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Received: 29 February 2016 Accepted in revised form: 4 July 2016 Published online: 29 July 2016 Strategies to improve follow-up of children after surgery for cataract: findings from Child Eye Health Tertiary Facilities in sub-Saharan Africa and South Asia

Abstract

Purpose We sought to conduct a systematic literature review on follow-up of children with ocular surgical management (primarily childhood cataract) in developing countries. Second, we sought to determine the current practices regarding follow-up for clinical, optical, low vision, rehabilitation, and educational placement among children receiving surgical services at Child Eye Health Tertiary Facilities (CEHTF) in sub-Saharan Africa (SSA) and South Asia. Methods A systematic literature review was conducted. Separately, we conducted a crosssectional study among CEHTF in SSA and South Asia (India, Nepal, and Bangladesh) to assess current capacities and practices related to follow-up and educational placement. *Results* The articles that met the systematic review eligibility criteria could be grouped into two areas: factors and strategies to improve post-operative follow-up and educational placement of children after surgery. Among the 106 CEHTF in SSA and South Asia, responses were provided by 75 CEHTF. Only 59% of CEHTF reported having a Childhood Blindness and Low Vision Coordinator; having a coordinator was associated with having appropriate follow-up mechanisms in place. Educational referral practices were associated with having a lowvision technician, having low-vision devices, and having donor support for these services. Conclusions The systematic literature review revealed evidence of poor follow-up after surgical interventions for cataract and other conditions, but also showed that follow-up could be improved significantly if specific

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strategies were adopted. Approaches to follow-up are generally inadequate at most facilities and there is little external support for follow-up. Findings suggest that funding and supporting a coordinator would assist in ensuring that good practices for follow-up (cell phone reminders, patient tracking, and reimbursement of transport) were followed. *Eye* (2016) **30**, 1234–1241; doi:10.1038/eye.2016.169; published online 29 July 2016

Introduction

Increasing the global knowledge base for planning for childhood eye care services is a top priority in order for children with visual impairment to realize their full visual potential. The body of knowledge on programmatic approaches to paediatric eye care in developing countries has significantly increased in the past 10 years, and evidence suggests that, with the reduction in vitamin A deficiency and measlesrelated blindness, childhood cataract requires increased global attention.¹

For many years, there has been considerable concern about the low levels of follow-up for distance corrections, optical low-vision devices, and educational placement for children receiving cataract and other ocular surgeries in many developing countries.^{2,3} Initial work in Tanzania identified reasons for poor follow-up⁴ and demonstrated strategies to address these.⁵ There is limited information on educational placement following sight-restoring or sight-improving surgery in children⁶ and existing information suggests that there are considerable challenges in ensuring that children are placed in the most

appropriate educational setting.^{7,8} We sought to conduct a systematic literature review on follow-up of children with ocular surgical management (primarily childhood cataract) in developing countries. Second, we sought to determine the current practices regarding follow-up for clinical, optical, low vision, rehabilitation, and educational placement among children receiving surgical services at Child Eye Health Tertiary Facilities (CEHTF) in sub-Saharan Africa (SSA) and South Asia.

Materials and methods

A systematic literature review was conducted including a search in MEDLINE using the terms "Follow up strategies", "childhood cataract surgery", "phone follow up", "text message", "visual impairment", and "school placement" for articles published in English language from 1 January 2001 to 30 June 2015. We also systematically searched the reference lists of included publications.

Separately, we conducted a cross-sectional study among CEHTF in SSA and South Asia (India, Nepal, and Bangladesh) to assess current capacities and practices related to follow-up. A list of CEHTF in SSA and South Asia was generated by our group with assistance for South Asia from ORBIS International and key personnel in the region. A questionnaire was designed and pretested with one facility; after this it was sent to the heads of CEHTF. The questionnaire included information on staffing, infrastructure, strategies used to improve follow-up, post-operative services provided, and educational placement practices (Supplementary Material). There were two open-ended questions on the survey, the first asking which children were least likely to return for follow-up and the second asking what the barriers to follow-up were. The questions, although related, reflect different perspectives on the same issue of poor follow-up after surgery. Responses to the questions were tallied by topic area. Respondents could provide multiple answers.

The study was approved by the University of Cape Town ethics committee and participants consented to use responses; all data were compiled and reported anonymously.

All CEHTF were contacted at least three times to obtain responses. Colleagues in Nigeria, Bangladesh, Nepal, India, and South Africa did follow-up contact with CEHTF who did not respond to the first two requests. Analysis was undertaken using Stata version 11.0 (College Station, TX, USA). Findings were reported as odds ratios (95% confidence intervals) and mean values.

