

Childhood Vision Screening in Western South Dakota: Examining Barriers to Post-Vision Screening Follow-up Referral

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Abstract

Background: Poor follow-up after post-screening referral is a challenge faced by vision screening organizations. This study examines barriers to follow-up eye care in children who were referred for a comprehensive eye exam following a vision screening event in western South Dakota.

Methods: Children referred for a comprehensive eye exam following a screening event by Northern Plains Eye Foundation Western South Dakota Lions Children's Vision Screening Initiative (CVSI) from September 2014 to February 2015 were identified for a telephone survey. Parents/guardians of these children were contacted and asked a series of questions aimed at assessing the barriers to obtaining eye care.

Results: Of the 282 children identified, parents/guardians of 63 were successfully surveyed (22.3 percent), 38 had attended an appointment (60.3 percent), and 19 (30.2 percent) brought the CVSI referral form when they attended the appointment. When parents/guardians of the 25 children who had not attended an appointment were surveyed, 12 (19 percent) were not aware the screening results indicated a full eye exam was recommended, 10 (15.9 percent) identified barriers to scheduling an appointment, and three (4.8 percent) had an appointment scheduled in the future or forgot a scheduled appointment.

Conclusion: The majority of surveyed parents/guardians reported their children having seen an eye care provider. Appropriate documentation has been limited due to reliance on parents/guardians to give referral forms to eye care providers and subsequent dependence on providers to forward completed referral forms to CVSI. Improved documentation is needed to assess the accuracy of the screening, support screening prevalence data, and evaluate the impact of CVSI.

Introduction

Amblyopia is a major cause of vision loss in children that can result in lifelong visual impairment and significant developmental dysfunction if left untreated.¹⁻⁵ Childhood vision screening has been established as an important means of identifying children who are at-risk for developing amblyopia and can help prevent vision loss by referring them for evaluation and treatment.^{6,7} The U.S. Preventative Services Task Force makes a grade B recommendation in regards to vision screening "for all children at least once between the ages of 3 and 5 years, to detect the presence of amblyopia or its risk factors."⁶ Additionally, the American Academy of Pediatrics has published guidelines concerning pediatric vision screening

that includes recommendations for screening beginning at 3 years of age.⁸

The primary goal of vision screening is to effectively refer at-risk children to an eye care professional to receive a comprehensive eye exam and treatment if needed. Poor follow-up rates after post-screening referral is an established limitation of vision screening programs.^{9,10} Several studies have evaluated potential barriers to follow-up referral after a failed vision screening.¹¹⁻¹³ Previously identified barriers include: inability to contact families, unawareness of need for follow-up, forgetting appointment, conflicts in scheduling, concerns about cost of an eye exam, and expecting a follow-up call to help schedule an appointment. The significance of any one of these barriers varies

depending on the design of the screening program and local population. The population of western South Dakota is one of the many groups that has not been evaluated for these barriers.

South Dakota is one of eight states that does not mandate childhood vision screening.¹⁴ A comprehensive proposal has never been brought forward in the state legislature. A previous study reported a referral rate of 11.9 percent for children participating in a screening event carried out by Northern Plains Eye Foundation Western South Dakota Lions Children's Vision Screening Initiative (CVSI).¹⁵ This study cited lack of follow-up data and demographic data as a major limitation and theorized about an association between post screening referral rate and the distinct "racial/ethnic makeup of the Black Hills of South Dakota." CVSI estimates follow-up rates after screening referral to be as low as 12 percent. Our study examined barriers to follow-up eye care in this population and analyzed potential demographic associations. Our study also evaluated the usefulness of an online response form as an alternative to a telephone-based survey. We hope the results of this study lend insight to help local vision screening programs improve their follow-up rates and better understand the western South Dakota population.

Methods

Vision screenings were carried out by CVSI. CVSI has an established process for administering the screenings. A detailed description of the CVSI screening process can be found in Table 1.

