Original Article

Identifying barriers to referrals in preschool-age ocular screening in Southern India

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Purpose: The aim of this study was to identify barriers to follow-up among children aged 0–5 years who failed ocular screening. **Methods:** A cross-sectional, descriptive study was conducted for screening children aged 0–5 years, covering three districts of South India from January 2012 to December 2012. Screening was performed under Lavelle Paediatric Eye Care Project, included under Integrated Child Development Services (ICDS) program. A survey was conducted within 60 days of the screening, with the parents of children who failed to follow up at base hospital. Family demographics, parental awareness of childhood eye diseases and eye care for children, and barriers to follow up eye care were assessed. **Results:** A total of 19,408 children were screened. Among them, 913 (4.7%) failed screening and were referred. 319 (35%) of those referred attended the base hospital, of which 133 (41.6%) had no abnormality on detailed examination. 111 (34.7%) had refractive errors, 10 (3%)) had strabismus, and three (1%) had amblyopia. 62 (19.4%) had other ocular conditions. Parents of 324/594 (65%) children who did not attend the base hospital were traced and completed the questionnaire. Low level of education, low income, types of occupation, and distance factors were the main barriers to follow-up of referral in preschool children. Factors such as cost of time taking off from work and monthly family income were statistically significant ($P < 0.001$). **Conclusion:** Education, financial status, and distance factors were the main barriers to follow up of referral in preschool children. Identification of these barriers to follow up and improving the referral services could help in detecting visual problem effectively.

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Periodic vision screening is recognized as an integral part of preventive pediatric health care. Vision problems, including amblyopia, strabismus, and significant refractive error, are some of the most common childhood conditions leading to decrease in visual acuity and poor academic performance. Vision screening is important to achieve the full academic potential of children and better quality of life, if carried out earlier at preschool.[1-5] Preschool and school vision screening is part of government health programs in many countries but referral criteria may somewhat vary.[1-6] To benefit from screening, children with abnormal screening test results must receive follow-up eye care, but this is usually delayed for months or years and very less attention is paid towards the cause of this delay.[7,8]

The U.S. Preventive Services Task Force recommendation on screening for visual impairment in children younger than age 5 years found fair evidence that screening tests have reasonable accuracy in identifying strabismus, amblyopia, and refractive error in children with these conditions.[3,4]

The Vision In Preschoolers (VIP) Study is a multicenter, multidisciplinary, prospective clinical study in the USA to evaluate screening tests for identifying preschool children in need of comprehensive eye examinations. They concluded that the best screening tests administered by eye care professionals were noncycloplegic retinoscopy, Retinomax Autorefractor, SureSight Vision Screener, and linear, crowded Lea Symbols visual acuity (VA) at 10 feet. The best screening tests administered by trained nurses and/or lay screeners were Retinomax, SureSight, and VIP single, crowded Lea Symbols VA screening test system at 5 feet.[9-11]

According to UK National Screening Committee's recommendations, vision screening for reduced acuity in either eye is advocated in all children aged 4–5 years and they advocated that screening at preschool age could give false positive results with no additional benefit for amblyopia treatment.[2]

However, much variations exists in screening protocols between different developing and developed countries. These variations can be attributed to content of vision screening program including the age at which preschool child is screened, referral criteria of screening program and different personnel administering tests such as photo screeners and vision charts, which are used in screening programs.

Preschool vision screening study in New Zealand found uptake of referral to be 79%. Among those who were seen at

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hospital, 214 (38%) had normal vision, 112 (20.1%) required no treatment, 23 (4.1%) refractive error, and 36 (6.4%) had amblyopia.[12]

Most of the published studies are conducted on visual screening failure in school or community-based settings.[8,13-15] Fewer studies have reported barriers to follow up in preschool children.[16-19] A previous large community-based study in the US preschool vision screening program found that only approximately half of those children who were referred received follow-up care.[20]

No similar data are available regarding follow-up from the primary care setting in India. Current national data on visual health and care of preschool children are not available. In India, there is lack of studies conducted on preschool children vision screening.