Results

Literature review

The literature review identified 431 articles; 340 articles were not included after the first review as they did not include any information on follow-up. Among the remaining 91 articles, 25 met the eligibility criteria; all were reviewed and 17 provided information on one or more topics related to post-operative follow-up of children with cataract or other eye surgical conditions. The articles could be grouped into two areas: factors and strategies to improve post-operative follow-up and educational placement of children after surgery.

The first article that addressed the issue of postoperative follow-up was conducted in Tanzania⁴ and included an assessment of the pre-surgical factors that predicted whether children returned for their 2-week and 10-week follow-ups. On the basis of this work, a second paper⁵ demonstrated the effect of specific strategies to improve follow-up. Similar studies have been conducted in India,⁹ Mexico,¹⁰ China,¹¹ and Nepal.¹² The findings from these studies suggest a significant range in followup from 21% in India⁹ to 98% in Mexico,¹⁰ most however, being low. Factors associated with poor follow-up included long distance to the surgical facility,^{4,9,10} being a girl,⁴ long delay in presentation,⁴ and cost and poor understanding of the need for follow-up.⁹ Specific followup strategies (use of cell phone as reminders, reimbursing travel, maintaining a tracking sheet, and dedicated counselling) undertaken in Tanzania increased the proportion of children returning for their 10-week followup from 43 to 83% and gender inequity in follow-up disappeared.⁵ Undertaking a similar approach, a team in Nepal increased the proportion of children returning for post-operative services from 60 to 81%.¹² Using a randomized trial approach, a team in China showed that SMS reminders were an effective approach to improve follow-up.11

There were only three papers, all from eastern Africa, that addressed educational placement after cataract surgery.^{6–8} There have been a number of surveys in schools for the blind that have noted the possibility of inappropriate educational placement,^{13,14} but only one in which educational placement was the focus of the study.⁷ The findings from these studies suggested that, although children had significantly improved vision post-operatively, they were not often placed in the most appropriate educational environment.

Among the 106 CEHTF in SSA (n = 46) and South Asia (n = 60), responses were provided by 75 (71% of total questionnaires sent) CEHTF (39 in SSA and 36 in South Asia). The majority of the missing data were from India (23 of 42 CEHTF reported).

Staffing and facilities

The CEHTF have been providing services for a median 10 years, ranging from <1 to 48 years. All except four facilities reported having an optometrist and all except 11 facilities reported having a low-vision specialist. Only 44 facilities (58.7%) reported having a Childhood Blindness and Low Vision Coordinator.

Dedicated children's outpatient rooms were found at 54 (72%) facilities and dedicated paediatric operating theatres were found at 39 (52%) of facilities. Most CEHTF (67; 89.3%) had an optical shop and 52 facilities (69.3%) made spectacles in the optical shop. Low-vision rooms were found in 52 (69.3%) of CEHTF.

Follow-up activities undertaken

All facilities report counselling to improve follow-up. Counselling is done by a wide range of people: childhood blindness coordinators (25; 33.3%), eye nurses (26; 34.7%), optometrists (6; 8%), and other people (16; 21.3%). Only 29 facilities (38.7%) had a system for tracking children and 34 CEHTF (45.3%) used cell phones for follow-up; 22 facilities (29.3%) provided reimbursement for transport if needed. Only 20 facilities (26.7%) reported having donor support for follow-up.

Refractive services (including spectacles) for children were available at 68 (90.7%) CEHTF. In just over half of the cases (n = 39; 52%), some of the costs for distance correction were covered by donors. In only three cases were some costs covered by government, and in 32 cases (42.7%), there was no mechanism to cover the costs. Availability of magnifying devices varied. High +spectacles were available at 64 facilities (85.3%); hand magnifiers at 62 facilities (82.7%); stand magnifiers at 52 facilities (69.3%); and telescopes at 48 facilities (64%). In half of the facilities, there were no mechanisms to support provision of low-vision devices (n = 37; 49.3%), whereas 30 facilities (40%) had support from donors and 5 facilities (6.7%) reported support from the government.

Respondents reported that children living far away were the least likely to return for follow-up; this factor accounted for 53 (43.4%) of a total 122 responses (multiple responses allowed). Children from poor families (including poorly educated families) accounted for 17.2% of responses and older children accounted for 9.0% of responses. The most common barrier to follow-up reported included indirect costs (eg, transport to hospital, meals, and accommodation for parents) of follow-up; 62 (41.3%) of 150 reports (multiple responses allowed). This was followed by distance (25.3%) and lack of knowledge, or negligence by parents (26.0%). The ranking of responses to both questions was the same for CEHTF in Africa and South Asia.

