☑ CE Article

Reports from Parents about Medical and Low Vision Services for Their Children with Albinism: An Analysis

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Structured Abstract: *Introduction:* The purpose of this study was to gain information from parents in the United States about their children with albinism. The article focuses on information and services related to medical care and low vision care. *Methods:* An online questionnaire was used to collect data, and parents had opportunities to submit additional information. One hundred ninety-two families, representing 223 children with albinism from 40 U.S. states, completed surveys. *Results:* A snapshot of the data indicates that for 8.6 out of 10 families, there were no known relatives with the condition; 55.8% of the children had visual acuities that met the criteria for legal blindness in the United States; and 48% of the children using optical devices had received clinical low vision evaluations by optometrists or ophthalmologists who specialized in low vision. *Implications for practitioners:* The data gathered suggest recommendations for medical service providers, including clinical low vision specialists who perform evaluations for improving the functional use of vision.

There are two major types of albinism: ocular albinism (affecting the eyes only) and oculocutaneous albinism (affecting both the eyes and the skin), with each type having multiple variants. Because individuals with variations of oculocutaneous albinism have less pigment in their hair and skin, their appearance will show white to blond hair, light blue eyes, and very pale skin tones. People with ocular albinism have a typical appearance and may have any inherited color in their irises. The visual manifestations of this form of albinism include one or more of the following: low visual acuity; foveal hypoplasia; photophobia; nystagmus; strabismus; and a lack of stereopsis, extreme nearsightedness, or farsightedness (Mayo Clinic, 2018b).

Due to differing ranges of pigmentation in children with albinism, full-body sun protection, including sun filters for light control and eye protection, may be needed and may affect the ability of a child with albinism to be outside as frequently or for the same duration as other children. This need to avoid the outdoors may affect their involvement in physical education classes. The Mayo Clinic (2018a) states, "Because albinism is a genetic disorder, it can't be cured. Treatment focuses on getting proper eye care and monitoring skin for signs of abnormalities" (paragraph 4).

The researchers chose to study children who have albinism for several reasons. Although their clinical measures, such as visual acuity or having light sensitivity, may be similar to other groups of children with visual impairments such as students with retinopathy of prematurity and aniridia, children with albinism also have unique characteristics, such as a different appearance than peers and their families, a need to care for their skin, variances in the optic nerve tracks, and nystagmus. This group was also chosen because of a strong consumer group presence that enabled the researchers to study a large group of children with this one visual diagnosis.

Professionals and parents of children with albinism are concerned with medical and low vision services (which combine medical and educational disciplines), as well as the appropriate identification and implementation of educational services to which these children are entitled. This article describes the medical information and low vision services related to these children; a subsequent article will provide information on education services and parental experiences in obtaining education services.

There are two major reasons to seek parents' reports to learn about the medical and low vision services their children receive. First, parents' reports directly reflect their knowledge and experiences. Second, learning about the extent to which parents have knowledge of their children's medical information and services provides valuable input for professionals whose jobs involve providing vital information to parents and advocating for quality services for these children who are their students.

The purposes of this study were: to gather medical information related to children with albinism, to learn about the extent to which low vision services are provided to children with albinism, and to identify which optical and electronic devices children with albinism are using for magnification and light control.

Review of the literature

Within the medical literature, several topics related to albinism have been published, including studies about diagnosis, genetics, physiology, surgical treatment (for instance, the Kestenbaum surgical procedure for nystagmus [Lee, 2002]), photophobia, optical devices, and skin protection. This review highlights those areas about which data were collected.

Writings by Schank (2015) and Urquhart (2015) include parents' accounts of medical confusion and a lack of knowledge regarding albinism at the time of the birth of their own children, which is when the children were diagnosed. Although educators often informally recount similar accounts of parents, this topic was not addressed within the medical or education literature.