The creation of a dataset from CVSI vision screening records and a survey methodology was approved by the University of South Dakota Institutional Review Board (IRB) and is in compliance with the U.S. Health Insurance Portability and Accountability Act of 1996. This dataset included children who underwent vision screening per CVSI protocol from September 2014 through February 2015 and were referred for a comprehensive eye exam. This dataset included parent/guardian contact and demographic information for 282 children ages 3 through 11. A phone survey of the parents/guardians in the dataset was conducted following a telephone script and using an electronic web-based data entry form. Failed attempts to contact the parents/guardians of these children via telephone resulted in either leaving a voicemail referring the parents/guardians to a website to complete the survey or documentation of why the call could not be completed. The survey was conducted six months after the screening was completed.

Table 1. CVSI Screening Process

Step	Description
Consent	In a pre-school (ages 6 months through 6 years) or elementary school (kindergarten, first and third grades) setting, standardized consent forms provided by CVSI are sent home to parents/guardians by the school in a folder routinely used by the school to deliver information to parents/guardians. The consent form includes sections for reporting the child's age, gender, and race/ethnicity as well as contact information such as phone number, e-mail address, and mailing address. Completed, signed, and dated consent forms are returned to the school by parents/guardians, collected, and returned to CVSI before the screening event. In a setting other than pre-school or elementary school, where parents/guardians may be in attendance with their child/children, parents/guardians complete, sign, and date consent forms on-site.
Screening	Only children with completed, signed, and dated consent forms are screened. Screenings are carried out by CVSI in conjunction with local Lions Club volunteers, who have undergone CVSI background checks and CVSI training on how to administer screenings using the Spot Vision Screener (PediaVision, Welch Allyn, Skaneateles Falls, NY). The device analyzes a child's vision and determines whether he or she should be recommended for a comprehensive eye exam. Studies have shown the Spot device to have a sensitivity of 87.7 percent and the specificity was 75.9 percent in the detection of amblyopia risk factors. ¹⁸ Details about CVSI's application of the Spot device are documented in a previously published study. ¹⁵
Results processing/referral	The CVSI vision screening results are compiled and information packets inclusive of the CVSI screening result are mailed to the addresses provided by the parents/guardians on consent forms. Children whose results indicate they would benefit from a comprehensive eye exam receive an expanded information packet including a list of area eye care providers, list of area resources, a referral evaluation form parents/guardians can give to their eye care provider, and instructions on scheduling an appointment.
Eye exam/follow-up	Parents/guardians bring the referral evaluation form with them to the appointment with their child's eye care provider. After a child is seen by an eye care provider, the provider is encouraged to fill out the referral evaluation form and forward it to CVSI. Evaluation of completed referral evaluation forms is the primary means of assessing follow-up after screening.

The parents/guardians who answered the phone were read an IRB-approved script explaining the study and were asked to give verbal consent.

Parents/guardians were asked six to eight questions depending on stepwise patient responses. The survey took approximately five minutes to complete. Survey questions assessed parental/guardian awareness of the screening event, awareness of the results of the screening, potential barriers to follow-up, personal view on the child's eye care, and insurance status of the child. When open-ended questions were used, the caller took special consideration to not prompt a parent/guardian response. If the parent/guardian had difficulty answering the questions, pre-determined prompts were provided. An online response form was used by callers to record telephone-based parent/guardian survey responses.

Parents/guardians who were unable to be reached on the phone, but had working voicemails, were left a message. The message notified the parents/guardians about the study and gave them the option to complete an online survey that mirrored the telephone-based survey. Web-based participants were linked to a unique identifier to assist in documentation of survey status. Potential participants were not given the option to participate in the online survey until after a telephone-based survey had been attempted. This was done to ensure information collected online did not interfere with the caller response rate. The online survey was powered by Google Forms and was redirected by a domain name service to a dedicated URL (www.visionstudysd.com).

Statistics

Data analysis was performed using MedCalc (MedCalc Software bvba, Belgium). The Fisher exact test of independence was used to test for association between follow-up rate and categorical variables with two possible values. Categorical variables with three or more possible values were evaluated for association with follow-up rate using chi-square test of independence. A *P* value of < 0.05 was considered significant. An experiment-wise error rate of 33.7 percent was calculated based on a total of eight comparisons. This must be considered when interpreting the results.

