) and 1.78 (1/60)	40	11.6	40	17.3
< 1.78 (1/60) and PL	42	12.2	42	18.2
NPL	26	7.5	0	0.0

BCVA: best-corrected visual acuity; PL: perception of light; NPL: no perception of light

[/]72,000 Rupees is approximately \$1,096 U.S. Dollars

Table 2

Prevalence of functional low vision in Coimbatore District.

Location	Cases	6–14 year old Population	Prevalence (%)	95% CI
Overall District	231	325434	0.071	0.062 – 0.008
Block/City				
Anaimalai	7	18367	0.038	0.010 – 0.066
Annur	7	15587	0.045	0.012 – 0.078
Coimbatore City ^a	52	58709	0.089	0.065 – 0.113
Karamadai	14	30119	0.046	0.022 – 0.071
Kinathukadavu	4	15141	0.026	0.001 – 0.052
Madukkarai	11	18564	0.059	0.024 – 0.094
Periyanyakkanpalayam	39	36476	0.107	0.073 – 0.140
Pollachi North	15	14479	0.104	0.051 – 0.156
Pollachi South	14	25847	0.054	0.026 – 0.083
Sarcarsamakulam	17	46874	0.036	0.019 – 0.054
Sulur	37	26298	0.141	0.095 – 0.186
Thondamuthur	14	18973	0.074	0.035 – 0.112

CI: confidence interval;

^a indicates a city rather than a block

Table 3

Causes of functional low vision by anatomic site.

Diagnosis ^a	Frequency	Proportion
Whole globe	15	6.5%
Cornea	1	0.4%
Lens	14	6.1%
Uvea	9	3.9%
Retina	69	30.0%
Optic nerve	7	3.0%
Normal globe		
Amblyopia	59	25.5%
Cortical visual impairment	26	11.3%
Other ^b /unknown	30	13.0%
Missing data	1	0.4%

^aDiagnosis categories/anatomic sites are defined according to the World Health Organization Eye Examination Record for Children [16]

^bOther causes included: craniosynostosis; presumed neurological etiologies without signs of optic nerve pathology; or presumed neurological etiologies without history or evidence of cortical visual impairment.

Table 4

Comparison of the prevalence of childhood functional low vision in various Indian studies.

Location	Urban/Rural	Ages (years)	Prevalence	95% CI
Coimbatore, Tamil Nadu ^{a,b}	both	6–14	0.071%	(0.062–0.080)
Andhra Pradesh [11, 14]	rural	7–15	0.275%	(0.137–0.492)
Delhi [12]	urban	5–15	0.235%	(0.129–0.395)
Pune [18] ^b	urban	0–15	0.06%	(0.04–0.08)
Southern Tamil Nadu [13]	rural	6–9	0.157%	not available

^a current study;

^b key informant study