

HHS Public Access

Author manuscript *J AAPOS*. Author manuscript; available in PMC 2016 April 01.

Published in final edited form as:

JAAPOS. 2015 April; 19(2): e1–e8. doi:10.1016/j.jaapos.2015.01.013.

Global Challenges in the Management of Congenital Cataract:

Proceedings of the International Congenital Cataract Symposium held on March 7, 2014 in New York City, New York

Phoebe D. Lenhart, MD¹, Paul Courtright, DrPH², M. Edward Wilson, MD³, David Samuel Taylor, FRCOphth, DSc (med)⁴, Susan Lewallen, MD², Marcelo C. Ventura, MD, PhD⁵, Richard Bowman, FRCS⁶, Lee Woodward, MD⁷, Lauren C. Ditta, MD⁸, Stacey Kruger, MD⁹, Danny Haddad, MD¹, Nihal El Shakankiri, MD¹⁰, Salma KC Rai, MD¹¹, Tehara Bailey, MD¹², and Scott R. Lambert, MD¹

¹ Department of Ophthalmology, Emory University School of Medicine, Atlanta, Georgia ² Kilimanjaro Centre for Community Ophthalmology International, Division of Ophthalmology, University of Cape Town, Cape Town, South Africa ³ Storm Eye Institute, Medical University of South Carolina, Charleston, South Carolina ⁴ University College London, United Kingdom ⁵ Altino Ventura Foundation, Recife, Brazil ⁶ Great Ormond Street Hospital for Children, London, England ⁷ Dell Children's Medical Center of Central Texas, Austin, Texas ⁸ University of Tennessee Health Science Center, Hamilton Eye Institute, Memphis, Tennessee ⁹ Stacey J. Kruger, MD & Associates, P.A., Miami, Florida ¹⁰ Alexandria University, Alexandria, Egypt ¹¹ Lumbini Eye Institute, Nepal ¹² Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY

Summary

Childhood cataracts have become a leading cause of preventable childhood blindness in many areas of the world. Here we summarize regional focus group discussions from the 4th Annual International Congenital Cataract Symposium on the current situation, challenges, and recommendations for the management of congenital cataracts in sub-Saharan Africa, the Middle East and North Africa, South Asia, Central America, South America, and developed nations. Strategies for managing congenital cataracts must be adapted and developed according to regional conditions. A basic framework for acceptable outcomes must focus on developing systems to address the critical components of education, access, quality care, and good follow-up.

^{© 2015} Published by the American Association for Pediatric Ophthalmology and Strabismus.

Corresponding Author: Phoebe Lenhart, M.D., Emory University School of Medicine, Department of Ophthalmology, 1365B Clifton Road N.E., Suite 5420, Atlanta, Georgia 30322 Phone: 404-778-5102 Fax: 404-778-5203 phoebe.lenhart@emory.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Institution: Emory Eye Center 1365B Clifton Rd., NE, Atlanta, Georgia 30322

Financial Interests: The authors have no financial interests to disclose. This material has not been previously presented or submitted for publication.

Introduction

A baby is born with congenital cataracts. Ideally, a pediatrician diagnoses the cataracts soon after birth and refers the child to a pediatric ophthalmologist who schedules cataract extraction in the first 2 months of life. That child receives timely changes in optical correction and amblyopia therapy throughout childhood. Good vision enables the child to attend mainstream schools and enter the workforce. In less than ideal settings, a child's white pupils are noted in the first years of life but a community health care worker advises the child's family to wait until the child is older to seek care. The child presents to an adult eye care facility at 6 years of age and the cataracts are removed. Glasses are prescribed postoperatively, but the family cannot afford them. The family to perform chores or attend school and requires a lifelong caregiver. Both of these situations exist today (Figures 1a and 1b), and the outcomes that result from differences in the early management of congenital cataract have a tremendous impact on the lives of individuals, their families, communities, and the socioeconomics of their countries.

During the past decades, tremendous advances have been made in the fight against childhood blindness. Public health initiatives have decreased the number of children going blind from measles and Vitamin A deficiency.¹⁻⁷ As a result, pediatric cataract is now emerging as a leading cause of avoidable childhood blindness in many developing countries.^{5,8,9} Of an estimated 19 million visually impaired children in the world, lens pathology accounts for a variable percentage based on location in the world. In 2012 Kong and colleagues¹⁰ estimated the percentage of lens blindness in each of the 6 World Health Organization regions: Africa, 22%; Americas, 5.8%; Eastern Mediterranean, 13.2%; Europe, 15.2%; Southeast Asia, 13.6%; and Western Pacific, 21.3%.¹⁰ Although rare, congenital cataracts are significant because of the morbidity and mortality associated with early-onset visual impairment.⁹⁻¹¹ While there is increasing recognition that timely, quality cataract surgery with optical rehabilitation and amblyopia treatment may provide affected children with functional vision, thereby permitting them access to mainstream educational services and reducing the economic burden on families and communities, significant barriers remain in many parts of the world.

With the above data as a backdrop, a group of experts in congenital cataract met in New York City on March 7, 2014, for the 4th International Congenital Cataract Symposium to discuss the challenges surrounding this issue in different regions of the world. In addition to presentations on various congenital cataract initiatives worldwide, small group discussions were held to address the current situation, challenges, and recommendations for the management of congenital cataracts in sub-Saharan Africa, the Middle East and North Africa, South Asia, Central America, South America, and developed nations. Developed nations were included to present barriers to care facing more industrialized nations, in which different challenges can still lead to low vision and blindness.