Skin care is an important component of medical care for people with albinism. Information about skin protection is included in many publications directed to these people, and visors, hats, and other means for reducing photophobia are described (Schwartz, 2010). Research

regarding early skin cancers, especially in geographic locations where sunscreens are not readily available, have addressed the risks for children with albinism (Lund & Taylor, 2008; Yasumizu et al., 2015).

Low vision specialists studied the optical corrections required by people with albinism. In a study by Woo, Bedell, Flom, and Perez (1996), contact lenses were used with one patient. Although this patient showed minimally increased clinical measures, he reported that he felt greater environmental comfort. Saeed (2012) investigated the factors that could influence visual acuity with patients with albinism and reported that those patients who had lower visual acuity with spectacle corrections gained more on LogMAR charts using contact lenses.

In recent years, medical organizations have issued positions and professional guidance for their members with regard to the provision of low vision services for children. In their study, the American Academy of Ophthalmology (2017) stated that children whose acuity cannot be corrected to better than 20/40:

> . . . should have a clinical low vision evaluation by a qualified ophthalmologist or optometrist trained and active in low vision rehabilitation, receive prescribed optical devices and/or electronic video magnifiers (assistive technology), and be given educational instruction in the use of any prescribed devices. Assessments for determining a child's reading medium or media allow for the use of these devices (p. 268).

The American Academy of Optometry's (2014) paper also calls for ongoing clinical low vision evaluations, use of strategies for enhancing a child's "remaining" vision, and encouragement of optometrists to provide information about vision to adults interested in the child's education and rehabilitation care.

During the same time period that the two medical organizations took a stand regarding vision rehabilitation and education services for people with low vision, the American Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) also adopted a position paper (Lusk, Lawson, & McCarthy, 2013), in which the three components of low vision services—clinical evaluation, provision of optical or electronic devices, and instruction in the use of prescribed devices—were also emphasized as important in determining an individual's most efficient reading medium (or media).

Although clinical low vision evaluations are described in textbooks (Wilkinson, 2010), and research has shown the functional benefits for students with low vision who use optical or electronic devices (Corn, Wall, & Bell, 2000; Farmer & Morse, 2007), these evaluations can be considered to be a "promising practice." There is anecdotal evidence that professionals in the education of students with low vision distribute optical devices without a clinical low vision evaluation. Within published descriptions of the roles and functions of orientation and mobility (O&M) specialists (Griffin-Shirley, Kelley, & Lawrence, 2006) or teachers of students with visual impairments (Spungin, Ferrell, & Monson, 2016), however, the selection and dispensing of optical devices are not identified as the responsibility of these professionals.

The *National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities* (Huebner, Merk-Adam, Stryker, & Wolffe, 2004) was developed by parents and educators who sought to improve educational services on a national level. Their first goal was that referrals for early intervention services or school services occur within 30 days of a diagnosis of visual impairment. Following the development of the *National Agenda*, there were efforts by parents and educators to work with the medical community to reduce the time frame between diagnosis and referral for interventions.

In summary, the literature describes the visual characteristics of children with albinism and professional position papers describe the three components of clinical low vision evaluations, instruction in the use of prescribed devices, and the roles and responsibilities of education professionals providing services to students with low vision. This article includes visual and other medical information about these children and provides information about clinical low vision evaluations and optical and electronic devices they are using.

Methods

Design

This quantitative study of a convenience sample involved a questionnaire developed by the researchers that included sections on demographics and medical, low vision, and educational information and services. When appropriate, respondents to the questionnaire were given an opportunity to provide narrative comment after or as a part of their responses to selected questions.

The initial draft of the questionnaire was forwarded to the National Organization for Albinism and Hypopigmentation (NOAH), where adults with albinism and the NOAH Scientific Advisory Committee reviewed the questions for accuracy and content. The authors revised the instrument after receiving that feedback.

The Institutional Review Board of the Cincinnati Children's Hospital Medical Center approved the study protocol, the instrument used for data collection, and the recruitment materials before the collection of any data.