This study was conducted to identify barriers to follow-up care faced by families that may delay seeking professional care following preschool eye screening program.

Methods

This was a cross-sectional, descriptive study conducted on age group 0–5 years included under Integrated Child Development Services (ICDS) from January 2012 to December 2012 in Southern India. This study was conducted adherent to the guidelines of the Declaration of Helsinki, and approval was taken from Institutional Review Board. Informed consent from parents was taken before screening. Informed consent was taken from the 324 parents/guardians who failed to follow up at base hospital for which they agreed to be interviewed. This study was conducted in three districts covering Tirunelveli, Tuticorin, and Kannyakumari of South India, as these districts lie within 12–49 miles from the base hospital [Fig. 1]. These selected district's ICDS centers were screened under Lavelle Paediatric Eye Care Project. ICDS is Government of India sponsored program dedicated for primary social welfare to tackle malnutrition and health problems in children under 6 years of age and their mothers. Each district has ICDS centers that are divided in urban, rural, and tribal centers. The ICDS team comprises the Anganwadi workers, Anganwadi helpers, supervisors, child development project officers (CDPOs), and district program officers (DPOs).

ICDS eye screening Program Planning was planned as per following: [Fig. 2]

1. **Government approval for the ICDS screening program:** Permission was obtained from the principal secretary/special commissioner of ICDS. After getting the approval for the screening program from the commissionerate of ICDS, the details of ICDS centers were obtained from the District Program Officer
2. **Awareness program for the Aganwadi teachers:** An awareness program was organized on the day of monthly meeting of the Aganwadi teachers at the ICDS block office. Community coordinator (field worker) distributed the pamphlets and posters on pediatric eye diseases and oriented them regarding the pediatric ICDS screening program
3. **Planning a route map of geographical target area:** A route map was prepared, seeking help of Aganwadi workers/preschool teachers of the ICDS centers, depending upon the distance between the ICDS centers and a particular place

Figure 1: Selected districts (Tirunelveli, Tuticorin, and Kannyakumari of South India) ICDS centers that were screened under "Lavelle Paediatric Eye Care Project". ICDS = Integrated Child Development Services

4. **Communication:** On previous day of the camp, the camp organizer visited the ICDS centers which they were planning to cover in the screening program and informed to the Aganwadi workers/preschool teachers of their respective ICDS centers, regarding the screening program, so that it can be communicated to the parents of the children of nearby area.

Pediatric eye awareness: Posters on refractive error, squint, and cataract were distributed to all the ICDS centers by the field workers. To screen 0–5 year's age group in ICDS centers, a team of one trained optometrist, one mid-level ophthalmic personal staff, and one community coordinator/field worker from a tertiary eye hospital in Tirunelveli went to each center of a particular area on a scheduled day.

With the help of noncycloplegic retinoscopy technique (NCR), children were screened by trained and experienced pediatric optometrist. Ocular history, external inspection of the eyes and lids, ocular motility assessment, cover–uncover test, pupil examination, and red reflex examination was performed by optometrist. The children with retinoscopy findings including anisometropia (cylindrical or spherical) >1.00 diopter (D), hyperopia >3.50 D in any meridian, and myopia >3.00 D in any meridian were referred to base hospital. Those with other defects such as cataract, strabismus, nystagmus, allergic conjunctivitis, and noncooperative children were referred to the base hospital. Parents/guardians of children who were referred to base hospital for further evaluation were provided with the information regarding community resources available for eye examination and a referral card in Tamil language (regional language of South India) by the team.