Results

Attempts were made to contact the parents/guardians of 282 children in the dataset. Of these, 89 (31.6 percent) had disconnected/incorrect phone numbers. 117 (41.5

percent) did not respond to calls and voicemails were left. Seventy-six (26.9 percent) were successfully contacted and 63 (22.3 percent) agreed to participate in the survey. This data was further analyzed based on self-reported ethnicity. Using chi-square test of independence, ethnicity was not a factor with regard to willingness to complete the survey (*P* = 0.88) in instances in which the parent/guardian was reachable via phone. Ethnicity was also not a factor in regard to calls that resulted in voicemails (*P* = 0.75). It was determined that overall response rates (*P* = 0.0024) and percentage of invalid numbers (*P* = 0.003) were associated with ethnicity. Parents/guardians who did not specify ethnicity on the consent form had a lower response rate than average (14 versus 22.3 percent) and had a higher percentage of invalid phone numbers (44 versus 31.6 percent). In comparison, response rates amongst American Indian and white participants were 17.3 and 37.8 percent, respectively. Percentage of invalid phone numbers was 37.3 percent for American Indians and 12.2 percent for white participants.

Demographic data of the 63 surveyed participants is detailed in Table 2. The results of the survey can be found in Table 3. Of the 63 survey participants, 38 had already attended an appointment (60.3 percent). Half of this group (*n*=19) remembered to bring the CVSI referral evaluation form with them when they attended the appointment with their eye care provider. When the parents/guardians of the 25 children who had not attended an appointment were surveyed, 12 (19 percent) were not aware their child needed to see an eye care provider, 10 (15.9 percent) identified barriers to scheduling an appointment, and an additional three (4.8 percent) either had an appointment scheduled in the future or forgot to

Table 2. Demographic (completed surveys)

Characteristic	n	Percentage of Total
Child's sex		
Male	35	55.5
Female	28	44.5
Child's ethnicity		
White	30	47.6
American Indian	26	41.3
Other	3	4.8
Not specified	4	6.3
Child's health insurance		
Medicaid	30	47.6
Private	29	46.0
Self-pay	4	6.4

attend a scheduled appointment. Of the 12 who were not aware their child needed to see an eye care doctor, six (9.5 percent) were not aware their child was screened, four (6.3 percent) did not remember receiving results, and two (3.2 percent) did not understand the results.

Follow-up status was evaluated based on history of a previous eye exam, health insurance status of the child, parental suspicion of vision abnormality prior to screening, and self-reported ethnicity. None of these factors showed a statistically significant association with likelihood of receiving a follow-up eye care exam. The results of this analysis are listed in Table 4.

Multiple barriers (more than one was allowed per participant) were identified by the 10 participants who did not schedule an appointment including: faced higher-priority family issues such as disability, illness, conflicts, or difficulty obtaining housing or food (n=3); forgot to schedule an appointment (n=2); concern they would not be able to schedule an appointment around their work schedule (n=2); expected follow-up calls to help schedule an appointment (n=2); confusion about which eye care provider to contact (n=2); concerns about cost/Medicaid coverage (n=2); perceived difficulty in arranging transportation to see an eye care provider (n=1). One parent/guardian believed their child's vision was sufficient despite the results of the survey and did not feel their child needed eye care. Another parent/guardian felt their child's disability prevented them from being evaluated by an eye care provider. One of the parents brought the referral evaluation form to their pediatrician and was told the degree of astigmatism was too minor to be corrected.

The effectiveness of a web-based survey was evaluated. None of the 117 voicemails referring potential participants to an online version of the study resulted in a completed survey.

Discussion

Results pertaining to the availability of potential survey subjects were comparable to other published studies. The percentage of disconnected phone numbers (31.6 percent)

Table 3. Results of Follow-up Survey

Characteristic	n	Percentage of Total
Total interviewed	63	
Appointment attended	38	60.3
Gave referral form to provider	19	30.2
Forgot to give referral form to provider	19	30.2
Appointment not attended	25	39.7
Obstacles to scheduling an appointment	10	15.9
Not aware of screening results	12	19.0
Not aware that child was screened	6	9.5
Do not remember receiving results	4	6.3
Did not understand results	2	3.2
Appointment scheduled in the future	2	3.2
Missed appointment	1	1.6