Results: Regional Challenges

Sub-Saharan Africa

Current Situation—The number of children in Africa is predicted to rise from 411 million in 2010 to 839 million in 2050.¹² If the prevalence of blindness from congenital cataracts in children in developing countries is estimated at 1-4 per 10,000 births,¹³ then in 2010, 41,100-164,400 children had congenital cataracts and 83,900-335,600 children will have them in 2050. The situation with regard to congenital cataract in sub-Saharan Africa was reviewed recently.¹⁴ In a recent population-based survey in Nigeria, unoperated cataracts were the leading cause of blindness among children.¹⁵ In a few settings in sub-Saharan Africa, children with cataracts are identified by means of key informants (KI),¹⁵⁻¹⁸ respected members of a community who are specifically trained to look for and report evidence of decreased vision in children in their local population. Research in various settings has shown that KIs can be effective in identification and referral of children with vision loss; however understanding referral networks, gender roles, and socioeconomic constraints is critical to successful implementation.¹⁵⁻¹⁹ There is no widespread red reflex screening program for infants, and health workers are unfamiliar with congenital cataract. As a result, there is often significant delay in presentation of children for cataract surgery, a key factor affecting visual outcome after surgery. Children with cataracts often present with nystagmus when they are older and the prognosis for visual recovery is often poor.

Although there is no routine data reporting across Africa, it is estimated that most pediatric cataract surgeries are performed in 28 child eye health tertiary facilities (CEHTF) that serve 10 of the 42 countries comprising sub-Saharan Africa.²⁰ While 21 of these CEHTFs serve an estimated 197 million people, resources vary, and it was found that the number of children receiving services was low.²⁰ All responding CEHTF ophthalmologists (77.8% of centers) reported they had received pediatric ophthalmology fellowship training, and a dedicated pediatric ophthalmology outpatient department or ward was reported in 48% and 24% of hospitals, respectively.²⁰ Because contact lenses are not available nor advisable in sub-Saharan Africa because of water constraints and poor hygiene in rural areas, intraocular lenses (IOLs) are nearly always implanted immediately following lens extraction. Residual refractive errors are usually corrected with glasses. In many CEHTF, follow-up after cataract surgery remains limited. Children with congenital cataracts in Africa are usually clustered in families, and the decision to bring a child for treatment and follow-up is complicated within family dynamics, often related to distance from the health center, and the level of poverty.¹⁹ It has been reported that only 2/3 of children received spectacle correction and only 15% received low-vision services.²⁰ Measures reported to improve follow-up have included telephone calls, patient tracking, parental counseling, and transportation reimbursement.²¹ There is considerable experience in developing country programs to treat childhood cataract in Africa, yet the coverage of these services is still limited.²²

Challenges and Recommendations—Low pediatric cataract awareness, delay in presentation for surgery, poor access to quality surgical care, and inadequate investment in follow-up are barriers to care in sub-Saharan Africa.^{19,23,24} Lack of financial resources,

inadequate facilities, and an insufficient number of providers were cited as major challenges in this region.

Ideas presented to forward public awareness of congenital cataract included mass marketing, specifically by means of radio and television campaigns, and cell phone pop-up advertisements; "white pupil" campaigns showing photographs of the pupil before and after cataract extraction; testimonials by patients and/or parent or sibling advocates sharing their surgical and visual outcome experience may help. All health care workers should be instructed to consider all eye conditions in children an emergency for immediate referral. As a large number of children on the African continent receive immunizations at 9 months of age, one possible way to improve screening for congenital cataracts might be for healthcare workers to examine the eyes of children at that time, however evidence of effectiveness of training health workers is limited.^{17,25,26} Mobile devices that may permit eye examination by means of a smartphone^{27,28} could be implemented by healthcare workers performing immunizations. Expanding the role of KI to include counseling and patient and family education as well as advocacy, particularly in terms of follow-up may strengthen community-based approaches to child eye health.

Recommendations for improving access to quality eye care for children with congenital cataracts centered around the current cornerstone for these efforts, the CEHTF. Increasing the number and quality of these facilities will require planning, human resources, and financing. Identifying appropriate locations so that there is one CEHTF per 10 million people will result in less overlap of resources. Another requirement is a local ophthalmologist who is motivated to establish a CEHTF and specialize in pediatric ophthalmology. Ideally, there would be some financial incentive for doing this. Additional eye care personnel including pediatric anesthetists, optometrists, orthoptists, low vision technicians, childhood blindness and low vision coordinators must be trained using a systematic approach. Also important is the ability to bring in experienced staff to help build the capacity of local caregivers. Finally, a CEHTF must be well-equipped to provide quality care and for doctors to be able to train.

Overall, governmental and philanthropic support for evidence-informed approaches to screening must be sought to promote a comprehensive care package including getting children in for appropriate eye care sooner, improving follow-up, and providing appropriate educational settings. Currently, funding all of these components involves identifying and learning how to obtain donor support; in the immediate future, the cost of tertiary pediatric eye care is beyond the capacity of most governments and individuals to support.²⁹ Of note, the increasing prevalence of insurance plans in Africa offers potential opportunities for financing services.