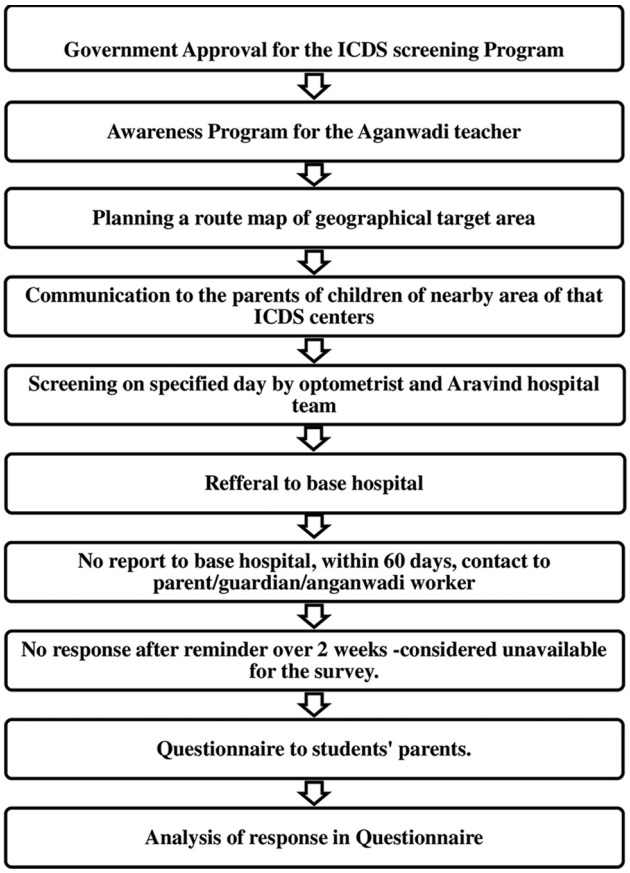

Figure 2: ICDS eye screening Program Planning and follow-up of failed referral cases. ICDS = Integrated Child Development Services)

The details of the children regarding their name, age, sex, father's/mother's/guardian's name, address, ICDS center name, and number were registered in the register note. Pediatric eye disease brochures were given to all the parents/guardians/ Aganwadi workers. After finishing the eye screening of children at one center, the team moved to the next nearby ICDS center for the screening of children in a single day or the other proposed planned day.

In case of no response from parent/guardian regarding referral or patient not reporting to base hospital within 60 days, the parent/guardian/Anganwadi worker were contacted inquiring about the status of the referral. The fieldworkers coordinated with Anganwadi workers to call parents/guardians of the absentees to ICDS center on a specified day. Families who were unable to reach their respective centers even after three attempts of calls, made either by field worker or Anganwadi worker, over 2 weeks of period, were considered unavailable for the survey.

A questionnaire was given to the parents/guardian of the absentees, in regional language, by the coordinator and details were obtained from them. The survey consisted of 22 questions regarding family demographics, parental awareness of childhood eye diseases and eye care for children, family history of eye diseases, and perceived barriers to follow up eye care and required approximately 20 min to complete it. Parents were asked to provide their answers without prompting. Educated parents were able to read and complete themselves, in case of any doubt field coordinator explained it to parents. For illiterate parents and guardian questionnaire was read out by field coordinator and their responses were filled by coordinator.

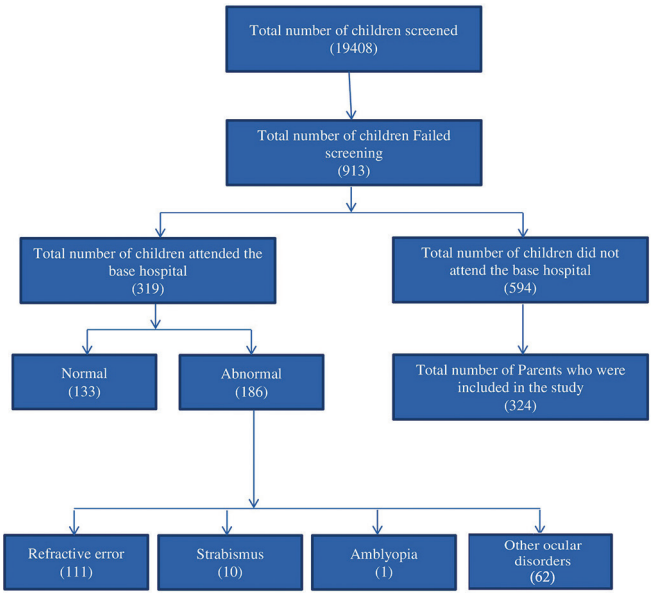

Figure 3: Vision screening results of preschool children

Analysis plan

The epi info software for the data entry of the study survey forms was used. The statistical analysis was performed by STATA11 (College Station, TX, USA). The Fisher exact test of independence was performed to identify variables affecting the likelihood of obtaining follow-up eye care.