Table 4. Patient Characteristics and Likelihood of Receiving Follow-up Eye Care

Characteristic	Receipt of Follow-up	P value
The child had prior eye exams?		0.99 ^a
Yes	63.2% (12/19)	
No	59.0% (26/44)	
Child's health insurance		0.99 ^a
None/self-pay	75.0% (3/4)	
Insurance (private or Medicaid)	59.3% (35/59)	
Suspicious of vision problems		0.07 ^a
Yes	50.0% (18/36)	
No	74.1% (20/27)	
Race		0.10 ^b
American Indian	50.0% (13/26)	
White	73.3% (22/30)	
Other	100.0% (3/3)	
Not specified	0.0% (0/4)	

^a Statistical significance calculated using Fisher's Exact test.

^b Statistical significance calculated using Chi-Squared test ("Not specified" not included).

P < 0.05 was considered statistically significant.

was consistent with a comparable study (32.3 percent) as well as the percentage of voicemails left (41.5 versus 30.2 percent), completed surveys (22.3 versus 29.1 percent), and unwillingness to take a survey (4.6 versus 8 percent).¹⁴ Our results showed the percentage of disconnected phone numbers varying by ethnicity, with American Indians and participants who did not specify an ethnicity being more likely to have disconnected phone numbers. The percentage of participants who completed surveys also varied by ethnicity. White participants were more likely to complete surveys than other ethnic groups.

The most common reason for unknown follow-up status was inefficient communication between parents/guardians,

eye care providers, and CVSI. The most common miscommunication occurred when a child received a comprehensive eye exam, yet referral evaluation documentation of the results was not sent to CVSI. In fact, the majority of children who are recommended to receive a comprehensive eye exam ($n=38$, 60.3 percent) following a post-screening referral by CVSI are being seen by an eye care provider. This figure is higher than results from similar studies.^{9,14} Su Zhuo et al. saw 47 percent of contacted guardians reporting that their child had already attended a follow-up appointment and Mark et al reported 25 percent. Variations in follow-up procedures may account for this difference. For example, only one attempt was made to contact participants in our study compared to five in the Su Zhuo paper. A potential association between availability of parent/guardian and follow-up rate may account for the difference. Overall, this value may overstate the actual follow-up rate because the population surveyed (parents who are willing to receive a call and participate in a study) may be more likely to prioritize their child's health and vision and secure a follow-up appointment.

This study has shown appropriate documentation of follow-up status is limited due to reliance on parents to give a referral evaluation form to their eye care provider and reliance on eye care providers to forward the completed referral evaluation form to CVSI. Based on these findings, it is worth examining ways to ensure parents/guardians bring the referral evaluation form with them when they attend an appointment with their eye care provider. Many of the respondents reported having given the referral evaluation form to their provider. Considering this finding, an effort to increase program awareness amongst local eye care providers is advisable. The offices of these eye care providers may not be aware of the need to forward completed referral evaluation forms to CVSI. Exam records are commonly transmitted via fax between the offices of ophthalmologists and referring optometrists. CVSI may benefit from encouraging a similar system of communication with these eye care offices.

A large portion of children who had not been scheduled to see an eye care provider would likely have benefitted from improved follow-up coordination. We attribute this to the nature of the barriers that prevented them from scheduling an appointment and lack of awareness about screening results. A common cause of follow-up failure was parent/guardian unawareness of need for follow-up care (19 percent). This is comparable to the results of

previous studies, which have cited 29 percent¹⁴ and 10 percent.¹⁶ In the screening model analyzed in this study, it is also feasible the packet of results was either lost or not received by the parent/guardian. This could be due to a change in address of parent/guardian or an inaccurate address provided on the consent form. In comparison, prior studies have shown a letter with screening results led to over 90 percent of parental awareness of screening failure.¹⁶ The higher percentage of parental unawareness might be attributed to a survey population more likely to have moved or provided an inaccurate address. However, this was not tested in this study.

Parental awareness of the screening result might be improved by implementing a signature verification step (a signature on the form with the results indicating the parent has seen the form) or by note of a school or screening representative who affirms they have spoken with the parent of a child who has been referred for a comprehensive eye exam. However, these ideas may not be feasible under CVSI's protocol. A lack of understanding of the results may arise when incomprehensible materials are sent to the parents/guardians. It is our belief that the materials provided by CVSI are appropriate in amount and content and do not hinder parents/guardians from pursuing an eye care appointment. Although quality and readability of the results and materials provided by CVSI appear to be exceptional, there may be value in assessing the opinions and perceptions of the study population by conducting a focus group centered on the materials provided in the results packet.