Summary

- Increase public awareness of childhood cataracts-mass media campaign.
- Explore the possibility of examining red reflexes when administering childhood immunizations.
- Use KIs to identify children and to assist in follow-up.

 Increase the number of CEHTF, provide training, and provide equipment and consumables.

Middle East and North Africa

Current Situation—This region according to the United Nations is comprised of countries bordered by the Arabian Gulf (Persian Gulf), the Mediterranean, Arabian, and Red Sea, and North Africa. Some countries are wealthy and have strong health care systems, whereas others, such as Sudan, Yemen, and non-oil-rich countries, lack broad health care services for all of their populations. Additionally, the cultural issue of consanguinity in the region contributes to high rates of congenital cataract and other ocular anomalies. In the Eastern Mediterranean region, lens pathology is responsible for 7%-20% of visual impairment in children, according to studies performed in Iran,^{30,31} Yemen,³² and Sudan.³³ Groups invested in strengthening eye care services for children with congenital cataracts include the Middle East Africa Council of Ophthalmology (MEACO) and its subspecialty organization, the Middle East Africa Pediatric Ophthalmology and Strabismus Society (MEAPOSS). Some countries, such as Lebanon, have instituted red reflex training for all pediatricians. However, the region is not homogenous with regard to how ophthalmology is practiced, and the standards of care between urban and rural areas vary greatly. There have been two studies of the use of KIs in case finding in the region, 30,34 and proactive approaches to case finding appear to be few.

Pediatric cataract surgeries are generally performed by highly skilled pediatric ophthalmologists with an international background. Most children are optically corrected after lensectomy with aphakic spectacles or IOLs,³⁵ because contact lenses are not viable in many settings. No data are available regarding patient follow-up after congenital cataract surgery in this region. Awareness exists among MEAPOSS members that the treatment of congenital cataracts following preferred practice guidelines improves outcomes, but there is wide regional variation in eye health programs for children.³⁶ For example, in wealthy Saudi Arabia, school eye health is part of the health system for children, whereas in economically diverse Pakistan programs are varied and with little overall coordination.³⁶ Efforts to reduce visual disabilities in general in children in the Middle East have centered on reducing nutritional and communicable disease, improving health care facilities, and promoting equitable distribution of human resources devoted to the control of childhood blindness.³⁷ A multidisciplinary approach to diagnosis and treatment is necessary, and involving family physicians, pediatricians, parents, and society in these efforts is crucial.³⁷

Challenges and Recommendations—Developing a dialogue within each country in this diverse part of the world was cited as critical to understanding the scope of the problem, areas of need, and barriers to delivery of care in this region. The focus group recommended the development of local and regional algorithms to facilitate early screening, prompt referral, quality surgical intervention, and long-term follow-up care. Such algorithms would include and channel red reflex screening, the identification of high-risk patients, and the development of referrals between primary and tertiary care centers. They would also focus on locating and developing skilled surgeons and developing interrelationships among surgeons. Evidence of effectiveness is needed prior to promotion of case finding or follow-

up approaches throughout the region. Partners to assist with implementation of these changes include regional ophthalmology organizations (eg, MEAPOSS and MEACO), national ophthalmological societies, nonophthalmologic physicians, nongovernmental organizations (NGOs), ophthalmologists in other areas of the world, genetics network partners, government, and industry sponsors. Funding is needed for IOLs, patient travel, medications, and travel for eye care specialists to academic meetings. Annual regional meetings of MEAPOSS and MEACO may be an opportunity to raise awareness.

Summary

- Develop algorithms to facilitate early screening, prompt referrals, high quality surgery and long-term care and test effectiveness and efficiency.
- Advocate for evidence and financing for congenital cataract programs in regional meetings such as MEAPOSS or MEACO and annual national ophthalmological society meetings.

South Asia

Current Situation—South Asia comprises the countries of India, Nepal, Sri Lanka, and Bangladesh. These countries bear a high percentage of the world's burden of childhood blindness. Rubella immunization coverage is estimated to be about 50% to 60%, ^{38,39} and there is a relatively high percentage of consanguineous marriages; these two characteristics likely increase the prevalence of childhood cataract. The Indian government and NGOs are currently creating child eye health centers but large disparities remain between urban and rural areas. A large percentage of eye care in South Asia is provided by nongovernmental organizations and private hospitals. Routine red reflex screening is not performed. Children with congenital cataracts are identified in some areas by KIs; the first setting in which this methodology was used was Bangladesh.⁴⁰ In other settings, primary care trained technicians and school screening camps are used; however, delayed presentation is common.⁹ There are excellent surgical training programs in the region, but most pediatric ophthalmologists do not live or work in rural areas. Pediatric cataract surgery is generally performed by either a pediatric or general ophthalmologist⁴¹ in 1 of 30-40 tertiary care centers. It has been noted that surgery for girls with congenital cataracts is more often performed in secondary care centers lacking the expertise of tertiary care centers. Children may also receive surgery for congenital cataracts as part of a rural eye camp. ⁴² Most children receive primary IOL placement or aphakic spectacles for optical rehabilitation because contact lenses often are not a viable option. Loss to follow-up at 6 months in one study in Chandigarh, India, ranged from 33% to 67%, depending on where the surgery was performed.⁴² In the setting of a clinical research study in Maharashtra, India, long-term outcomes of 258 bilateral congenital and developmental cataract surgeries in 129 children were reported with an average duration of follow-up of 4.4 years.⁴¹