Recruitment

Flyers regarding the online questionnaire were distributed at the biennial NOAH conference in July 2014. Multiple professional, consumer, and parent organizations, including The National Association of Parents of Children with Visual Impairments and the Division on Visual Impairments and Deafblindness of the Council for Exceptional Children, assisted with recruitment by distributing the flyer via periodicals and other methods. The questionnaire was available in hardcopy format at the 2014 NOAH conference and was put online for responses to be collected using SurveyMonkey from July 2014 until March 2015. Parents could request a copy of the questionnaire in print, large print, or braille, and there was also an option to complete the questionnaire by telephone.

Results

Three hundred and twenty-two families accessed the questionnaire. A total of 192 families of children with albinism who lived in the United States and whose children had not completed their secondary education completed a majority of the

questions and were included in the sample. Of those 192 families, 25 reported information for 2 children with albinism, and three families reported information for 3 children. Therefore, a total of 223 children were represented in the data. Surveys were returned from 40 states, including all regions of the United States.

All 192 families responded to the question about whether any of their child's family members were known to have albinism. This was not the case for 86.5% ($n = 166$) of the families, who reported they did not know of a family member with albinism or they had no information about whether there was a family member with albinism. Those families who responded in the affirmative included 2.6% ($n = 5$) in which the mothers and 1.6% ($n = 3$) of the fathers had albinism. In 3.1% ($n = 6$) of the families, one of the grandparents was affected, and 10.4% ($n = 20$) of respondents reported an "other" family member as having the condition. It was also reported that none of the children had a step-parent with albinism, although 1.6% ($n = 3$) of the children had an adoptive or foster parent with albinism. Some families may have had multiple relatives with albinism such as both a mother and an uncle.

Parents responded to the question about their child's ethnicity. Of the 192 respondents who answered this question, 68.2% reported that their children were Caucasian-White; 13.5% were Asian–Pacific Islander; 5.7% were African American, 4.7% were Hispanic; 5.2% were of multiple ethnic backgrounds; 2.1% were "other"; and 0.6% chose "I don't know" as a response.

To gather information about the range of ages of the children, a question was asked about grade placement; responses were received for 217 children. At the time their parents completed the survey, 63 of the children were in infant or preschool programs; 73 were in kindergarten through fifth grade; 72 were in sixth through 12th grades; and nine were listed as being in a program for 18- to 21-year-old students, in an ungraded program, or home schooled.

Medical information

Parents were asked to include information about their children's diagnosis, disabilities, and visual characteristics. Of 221 responses, parents reported that 87.8% ($n = 194$) had oculocutaneous albinism and 10.4% ($n = 23$) had ocular albinism; the remaining 1.8% ($n = 4$) of parents were unsure about which type of albinism their child had. Parents were also asked the age at which their children were first diagnosed with albinism. For 220 children, 92.7% ($n = 204$) received their diagnosis between birth and 12 months of age; 2.3% ($n = 5$) were diagnosed at age 1 year; 0.9% ($n = 2$) at 3 years of age; 1.4% ($n = 3$) at 4 years of age; and 0.5% ($n = 1$) at 8 years of age. For 2.3% ($n = 5$), their parents did not recall the age of their child's diagnosis.

Parents were asked if their children had additional disabilities; parents' reports were provided for 220 children, with 26.4% ($n = 58$) reported to have one or more additional disabilities. The most prevalent additional disability reported was for 20 children (9.1%) who were noted to have a social or emotional disability, followed by 10 children (4.6%) with a speech or language disorder. An

Table 1
Visual acuities of children with albinism ($N = 166$).