Educational placement activities

For school-age children, educational placement is reported to be discussed with parents in 60 facilities (80%) and with teachers in 12 facilities (16%). Children have different educational needs and CEHTF would be expected to have similar referral patterns if all services were available, and CEHTF staff utilized the options appropriately. This was not the case as the CEHTF refer children to schools for the blind (n = 57; 76%) and into mainstream schools (n = 47; 62.7%) more frequently compared with annexes or resource centres (n = 27; 36%). Some respondents (n = 27; 36%) did not know if children at schools for the blind or annexes were examined prior to the enrolment. Only 23 CEHTF (30.7%) reported that children were assessed clinically prior to the enrolment; 25 CEHTF (33.3%) said that children were not examined prior to the enrolment. Most CEHTF (n = 48; 64%) reported that there was an educational facility for children with other disabilities and 46 reported (61.3%) that there was a rehabilitation facility for children with other disabilities. There were significant differences between CEHTF in SSA and South Asia with South Asian CEHTF, generally more likely to have the staffing complement, facilities, strategies to improve follow-up, and follow-up services for children compared with the SSA CEHTF (Table 1).

Factors associated with good follow-up and referral for educational placement

In the earlier study of CEHTF in Africa,¹⁵ it was noted that predictors of productivity (number of children receiving surgery per year) were related to manpower, in particular, having a dedicated optometrist, low-vision technician, Childhood Blindness and Low Vision Coordinator (henceforth referred to as the "Coordinator"), and a dedicated anaesthetist. Having a Coordinator is still uncommon, particularly in SSA, yet CEHTF with a Coordinator are more likely to have strategies to improve follow-up, donor support, and plans for educational placement (Table 2). Having a low-vision technician was not associated with having any specific strategies to improve follow-up. Among the 75 institutions, 25 (33.3%) have support from donors (external or government) for both spectacles and lowvision devices, whereas 26 (34.7%) have no mechanism of support for either spectacles or low-vision devices. The remaining CEHTF have a mix of support or no support.

Analysis of the factors associated with referral to mainstream schools and schools for the blind, and/or annexes was undertaken. Although referral patterns would be expected to match the needs of children, of the 47 CEHTF that referred to mainstream schools, 40 (85.1%)

Table 1 Comparison of findings from CEHTF in sub-Sahara Africa and South Asia

	Sub-Saharan Africa N = 39	South Asia $N = 36$	Odds ratio (95% CI)	
	n (%)	n (%)	P-value	
Personnel				
Optometrist				
Present	35 (92.1)	36 (100)	Cannot calculate	
Absent		3 (7.9)	0	
Low-vision technician				
Present	31 (79.5)	33 (94.3)	0.23 (0.05–1.19)	
Absent	8 (20.5)	2 (5.7)	P = 0.06	
Childhood Blindness and Low Vision	Coordinator			
Present	16 (41.0)	28 (77.8)	0.19 (0.07-0.54)	
Absent	23 (59.0)	8 (22.2)	P = 0.002	
Facilities				
Years in operation	8.9 (8.7)	15.0 (9.9)	P = 0.006	
Child outpatient room Present	18 (46.2)	36 (100)	Cannot calculate	
Absent	21 (53.8)	0	Carinot calculate	
Paediatric operating theatre				
Present	13 (33.3)	26 (72.2)	0.19 (0.07–0.51)	
Absent	26 (66.7)	10 (27.8)	P = 0.001	
Optical shop				
Making spectacles	23 (59.0)	29 (80.6)	0.35 (0.12–0.98)	
Not making specs	8 (20.5)	7 (19.4)	P = 0.04	
No optical shop	8 (20.5)	0		
Low-vision room				
Present	19 (51.4)	33 (91.7)	0.09 (0.02–0.37)	
Absent	18 (48.6)	3 (8.3)	P = 0.001	
Strategies to improve follow-up				
Tracking	7 (17.9)	22 (61.1)	0.14 (0.05–0.41)	
No tracking	32 (82.1)	14 (38.9)	P = 0.001	
Cell phone calls	13 (33.3)	21 (58.3)	0.35 (0.14-0.91)	
No cell phone calls	26 (66.7)	15 (41.7)	P = 0.03	
Reimburse travel	11 (28.2)	11 (44.0)	0.89 (0.33-2.41)	
No reimbursement	28 (71.8)	25 (56.0)	P = 0.83	
Donor support for follow-up				
Present	10 (25.6)	10 (27.8)	0.89 (0.32-2.49)	
Absent	29 (74.4)	26 (72.2)	P = 0.83	
Counselling done by:				
Childhood coordinator	11 (29.7)	14 (38.9)		
Eye nurse	17 (45.9)	9 (25.0)		
Optometrist	3 (8.1)	3 (8.3)		
Other person	6 (16.2)	10 (27.8)		
Services provided at the CEHTF				
Spectacles can be obtained				
Yes	32 (82.1)	36 (100)	Cannot calculate	
No	7 (17.9)	0	Currier curculate	
Caste for exactacies covered by:				
Costs for spectacles covered by: Donor support	12 (31.6)	27 (75.0)	0.17 (0.06-0.46)	
Government	2 (5.3)	1 (2.8)	P = 0.001	
	- (0.0)	- ()	1 - 0.001	