Challenges and Recommendations—Although there has been tremendous progress in establishing CEHTFs in South Asia, many gaps in service availability remain. A 2010 study of the cost of pediatric cataract surgery in Maharashtra, India, found the surgery to be expensive and recommended that pediatric ophthalmologists decide on cost effective

standards of care for this service.⁴³ The focus group cited the need for good primary eye care facilities with well-trained ancillary personnel, functioning equipment, and appropriate funding systems in place. They also recommended training more pediatric cataract surgeons because the current number of trained providers is insufficient. Providing transportation after screening and counselors to raise awareness about pediatric cataract were components of the Aravind model^{44,45} of adult cataract service delivery that should be carried over to pediatric cataract services.

Summary

- Train more ophthalmologists for pediatric cataract surgery.
- Provide transportation for children to urban centers for cataract surgery.
- Establish more CEHTFs.

South America

Current Situation—Among children receiving low-vision services in Brazil and Chile, 6% to 13% had vision loss due to cataract.⁴⁶⁻⁴⁸ Red reflex screening is mandated by law in Brazil but is not consistently performed elsewhere in South America. As a result, congenital cataracts are often diagnosed at a later age by a parent who notices leukocoria, strabismus, or nystagmus.⁴⁶ Delayed presentation for management of congenital cataract is still a significant problem, affecting 47% of children in one study in Rio de Janeiro, Brazil.⁴⁶ Another review of 44 patients with congenital cataracts in Brazil revealed that 43% had lensectomy at >1 year of age.⁴⁹ Leite and Zin^{46} found that having insurance and being an only child were two factors associated with early diagnosis and treatment. Surgery for childhood cataract in Brazil is performed in private and public tertiary centers, with varied availability and quality. Leite and Zin⁴⁶ noted regional differences according to socioeconomic factors and health status. In one study, only 13.6% of 44 patients undergoing congenital cataract surgery in Brazil received IOL implantation, whereas 61.4% received glasses.⁴⁹ Whether or not an IOL is implanted varies greatly in different regions of Brazil and from institution to institution. Some surgeons implant IOLs as early as 6-8 weeks of age in the majority of patients.⁵⁰⁻⁵² While existing studies have described the causes of visual impairment of children in South America^{47,48} and the need for early diagnosis and treatment for congenital cataracts there, ^{46,49} few studies have included information about follow-up after congenital cataract surgery in South America.⁵⁰⁻⁵² In addition, in Peru parents are required to purchase the surgical supplies needed including an IOL when cataract surgery is performed in public hospitals. This is a significant financial burden to the parents of many children with cataracts.

Challenges and Recommendations—There is a need for improvement in early detection, prompt referral, and appropriate treatment for congenital cataracts.⁴⁶ Merula and Fernandes⁴⁹ concluded that families and pediatricians need more information about congenital cataract and surgery, optical rehabilitation, and timely amblyopia therapy. Ways to improve primary care physicians' knowledge and practice of the basic eye examination, including red reflex screening, is recognized as a need throughout the region. This requires improved training in medical school and during pediatrics residency. The medical

community and parents should be better educated to promote early referral for congenital cataract. Proposals included creating a public health initiative for the creation of a national database in countries of children with congenital cataracts, an internal network between pediatric ophthalmologists nationwide and networks between surgeons and rehabilitation centers. Discussion also centered on increasing the number of surgeons as well as improving the surgical training of surgeons and ancillary staff, from nurses to anesthesia, with regard to caring for children with congenital cataracts. Financial constraints were identified as a barrier to creating and maintaining systems for pediatric eye care in South America.

Summary

- Mandate red reflex screening for all newborns in South America.
- Educate the medical community about the importance of early referrals.
- Better networking between pediatric ophthalmologists.
- Create national databases.

Central America

Current Situation—Little information is available about the scope of the problem of congenital cataract or the ways in which children with congenital cataracts are identified in Central America. A retrospective review performed in Guatemala in 2011 of 328 cases of congenital (44.2%) and acquired (55.8%) cataracts in children 0-14 years of age found that the mean age of diagnosis for congenital cataract was 34.9 months, and treatment was not pursued in 71% of these cases.⁵³ There are no red reflex screening programs for newborns. Pediatric cataract surgeries are performed by ophthalmologists trained in pediatric surgery at hospital referral centers or by physicians volunteering for private organizations providing mobile eye services to underserved populations in Central America. Unlike adult cataract surgery is being performed only in the large cities, long distances from many of the cataract-blind children. Early detection and referral may not occur in remote areas if the outreach efforts are concentrating only on the detection and treatment of adult cataracts. In these areas, children could be identified and transported to the pediatric surgery centers. In reality, this does not occur consistently in Central America.