Visual acuity (U.S)	Number	Percent
Better than 20/50	7	4.2
20/50–20/60*	12	7.2
20/70–20/100**	42	25.3
20/120–20/400***	104	62.7
Worse than 20/400	1	0.1

Note: * The American Academy of Ophthalmology considers children who cannot be corrected to 20/40 to have low vision. 20/50 represents the next line on the standard Snellen eye chart.
** Most states require a child to have a corrected visual acuity in the better eye of 20/70 or worse as the criterion for eligibility for special education programs due to a visual acuity measure.
*** These children are considered to be legally blind; those with acuity measurements between 20/120 and 20/200 would measure 20/200 on the standard Snellen eye chart, as there are no acuity lines available between 20/100 and 20/200 (American Foundation for the Blind, 2018).

additional 7 were reported to have a specific learning disability, 3 were identified as having a physical disability, 2 were described as having a hearing impairment, and 2 were reported to have cognitive disabilities. For 18 children, their parents indicated "other" disabilities. It should be noted that missing from the options of disabilities were health impairments and dyslexia (conditions that are not listed as a disability in many U.S. states).

For statistical purposes, the children's reported visual acuities are grouped into categories that reflect commonly used demarcations. The reported visual acuities reflect the children's measures with standard correction; that is, glasses or contact lenses. Of 188 responses, 11.7% ($n = 22$) of the parents did not know their child's acuity. The 166 responses for which acuities were provided are listed in Table 1; 105 of the children (55.8%) reportedly have visual acuities that meet the federal definition of legal blindness.

Parents were asked if they perceived their children to have photophobia (sensitivity to light). For 220 responses, 33.2% ($n = 73$) reported severe light sensitivity, 46.8% ($n = 103$) reported moderate light sensitivity, and 16.8% ($n = 37$) reported mild light sensitivity. Only 1.4% ($n = 3$) reported no light sensitivity; 1.8% ($n = 4$) of parents were unsure of their child's level of light sensitivity.

For 220 children, families responded to the questions about which medical examinations their children had within the last three years. Table 2 shows this information. Ophthalmologists reportedly provided eye care for most of the children, and 90.0% ($n = 198$), and 28% ($n = 62$)

Table 2
Medical examinations within the last three years ($N = 220$).

Exam (professional)	Number	Percentage of children in responses
Eye exam (ophthalmologist)	198	90.0
Eye exam (optometrist)	62	28.2
Clinical low vision evaluation (ophthalmologist or optometrist)	114	51.8
Exam or evaluation (neurologist)	14	6.4
Exam or evaluation (dermatologist)	70	31.8
Exam or evaluation (pediatrician)	157	71.4
Other	23	10.5
I don't know	2	0.9

Table 3
Optical and electronic device use ($N = 153$).

Category	Type	Number	Percentage of devices used, by category	Percentage of individual devices used
Near optical devices (total: 180)	Handheld magnifier	79	43.9	48.5
	Dome or stand magnifier	82	45.6	50.3
	High plus reading glasses	19	10.6	11.7
Distance optical devices (total: 109)	Handheld monocular	95	87.2	58.3
	Bioptic telescopic system	14	12.8	8.6
Light control (total: 125)	Low light transmission contact lenses	5	4.0	3.1
	Opaque or light-blocking contact lenses	12	9.6	7.4
	Sunglasses	108	86.4	66.3
Electronic devices (total: 89)	Handheld video magnifier	18	20.2	11.0
	Desktop video magnifier	49	55.1	30.1
	Combined video magnifier for near and distance vision	22	24.7	13.5

had seen optometrists within the past three years (some children may have seen both professionals). It is important to note that 70 children (31.8%) were reported to have been seen by a dermatologist. Table 2 includes other medical evaluations.

Prior to a question about the age at which children had their first clinical low vision evaluation, a statement was presented on the survey that explained that these evaluations differ from ophthalmological evaluations in that they examine the child's functional use of vision and also determine if optical or electronic devices could be helpful. Parental responses were given for 213 children. Parents reported that 30 children had not received a clinical low vision evaluation, and 4 parents did not know the age at which their children received this evaluation. The majority (113) had received this evaluation before 2 years of age. The remainder of the children received their first clinical low vision evaluation between 3 and 5 years of age ($n = 39$), 23 children received the evaluation between 6 and 8 years of age, and 4 children received their first clinical low vision evaluation after 9 years of age.