Results

The demographic details and family background characteristics are presented in Tables 1 and 2.

Of 19408 preschool children screened, there were 11,002 were boys and 8406 were girls. The mean age was 4.1±0.56 years. Among them, 913 failed the screening and 319 (35%) attended the base hospital. Four children who were not cooperative were referred to hospital. Total 594 (65%) children did not attend the base hospital, of which 324 (54.5%) parents of these children completed the survey with us. Parents of 270 (45.4%) children were unavailable for the survey, even after repeated attempts made to call them. Of the 319 children who attended to base hospital, 133 (41.6%) were normal, 111 (34.7%) had refractive errors, 10 (3.1%) were diagnosed with strabismus, and three (1%) with amblyopia [Fig. 3]. Others (62) had ocular diseases such as allergic conjunctivitis, nystagmus, microcornea, and colobomas. Thirty-one had allergic conjunctivitis, seven had acute catarrhal conjunctivitis, four had congenital naso lacrimal duct obstruction, six had hordeolum internum, two had microcornea, four had chalazion, three had iris coloboma and retinochoroidal coloboma, two had congenital ptosis, and three had nystagmus which were treated accordingly.

Seventy-nine children were prescribed glasses which were free of cost. Rest 32 children had astigmatism <1.0 diopter cylinder and myopia <0.75 D and for these cases parents were counseled that glasses could be needed later.

The mean age of children who did not follow to the base hospital was 4.20 ± 1.09 (2–5) years. Family income was <81.104 USD (5000) in 83.0%. Parent's responses to the questions concerning their awareness of childhood eye diseases and eye care for children are described in Table 3. In our study, 98.8%

Table 1: Demographic characteristics of preschool children who failed to follow-up at base hospital (*n*=324)

Variable	*n* (%)
Age (years)	
Mean (SD)	4.20 (1.0)
Range	2-5
Sex	
Male	169 (52.2)
Female	155 (47.8)
Area	
Rural	291 (89.8)
Urban	33 (10.2)

n: number of children; %: percentage

Table 2: Family educational, income, occupational, and family support background of children who failed to follow-up

Variable	*n* (%)
Father's education	
High school	153 (47.4)
Illiterate	135 (41.8)
Intermediate (+12)	28 (8.7)
Graduate	7 (2.2)
Mother's education	
Illiterate	149 (46.1)
High school	124 (38.4)
Intermediate (+12)	42 (13.0)
Graduate	8 (2.5)
Monthly family income	
<5000	269 (83.0)
5000-10,000	46 (14.2)
>10,000	9 (2.8)
Occupation of father	
Daily wages	263 (81.9)
Private employee	34 (10.6)
Self-business	17 (5.3)
Government employee	7 (2.2)
Occupation of mother	284 (87.9)
House wife	24 (7.4)
Daily wages	10 (3.1)
Government employee	3 (0.9)
Self-business	2 (0.6)
Private employee	
Family support	
Nuclear family	248 (76.5)
Joint family	67 (20.7)
Single parent	8 (2.5)
Authorized guardian	1 (0.3)
Age group of children	
1-4 years	289 (89.2)
Above 4 years	33 (10.2)
0-1 year	2 (0.6)

n: number of children; %: percentage

parents were aware about the Eye Screening program at ICDS center; 98.2% of parents knew where/how to go for eye checkup after screening for follow-up care.