Because of an insufficient number of providers, NGOs and philanthropic organizations have been partnering with local governments to create or strengthen pediatric ophthalmology fellowships in Central America. The governmental approval process to establish a new training program can be arduous and time consuming. Even with an increase in the number of training opportunities for ophthalmologists wishing to specialize in pediatric eye surgery, adequate equipment and anesthesia support to operate on congenital cataracts is often lacking in small or medium-sized cities. For those trained pediatric eye surgeons who wish to practice in more remote locations, establishing the infrastructure and acquiring the necessary equipment to treat childhood cataracts may not be possible, and referral to a capital city becomes the default, requires long travel times for patients and families. Even at surgical centers, foldable IOLs often require additional out-of-pocket expense for the family. Children who receive surgery for congenital cataract in Central America still commonly

receive optical correction with a nonfoldable polymethylmethacrylate IOL. Follow-up after cataract surgery is limited. The family may not understand that long-term follow-up is needed, or they may not have the resources to reach the follow-up location or be reluctant to incur additional out-of-pocket expenses.

Challenges and Recommendations—A diversity of governmental health structures exists in Central America, and although urban centers are striving to reach international standards, pediatric ophthalmologists are few in number and reside mostly in urban centers. In many settings facilities, equipment, and consumables are inadequate. Central America is easily accessible from the US and therefore receives many visiting surgical teams. However, few believe that "mission trips" offer a sustainable solution to capacity building in the region and cite the need to build local infrastructure for management of children with congenital cataracts and extend the infrastructure beyond the capital cities to reach the underserved population. NGO support should be provided to the existing urban pediatric ophthalmology fellowship training programs so they can become regional, rather than merely national, centers of excellence. In addition, advocacy to local and national decision makers is needed so that infrastructure and manpower needs for the management of congenital cataracts can be provided in more locations, closer to cataract-blind children that reside outside of the major urban centers. This would also promote earlier detection and better postoperative follow-up. Optical correction and low-vision rehabilitation could then be provided near the family's home and at regular intervals during the growing years.

Summary

- National governments and NGOs must collaborate to improve and expand pediatric ophthalmology training programs within Central America.
- When fully trained pediatric eye surgeons return to their home regions outside of the capital cities, arrange for them to have the infrastructure to perform the high-quality surgery they were trained to perform, thus reducing the need for long travel times to the capital city when surgery is needed.
- Promote early detection and prompt referral of children with visually significant cataracts to the nearest place where appropriate equipment and safe general anesthesia are located by screening children in every location where outreach adult cataract surgery is performed.

Developed Nations

Current Situation—The birth prevalence of visually significant infantile cataract was 3.0-4.5/10,000 live births in a defined US population in 2003.⁵⁴ An Israeli center that instituted uniform newborn red reflex screening in 2010 reported an incidence of congenital cataracts of 1:2300.⁵⁵ A 2008 joint policy statement from AAP, AAPOS, AAO, and AACO identified red reflex examination as a vital component of all neonatal, infant, and child pediatric examinations.⁵⁶ The statement described the importance of red reflex testing, provided detailed instructions regarding how to perform red reflex testing, and identified indications for referral for children found to have an abnormal red reflex.⁵⁵ Most pediatric cataract surgeries are performed by pediatric ophthalmologists or adult cataract surgeons.⁵⁷

These surgeries are usually performed in hospital operating rooms, where experienced pediatric anesthesia services are available. Most children >1 year of age receive primary IOL implantation, whereas children <1 year are usually left aphakic and receive contact lens correction with later secondary IOL implantation.⁵⁸ The use of aphakic spectacles is generally avoided unless necessary because an IOL cannot be implanted or a family is unable to pay for or manage contact lenses. In general, the standard of care is for children to return after cataract surgery at postoperative day 1, week 1, month 1, and then at postoperative months 3, 6, and 12. In general, children under 2 years of age are followed more closely because of the need for frequent optical correction changes and aggressive amblyopia therapy.

Challenges and Recommendations—Inadequate or delayed screening for the abnormal red reflex may still lead to late presentation of children with congenital cataracts. Prior to institution of a red reflex screening mandate in 2010, a 2-year study in Israel showed that only 12 of 27 neonatology units routinely evaluated the red reflex. Difficulties with vision testing in preverbal infants in primary care settings and poor reimbursement for pediatric vision screening were noted to be current challenges in the US. Barriers to access centered on the need for expedited referrals. In particular, a lack of understanding of urgency on the part of referring providers, parents, call center employees, and insurers was noted. Public education campaigns and an increased volume of targeted educational material including online resources and videos were recommended. The question of whether to channel all children with cataracts to tertiary referral centers was raised, but countered by the idea that traveling great distances to these centers presents a barrier to follow-up care. The ideas of having nonphysician counselors to educate families, support/social media groups for parents, and the use of electronic reminders to improve patient follow-up were also discussed.

Financial challenges addressed revolved around the burgeoning cost of healthcare in the US. Kruger and colleagues⁵⁹ found that the 5-year treatment cost for children with surgery for unilateral cataract was \$27,090 for IOLs and \$25,331 for contact lens. Numerous questions arose about how the Affordable Health Care Act will affect management of congenital cataracts. Some facilities may be ill-equipped to manage children with cataracts due to the cost or availability of equipment and/or providers. Furthermore, contact lenses for aphakic rehabilitation are currently not covered by most insurance plans. In fact, patient cost doubles with contact lens versus IOLs.⁵⁹ Concerns were also raised about coverage and the affordability of infant spectacles/frames. Legislation was proposed to rectify this situation. Third, an insufficient number of pediatric eye care providers was cited, particularly in more rural locations. Finally, improving reimbursement for pediatric cataract management was proposed as this is a deterrent for residents choosing to pursue subspecialty training in pediatric ophthalmology and strabismus.⁶⁰

Summary

• Children with cataracts should be referred to high-volume regional centers for cataract surgery to reduce surgical complication rates—follow-up care can then be provided by local doctors.