Children included in this study were using a variety of optical and electronic devices. A total of 163 parents responded to this question; 6.1% ($n = 10$) of parents reported that they did not know what devices their children were using. Table 3 shows which devices were being used. Handheld, dome, and stand magnifiers accounted for 89.5% of the near vision devices used, while 10.6% of the devices were high plus reading glasses. Children were also using mostly handheld monoculars for distance viewing ($n = 95$; 87.2%); 12.8% ($n = 14$) were using bioptic telescopic systems. For light control, 108 (86.4%) of the children were provided with generic sunglasses, while 17 children (13.6%) were prescribed low light transmission or opaque contact lenses. Of the 55.1% of children who were using electronic devices, 18 were using handheld video magnifiers, 49 were using desktop video magnifiers, and 22 children were using devices

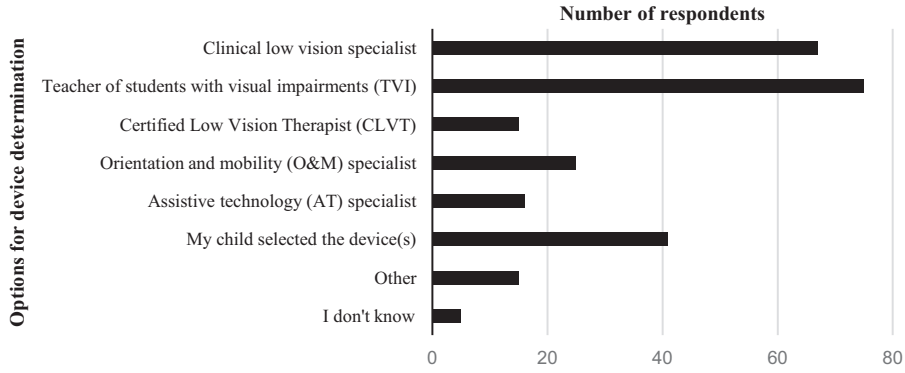

Figure 1. Professionals' determination of optical and electronic devices ($n = 139$).

that had the capability of electronically magnifying information at near and at a distance.

A total of 139 parents responded to a question regarding which professional made the determination of which optical and electronic devices their child should be using. Figure 1 shows this information, with only 48% ($n = 67$) of the parents reporting that their child's clinical low vision specialist made this determination.

Discussion

One of the strengths of this study is the representation of parents from 40 states and from all regions of the United States. Another strength is that it includes 192 parent surveys reporting on 223 children, which is a sizable sample for a study of children with visual impairments; the responses are even more remarkable in that the sample includes children with one etiology.

This study yielded new demographic information about children with albinism. For example, it appears based on these data that when a child with albinism is born, more than 7 out of 10 families do not know of a relative with albinism. This finding suggests that medical personnel should be more assertive in recommending that families seek early intervention and other supports. Of particular importance would be for medical providers to provide information about NOAH to families of children with albinism. Support from professionals, families of children with albinism, or adults with albinism can be helpful to all families, but especially to those for whom albinism is an unexpected and unknown diagnosis.

The findings suggest that the ratio between people with oculocutaneous albinism and individuals with ocular albinism is approximately nine to one. Further research, however, is recommended to confirm this ratio, since the recruitment of parents for this study from NOAH, the major organization that assisted the researchers, may have influenced this finding. Parents of children with oculocutaneous albinism may be more likely to participate in consumer groups for those with albinism than parents of children with ocular albinism, which is a less identifiable variant of the condition.

Another finding was that 55.8% of the children were reported to have visual acuities that would classify them as legally blind in the United States, a designation

often needed for specific services such as educational materials being provided to schools on federal "quota accounts." (American Printing House for the Blind, n.d.). The reported visual acuities of the children in this sample generally reflected information found in medical texts. Schwartz (2010) described visual acuities of children with albinism to be in the 20/60 to 20/400 range. In this study, 4% of the reported visual acuities were outside the range of 20/50 to 20/400.