The inconsistent nature of reported barriers to scheduling an appointment by participants ($n=10$) makes it difficult to propose a recommendation for screening improvement. However, we believe many of these barriers could be addressed through improved education about childhood vision conditions and routine follow-up calls. For example, improved education may benefit three participants (out of 10 who listed barriers to scheduling an appointment) who stated higher priorities/family related issues were more important than their child's vision concerns or the participant who stated they did not believe their child required further eye care. Routine follow-up calls may benefit the two participants who forgot to schedule an appointment, the two who did not know which eye doctor to call, or the two who expected a call to schedule an appointment.

In one instance, parents brought the results of the



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screening to their pediatrician for review. The pediatrician did not feel the magnitude of astigmatism warranted an eye exam. This scenario depicts a common misconception about the screening process in which non-eye care providers treat screening results as equivalent to a comprehensive eye exam. The screening test in itself does not diagnose eye conditions and the positive predictive value (PPV) for the detection of amblyopia risk factors using automated vision screening devices such as the Spot device has been found to be between 73 and 78 percent for screening in preschool age children without unusual suspicion for amblyopia.¹⁷⁻¹⁹ The purpose of screening is to identify at-risk children and provide an appropriate referral rather than make a diagnosis. It is conceivable the child had greater or lesser astigmatism than indicated by the screening test. Interpretation of screening results without a corresponding evaluation by an eye care provider can result in false parental assurance.

A previous study suggested the unique racial makeup of western South Dakota may impact the vision screening process.¹⁵ Our study features four ethnic categories: white (47.6 percent) American Indian (41.3 percent), other (4.8 percent), and not specified (6.3 percent). Our results indicated ethnicity was not a statistically significant factor in children receiving a follow-up exam ($P = 0.10$). We believe that all groups would benefit from receiving additional education and follow-up coordination and it is unknown whether any ethnicity group would benefit from added attention. We also determined parents/guardians who did not specify ethnicity on the consent form were less likely to complete the survey and had a higher percentage of invalid phone numbers. This association may suggest a trend towards generalized noncompliance in this group.

It is unlikely a web-based follow-up would be successful given the absence of any responses on the vision study website. However, it remains unknown whether follow-up phone calls are the best way to reach the referred screening population due to the low percentage of parents/guardians who were accessible via phone.

This study was subject to several limitations. It is of note that 77.7 percent of parents/guardians remained unreachable. Of these, 40.8 percent were without a working phone number. Due to time and resource constraints, only one attempt was made to reach most of the 282 potential participants. Also, all calls were made between 5:00 p.m. and 7:30 p.m. in the local time zone, so subjects that are unavailable during that period were excluded from the

study by design. We believe there may be a relationship between the people that were more likely to participate by phone as opposed to those that were unlikely to answer a call from an unknown number. This study also had a relatively large experiment-wise error rate and all comparisons must be interpreted with this in mind.

Because it is not possible to measure post-screening outcomes of children who have guardians unable to be contacted (disconnected listed phone number, change of address), our study lacks the ability to follow up on what we believe is the largest potential population in need to follow-up barrier analysis. Possible solutions to this would most likely have been related to gathering information from guardians through the child's currently enrolled school.

Although it is encouraging many of the surveyed parents/guardians had children already seen by an eye care provider, documentation, in the form of the completed referral evaluation form, from these comprehensive eye exams is needed to adequately assess the accuracy of the screening (including accuracy of Spot Vision Screening device). This data is also needed to ensure reliable reporting on the prevalence of vision disorders, as well as to assess the impact of the CVSI screening initiative. Improved documentation of follow-up eye care and a corresponding reduction in the number of children with unknown follow-up status would assist CVSI in appropriately targeting parents/guardians of children who face barriers to obtaining follow-up eye care. We hope the results of this study will help vision screening programs increase follow-up rates amongst at-risk children and improve the documentation of children who have already been seen by an eye care provider.

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