Contact lenses should be covered by medical insurance.

Conclusions

Strategies for managing congenital cataracts must be adapted and developed according to the constraints in different countries. A basic framework for acceptable outcomes must focus on developing systems to address the following critical components: education, access, quality care, and good follow-up.

CEHTFs operating within high-volume, financially sustainable eye hospitals may be best equipped to train staff and provide care for children with cataracts.

There is a shortage of fellowship-trained pediatric ophthalmologists in every part of the world. Doctors in training should be encouraged to pursue subspecialty training in pediatric ophthalmology as caring for children with cataracts is challenging and not as financially rewarding as performing adult cataract surgery. Efforts should also be made to train and retain pediatric ophthalmologists in low- and middle-income countries such as Asia and Africa, where nearly 30% of health professionals in training anticipate migrating abroad.⁶¹

Acknowledgments

The authors thank Jamal Bleik, MD, of the University Medical Center, Rizk Hospital, Beirut, Lebanon; Victoria M. Sheffield, President & CEO of International Eye Foundation; and Marilyn T. Miller, MD, of the University of Illinois at Chicago.

Supported by National Institutes of Health Core Grant P30EY006360 (Department of Ophthalmology) and Research to Prevent Blindness, Inc, New York, New York (Department of Ophthalmology)

References

- 1. UNICEF. The State of the World's Children 2008: Child Survival. UNICEF; New York: 2008. Available at http://www.unicef.org. [November 9, 2014]
- 2. World Health Organization. State of the World's Sight: VISION 2020: the Right to Sight: 1999-2005. World Health Organization; Geneva: 2005. http://www.who.int/pbd/blindness/ vision_2020/v2020_therighttosight.pdf. [November 9, 2014]
- 3. Chiramblo MC, Tielsch JM, West KP, Katz J, Tizazu T, et al. Blindness and visual impairment in southern Malawi. Bull World Health Organ. 1986; 64:567–72. [PubMed: 3490926]
- 4. Kalua K, Patel D, Muhit M, Courtright P. Causes of blindness among children identified through village key informants in Malawi. Can J Ophthalmol. 2008; 43:425–7. [PubMed: 18711455]
- 5. Gogate P, Kalua K, Courtright P. Blindness in childhood in developing countries: time for a reassessment? PLoS Med. 2009; 6:e1000177. [PubMed: 19997501]
- Sommer A, Taylor HR, Ravilla TD, et al. Council of the American Ophthalmological Society. Challenges of ophthalmic care in the developing world. JAMA Ophthalmol. 2014; 132:640–44. [PubMed: 24604415]
- 7. Sommer A. Preventing blindness and saving lives. JAMA Ophthalmol. 2014; 132:115–17. [PubMed: 24407830]
- Courtright P, Hutchinson AK, Lewallen S. Visual impairment in children in middle- and lowerincome countries. Arch Dis Child. 2001; 96:1129–34. [PubMed: 21868404]
- 9. Gogate P, Khandekar R, Shrishrimal M, et al. Delayed presentation of cataracts in children: Are they worth operating upon? Ophthalmic Epidemiol. 2010; 17:25–33. [PubMed: 20100097]