As expected, almost all the children were reported by their parents to have some level of photophobia, with approximately 80% reported to have moderate to severe levels. Information pertaining to the range of this characteristic may encourage eye medical professionals to write prescriptions for various types of light control lenses, such as low light transmission or opaque contact lenses.

Several of the responses indicated that parents could benefit from additional information regarding their children's medical and low vision needs. The authors were surprised to learn that 12% of the parents indicated that they did not know their children's visual acuities. This information may or may not have been provided to parents, but the fact that they were uncertain of this measure suggests that medical professionals may need to spend more time with providing explanations of the meaning of the measures and how they are used for gaining education services.

Parents were provided with a descriptive definition of the professionals who conduct clinical low vision evaluations and the purposes of the evaluations for which they are responsible. These evaluations are generally conducted starting at about 3 years of age. It was disconcerting that more than 50% of the children were reported to have received their first clinical low vision evaluation between the ages of birth through 2 years of age, and the majority of these children were reported to have received their first clinical low vision evaluation between birth and 1 year of age. Many parents do not appear to have a clear understanding of the difference between a general ophthalmology or optometry examination and a clinical low vision evaluation. Alhough a low vision evaluation does not and should not replace the eye health examination, both are considered to be important for children with low vision in order to maximize functional use of vision and access to curriculum and other materials. (American Academy of Ophthalmology, 2017).

Also, it appears from these data that only 48% of the children who used optical devices had a clinical low vision specialist contribute to the selection of the device or devices. Parents may need additional information about this medical service, the differences in potential prescriptions that these professionals can write, and the selection of devices by a teacher or O&M specialist. For example, the low light transmission or opaque contact lenses may ease discomfort for individuals with albinism and photophobia, but these would not be considered without a clinical low vision evaluation.

Albinism is a condition that is not known to manifest itself with a social or emotional disability. The authors were surprised that parents reported that 9% of these children have behavioral or emotional disabilities. Further study is needed to determine if there is a relationship between albinism and social-emotional or behavior disabilities. It is also unknown if children who

have received diagnoses of social-emotional disabilities are receiving appropriate educational services, psychological help, and instruction in social skills. Researchers may also learn whether there are early interventions that could reduce or mitigate the social-emotional problems experienced by these children.

Limitations of the study

It should be noted that generalizations of the findings of this study are limited by several factors. Among these is that the researchers used a convenience sample and, therefore, participants may or may not be representative of the population of parents whose children have albinism. In addition, the information about these children was gathered in an indirect manner through a questionnaire, and all data were based on parents' reports. It is also possible that language barriers influenced the findings, since study materials were offered in English and involved the use of professional language. The authors attempted to provide descriptions and definitions for terms that may have been unfamiliar to parents, but these explanations might not have been sufficient in eliminating all misunderstandings.

Although these limitations occur in similar types of studies, the researchers believe there were also definite advantages in conducting the study in the manner chosen. The size of the sample, receipt of information directly from parents of these children, and the ability to provide unique identifiers for the survey respondents yielded valuable data without the concern that their responses would be attributed to them or to their children.

Recommendations

We strongly recommend a longitudinal study of the medical services and low vision care provided to children with albinism and the outcomes of these interventions. Although clinical measures may not be expected to show much change over periods of time, children's functional abilities with various types of prescriptions, and instruction in the use of their unaided vision and with prescribed devices, would yield valuable information to service providers. As part of this research, the creation of a database of the medical and low vision descriptors of this population would be valuable.

As already discussed, other recommendations supported by these findings include further investigation into the prevalence of socio-emotional disabilities among children with albinism and investigations of differences in the vision-related and other medical needs of children with the ocular and oculocutaneous variants of this condition.

Finally, it seems clear that there is a need for parents to receive more detailed and timely information about the potential needs of their children with albinism and the medical, low vision, and educational professionals who can meet these needs. Of particular importance is information about the services that only a clinical low vision specialist can provide.

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