Cost of taking time off from work and distance factor were most influential factors [Table 4]. Monthly income, costs for transport, and fees for service were not associated with uptake

Table 3: Survey participant responses to questions about childhood eye diseases and eye care awareness for children

Variable	*n* (%)
History of any know ocular eye disease in the family?	
Yes	157 (48.5)
No	167 (51.5)
Do you know where or how to go for eye checkup?	
Yes	318 (98.2)
No	6 (1.8)
Whether there was proper communication by field worker or Anganwadi workers?	
Yes	320 (98.8)
No	4 (1.2)
Are you aware about child's ocular problem?	
Yes	290 (89.5)
No	34 (10.5)
Is there unwillingness to wear glasses (psychosocial)?	
Yes	34 (10.5)
No	290 (89.5)
Is there any other morbidity of child which led to absenteeism?	
Yes	4 (1.2)
No	320 (98.8)
Is there no one else to look after the other children?	
Yes	12 (3.7)
No	312 (96.3)
Did you proper to consult any other eye hospital or doctor?	
Yes	11 (3.4)
No	313 (96.6)
Did you forget to come base hospital?	
Yes	14 (4.3)
No	310 (95.7)
Whether other family member ill?	
Yes	3 (0.9)
No	321 (99.1)

of referrals [Table 5]. Factors such as monthly income vs. cost of transport to hospital and doctor's fees were not statistically significant ($P = 0.088$ and $P = 0.553$ respectively) [Tables 6a and b].

Factors including education of both of the parents, their income, occupation, cost of time taking off from work, and distance–time were the main barriers. The factors that were not responsible for failure to referral include the surveyed parent family support, family history of eye diseases, and unwillingness to wear glasses, or other family member illness, communication failure, to take care of other sibling, and preference to other hospital.

Discussion

Studies conducted by Simons, Castanes, Kemper *et al*. and Alley *et al*. in preschoolers in the USA showed that visual impairment caused by refractive errors, amblyopia, and strabismus are common conditions among young children, affecting 5%–10% of all preschoolers.[13,17-19] A recent estimate from Southern India shows that around 1% of school children are affected by

Table 4: Influence of cost and distance barrier factor

	Least influential	Moderate influential	Most influential
Cost of transportation	156 (48.2)	96 (29.6)	72 (22.2)
Cost of hospital and doctor's fees	79 (24.5)	172 (53.2)	72 (22.3)
Cost of taking time off from work	33 (10.2)	105 (32.4)	186 (57.4)
Distance factor time	40 (12.3)	103 (51.8)	181 (55.9)
Distance factor transportation	161 (49.7)	100 (30.9)	63 (19.4)

Table 5: Barrier relating to Monthly family income vs. cost of taking time off from work

Monthly income (in Rs)	Barrier factor (taking time off from work)			Total	*P**
	Least influential	Moderate influential	Most influential		
<5000	32 (11.8)	97 (36.05)	140 (52.04)	269 (100)	<0.001
5000-10,000	1 (2.1)	5 (10.8)	40 (86.95)	46 (100)	
>10,000	-	3 (33.33)	6 (66.67)	9 (100)	
Total	33 (10.18)	105 (32.4)	186 (57.4)	324 (100)	

Table 6a: Barrier relating to monthly family income vs. hospital and doctor's fees

Monthly income (in Rs)	Barrier factor (hospital and doctor's fees)			Total	*P**
	Least influential	Moderate influential	Most influential		
<5000	61 (22.7)	144 (53.7)	63 (23.6)	268 (100)	0.553
5000-10,000	15 (32.6)	23 (50)	8 (17.4)	46 (100)	
>10,000	3 (33.3)	5 (55.6)	1 (11.1)	9 (100)	
Total	79 (24.4)	172 (53.3)	72 (22.3)	323 (100)	

*Fisher's exact test

Table 6b: Barrier relating to monthly family income vs. cost of transportation to hospital

Monthly income (in Rs)	Barrier factor (cost of transportation)			Total	*P**
	Least influential	Moderate influential	Most influential		
<5000	137 (51)	77 (28.6)	55 (20.4)	269 (100)	0.088
5000-10,000	15 (32.6)	15 (32.6)	16 (34.8)	46 (100)	
>10,000	4 (44.4)	4 (44.4)	1 (11.1)	9 (100)	
Total	156 (48.1)	96 (29.6)	72 (22.3)	324 (100)	