- Kong L, Fry M, Al-Samarraie M, Gilbert C, Steinkuller PG. An update on progress and the changing epidemiology of causes of childhood blindness worldwide. J AAPOS. 2012; 16:501–7. [PubMed: 23237744]
- Wilson ME, Pandey SK, Thakur J. Paediatric cataract blindness in the developing world: surgical techniques and intraocular lenses in the new millennium. Br J Ophthalmol. 2003; 87:14–19. [PubMed: 12488254]
- African demography: The dividend is delayed. The Economist, March 8, 2014. Based on: Guengant J-P, May J. "African Demography.". Global Journal of Emerging Market Economies. 2013; 5:215–267.
- Foster A, Gilbert C, Rahi J. Epidemiology of cataract in childhood: a global perspective. J Cataract Refract Surg. 1997; 23:601–4. [PubMed: 9278811]
- Courtright P. Childhood cataract in sub-Saharan Africa. Saudi J Ophthalmol. 2012; 26:3–6. [PubMed: 23960961]
- 15. Duke R, Ameh S, Nwagyara E, Lewallen S, Courtright P. Challenges faced by key informants practicing case funding for vision loss in children: the experience in Cross River State, Nigeria. Int Health. 2013; 5:259–65. [PubMed: 24105974]
- 16. Duke R, Otong E, Iso M, et al. Using key informants to estimate prevalence of severe visual impairment and blindness in children in Cross River State, Nigeria. J AAPOS. 2013; 17:381–4. [PubMed: 23911130]
- 17. Shija F, Shirima S, Lewallen S, Courtright P. Comparing key informants to health workers in identifying children in need of surgical eye services. Int Health. 2012; 4:1–3. [PubMed: 24030874]
- Kalua K, Patel D, Muhit M, Courtright P. Productivity of key informants for identifying blind children: evidence from a pilot study in Malawi. Eye. 2009; 23:7–9. [PubMed: 18344959]
- Schulze Schwering M, Finger RP, Barrows J, Nyrenda M, Kalua K. Barriers to uptake of free pediatric cataract surgery in Malawi. Ophthalmic Epidemiol. 2014; 21:138–43. [PubMed: 24597953]
- Agarwal PK, Bowman R, Courtright P. Child eye health tertiary facilities in Africa. J AAPOS. 2010; 14:263–6. [PubMed: 20603061]
- Kishiki E, Shirima S, Lewallen S, Courtright P. Improving postoperative follow-up of children receiving surgery for congenital or developmental cataract in Africa. J AAPOS. 2009; 13:280–82. [PubMed: 19285887]
- 22. Courtright, P.; Bowman, R.; Gilbert, C.; Lewallen, S.; van dijk, K.; Yorston, D. Cataracte de l'enfant en Afrique. Dark & Light Blind Care; Veenendaal, Netherlands: 2010.
- Erikson JR, Bronsard A, Mosha M, Carmichael D, Hall A, Courtright P. Predictors of poor followup in children that had cataract surgery. Ophthalmic Epidemiol. 2006; 13:237–43. [PubMed: 16877282]
- 24. Bronsard A, Geneau R, Shirima S, Courtright P, Mwende J. Why are children brought late for cataract surgery? Qualitative findings from Tanzania. Ophthalmic Epidemiol. 2008; 15:383–8. [PubMed: 19065431]
- Kalua K, Nyirenda M, Lewallen S, Courtright P. Three-year follow up of primary health care workers trained in identification of blind and visual impaired children in Malawi. Health. 2013; 5:1791–5.
- 26. Kalua K, Gichangi M, Barassa E, Eliah E, Lewallen S, Courtright P. A randomized controlled trial to investigate effects of enhanced supervision on primary eye care services at health centres in Kenya, Malawi, and Tanzania. BMC Health Services Research. 2014; 14(Suppl 1):1–8. [PubMed: 24382312]
- [November 9, 2014] Peek—the optician's clinic that fits in your pocket.. London School of Tropical Hygiene and Tropical Medicine. 2014. http://www.peekvision.org.
- 28. Gallagher, J. [November 14, 2014] "Pocket optician" trialled in Kenyan schools.. BBC News Health. Feb 2. 2014 http://www.bbc.com.
- 29. Evans CT, Lenhart PD, Lin D, et al. A cost analysis of pediatric cataract surgery at two child eye health tertiary facilities in Africa. J AAPOS. 2014; 18:559–62. [PubMed: 25454021]

- Dehghan A, Kianersi F, Moaam E, Ghanbari H. Causes and anatomical site of blindness and severe visual loss in Isfahan, Islamic Republic of Iran. East Mediterr Health J. 2010; 16:228–32. [PubMed: 20799580]
- 31. Ramezani A, Pardis M, Rafati N, et al. Causes of visual impairment among patients referred to a visual rehabilitation clinic in Iran. Korean J Ophthalmol. 2012; 26:80–83. [PubMed: 22511832]
- 32. Baashmus MA, Al-Akily SA. Profile of childhood blindness and low vision in Yemen: a hospital based study. East Mediterr Health J. 2010; 16:425–8. [PubMed: 20795428]
- Zeidan Z, Hashim K, Muhit MA, Gilbert C. Prevalence and causes of childhood blindness in camps for displaced persons in Khartoum: results of a household survey. East Mediterr Health J. 2007; 13:580–85. [PubMed: 17687831]
- Razavi H, Kuper H, Rezvan F, et al. Prevalence and causes of severe visual impairment and blindness among chilfen in the lorestan province of iran, using the key informant method. Ophthalmic Epidemiol. 2010; 17:95–102. [PubMed: 20302431]
- Kleinmann G, Zaugg B, Apple D, Bleik J. Pediatric cataract surgery with hydrophilic acrylic intraocular lens. J AAPOS. 2013; 17:367–70. [PubMed: 23928003]
- 36. Eastern Mediterranean Regional Office of the International Agency for the Prevention of Blindness (EMR-IAPB); World Health Organization regional office for the Eastern Mediterranean Regional Office (WHO-EMRO); Prevention of Blindness Union (PBU). Guidelines for school eye health for the eastern Mediterranean region (EMR). Mar 8.2010
- Khandekar R. Visual disabilities in children including childhood blindness. Middle East Afr J Ophthalmol. 2008; 15:129–34. [PubMed: 21369469]
- Vijayalakshmi P, Rajasundari TA, Prasad NM, et al. Prevalence of eye signs in congenital rubella syndrome in South India: a role for population screening. Br J Ophthalmol. 2007; 91:1467–70. [PubMed: 17947267]
- Lambert SR. Congenital rubella syndrome: the end is in sight. Br J Ophthalmol. 2007; 91:1418–19. [PubMed: 17947261]
- 40. Muhit MA, Shah SP, Gilbert CE, Hartley SD, Foster A. The key informant method: a novel means of ascertaining blind children in Bangladesh. Br J Ophthlamol. 2007; 91:995–9.
- 41. Gogate PM, Sahasrabudhe M, Shah M, et al. Long term outcomes of bilateral congenital and developmental cataracts operated in Maharashtra, India. Miraj Pediatric cataract study III. Indian J Ophthalmol. 2014; 62:186–95. [PubMed: 24618489]
- 42. Ram J, Sukhija J, Thapa BR, Arya VK. Comparison of hospital versus rural eye camp based pediatric cataract surgery. Middle East Afr J Ophthalmol. 2012; 19:141–6. [PubMed: 22346130]
- Gogate P, Dole K, Ranade S, Deshpande M. Cost of pediatric cataract surgery in Maharashtra, India. Int J Ophthalmol. 2010; 3:182–6. [PubMed: 22553549]
- Ravilla T, Ramasamy D. Efficient high-volume cataract services: the Aravind model. Community Eye Health. 2014; 27:7–8. [PubMed: 24966455]
- 45. Natchiar G, Robin AL, Thulasiraj RD, Krishnaswamy S. Attacking the backlog of India's curable blind. The Aravind Eye Hospital model. Arch Ophthalmol. 1994; 112:987–93. [PubMed: 8031283]
- 46. Leite C, Zin A. Health seeking behavior of the families of children with cataract attending an eye clinic in Rio de Janeiro, Brazil. Arq Bras Oftalmol. 2011; 74:271–8. [PubMed: 22068855]
- 47. Haddad MAO, Sei M, Sampaio MW, Kara-Jose N. Causes of visual impairment in children: a study of 3,210 cases. J Pediatr Ophthalmol Strabismus. 2007; 44:232–40. [PubMed: 17694828]
- Haddad MAO, Lobato FJC, Sampaio MW, Kara-Jose N. Pediatric and adolescent population with visual impairment: study of 285 cases. CLINICS. 2006; 61:239–46. [PubMed: 16832557]
- Merula RV, Fernandes LC. Catarata infantile: importancia do diagnostic e tratamento precoces. Arq Bras Oftalmol. 2005; 68:299–305. [PubMed: 16059558]
- Ventura MC, Ventura BV, Ventura CV, Ventura LO, Arantes TE, Nose W. Outcomes of congenital cataract surgery: intraoperative intracameral triamcinolone injection versus postoperative oral prednisolone. J Cataract Refract Surg. 2014; 40:601–8. [PubMed: 24530023]
- Ventura MC, Sampaio VV, Ventura BV, Ventura LO, Nose W. Congenital cataract surgery with intraocular lens implantation in microphthalmic eyes: visual outcomes and complications. Arq Bras Oftalmol. 2013; 76:240–43. [PubMed: 24061837]

- Ventura MC, Ventura BV, Ventura CV, Ventura LO, Nose W. Congenital cataract surgery with intracameral triamcinolone: pre- and postoperative central corneal thickness and intraocular pressure. J AAPOS. 2012; 16:441–4. [PubMed: 23084381]
- 53. Zimmermann-Paiz MA, Quiroga-Reyes CR. Pediatric cataract in a developing country: retrospective review of 328 cases. Arq Bras Oftalmol. 2011; 74:163–5. [PubMed: 21915440]
- Holmes JM, Leske DA, Burke JP, Hodge DO. Birth prevalence of visually significant infantile cataract in a defined U.S. population. Ophthalmic Epidemiol. 2003; 10:67–74. [PubMed: 12660855]
- 55. Litmanovitz I, Doflin T. Red reflex examination in neonates: the need for early screening. IMAJ. 2010; 12:301–2. [PubMed: 20929085]
- American Academy of Pediatrics; Section on Ophthalmology; American Association for Pediatric Ophthalmology and Strabismus; American Academy of Ophthalmology; American Association of Certified Orthoptists. Red reflex examination in neonates, infants, and children. Pediatrics. 2008; 122:1401–4. [PubMed: 19047263]
- 57. Wilson, ME.; Trivedi, RH.; Pandey, SK., editors. Pediatric Cataract Surgery: Techniques, Complications, and Management. Lippincott Williams & Wilkins; Philadelphia: 2005.
- Wilson ME, Trivedi RH, Buckley EG, et al. ASCRS White Paper. Hydrophobic acrylic intraocular lenses in children. J Cataract Refract Surg. 2007; 33:1966–73. [PubMed: 17964406]
- 59. Kruger S, DuBois L, Becker ER, et al. Infant Aphakia Treatment Study. Cost of intraocular lens vs. contact lens treatment after unilateral congenital cataract surgery in the Infant Aphakia Treatment Study: retrospective analysis at age 5 years. Ophthalmology. 2015; 122:288–92. [PubMed: 25439604]
- 60. Simon JW, Bradfield Y, Smith J, Ahn E, France TD. Recruitment and manpower in pediatric ophthalmology and strabismus. J AAPOS. 2007; 11:336–340. [PubMed: 17689824]
- Silvestri DM, Blevins M, Afzal AR, et al. Medical and nursing students' intentions to work abroad or in rural areas: a cross-sectional survey in Asia and Africa. Bull World Health Organ. 2014; 92:750–59. A. [PubMed: 25378729]



FIG 1.

Significant differences exist in age at presentation for cataract extraction and management following cataract extraction in many parts of the world. A, 8-year-old boy with exotropia presents for bilateral cataract extraction in Subsaharan Africa. B, 1-year-old bilateral aphake in a developed nation has worn rigid gas permeable contact lenses since her congenital cataracts were removed at 6 weeks of age.