*Fisher's exact test

amblyopia and nearly a third are having severe form of the disease.[15] Menon *et al*. reported that vast majority of patients with amblyopia in the study presented between 4 and 10 years of age.[21] Amblyopia is the most frequent cause of monocular visual impairment in both children and adults.[21,22]

Approximately 80% of preschool age children never undergo an eye examination.[17] Preschool vision screening typically seeks to detect amblyopia, strabismus, and high refractive errors.

In India, there is lack of studies conducted in preschool children vision screening. In our study, 98.8% parents were aware about the Eye Screening program at ICDS center and where to go for follow-up but uptake of referral was only 35%. In contrast, study conducted by Forster *et al*. in primary eye care setting at Connecticut, USA found that miscommunication of visual acuity screening failure was the main reason for not obtaining follow-up.[22] Approximately 30% of parents said they did not have information sources about eye diseases. Most of the surveyed parents in their study did not understand the risks of untreated strabismus and amblyopia, limitations of a visual acuity screening, or the difference between a screening and an eye examination.[22]

Parents of 270 (45.4%) children were unavailable for the survey, even after repeated attempts made to call them. This can be attributed to the occupation of the parents; majority among them were daily-wage worker; leaving the work even for a single day was not affordable for them. Furthermore, our study population was a predominantly rural population, and over half of the surveyed parents both mother and father were illiterate. Most of the parents were single working and were daily-wage workers, earning < 80 USD a month; therefore, to take time off from work was a reason of financial loss, hence a major factor for barrier to follow-up. Cost of taking time off from work and distance factor were the most influential factors among cost and distance factors. Cost of transportation to hospital and hospital fees was not major reason for failure of follow-up.

Kemper *et al*. in a study of Preschool Vision Screening in Pediatric Practices found that common barriers were

time-consuming screening tests and uncooperative children. Half of them reported that there should be separate reimbursement for vision screening.[16]

Castanes in his study stated that social contextual barriers including lack of awareness, inconvenience, language, and a lack of providers, along with financial barriers and political barriers were major factors.[15] Lack of awareness remains a major problem at all levels. Moreover, there are additional factors that put preventative medicine for vision at a disadvantage compared to other pediatric demands like immunizations.[16]

The results of our study may not be applicable to other demographic settings. The limitation of this study was that only non-cycloplegic refraction was used and other vision screening methods were not used; therefore, some of the children with vision problems, even if they were part of the screening program, could have been missed. Another major limitation was that the questionnaire was not pretested and validated which could influence responses by parents and thus results. The cost-effectiveness of this preschool screening could not be exactly determined as it was a part ofLavelle Paediatric Eye Care Project which was for period of 3 years for pediatric age upto 15 years plz remove of and replace it by upto.

In developing countries like India, there is a possibility that parents of low socioeconomic state residing in rural areas will not send their children to school before 5 years and non-cyloplegic retinoscopy therefore remains mainstay of screening. The screening protocols regarding appropriate age can be entirely different for urban preschool population even in developing countries.

Conclusion

In this study, 4.7% of children failed screening. Among those who attended the base hospital 41.6% were normal. The proportion who were normal or without an abnormality the parents could readily detect is likely to be even higher amongst children who did not attend the base hospital. Failure to attend the base hospital may be because their child was normal or conditions like allergic conjunctivitis or red eye might have resolved.

This study emphasizes the need for preschool screening and provides insight for recommendations which could be laid for improving referral follow-up by creating awareness among ICDS workers and regular SMS reminder or postal letter communication to parents.

Furthermore, regular screening during the preschool years is advisable as vision defects may arise at various stages in childhood. Strategies to improve follow-up rates after a failed screening may include communicating the results clearly and consistently, providing education about the importance of timely follow-up, and offering logistic support for accessing eye appointments to families.

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Conflicts of interest

There are no conflicts of interest.

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