Table 1. (Continued)

	Sub-Saharan Africa N = 39	South Asia $N = 36$	Odds ratio (95% CI)	
	n (%)	n (%)	P-value	
No mechanism	24 (63.1)	8 (22.2)		
Low-vision devices can be obtain	led			
High mag glasses	31 (83.8)	33 (97.1)	0.16 (0.02–1.38)	
No high mag glasses	6 (16.2)	1 (2.8)	P = 0.06	
Hand magnifiers	28 (73.7)	34 (100)	Cannot calculate	
No hand magnifiers	10 (26.3)	0		
Stand magnifiers	19 (61.3)	33 (97.1)	0.05 (0.00-0.40)	
No stand magnifiers	12 (38.7)	1 (2.9)	P = 0.001	
Telescopes	18 (56.3)	30 (91.7)	0.13 (0.03-0.51)	
No telescopes	14 (43.7)	3 (8.3)	P = 0.001	
Cost of low-vision devices covered	ed hv			
Donor support	14 (36.8)	16 (47.1)	0.46 (0.18–1.18)	
Government support	1 (2.7)	4 (11.8)	P = 0.10	
No mechanism	23 (60.5)	14 (41.1)		
Educational placement of children				
Meet teacher	4 (10.3)	8 (22.2)	0.40 (0.11–1.46)	
Do not meet teacher	35 (89.7)	28 (77.8)	P = 0.15	
Meet parent	31 (79.5)	29 (80.6)	0.93 (0.30-2.90)	
Do not meet parent	8 (20.5)	7 (19.4)	P = 0.90	
Referral of school-age children to	:			
School for the blind	33 (86.8)	24 (66.7)	3.3 (1.03–10.6)	
Not school for blind	5 (13.2)	12 (33.3)	P = 0.04	
Annex	12 (31.6)	15 (41.7)	0.64 (0.25–1.67)	
Not annex	26 (68.4)	21 (58.6)	P = 0.37	
Mainstream school	20 (52.6)	27 (75.0)	0.37 (0.14-0.99)	
Not mainstream	18 (47.4)	9 (25.0)	P = 0.04	
Are children assessed prior to en				
Yes	12 (30.8)	11 (30.6)	1.01 (0.38–2.70)	
No	15 (38.5)	10 (27.8)	"no"+"don't know"	
Don't know	12 (30.8)	15 (41.7)	Combined	
Education facility for children wi		20 (55.1)		
Present	28 (73.7)	20 (57.1)	2.1 (0.78–5.62)	
Absent	10 (26.3)	15 (42.9)	P = 0.14	
Rehabilitation facility for childrer Present		20 (55 6)	1 60 (0 62 4 09)	
Absent	26 (66.7) 12 (22.2)	20 (55.6)	1.60 (0.63-4.08) P = 0.33	
ADSent	13 (33.3)	16 (44.4)	P=0.33	

also referred to schools for the blind or annexes, whereas among the 27 CEHTF that did not refer to mainstream schools, 20 (74.1%) referred only to schools for the blind or annexes; seven CEHTF did not refer at all. If a CEHTF had a low-vision technician, it was 1.86 times (95% CI 0.48–7.14) more likely to refer children to the mainstream schools. More importantly, if a CEHTF provided lowvision devices (high+spectacles, hand magnifiers, stand magnifiers, and telescopes), it was more likely to refer to the mainstream schools (Table 3). Having donor or government support (as opposed to no support) for lowvision services was also associated with likelihood of referral to the mainstream schools, more so in South Asia than SSA (Table 3).

Discussion

The systematic literature review revealed evidence of poor follow-up after surgical interventions for cataract and other conditions, but also showed that follow-up could be improved significantly if specific strategies (cell phone contact, reimbursing transport, maintaining tracking sheets, and dedicated counselling) were adopted. These strategies require both funding and manpower, generally in the form of a Coordinator.

Table 2	Associat	ion between h	naving	; a (Childho	od	Blindness
and Low	Vision	Coordinator,	and	like	lihood	of	adopting
different strategies to improve follow-up							

	Has CBLVC	No CBLVC	Odds ratio (95% CI)
			P-value
Tracking			
Present	24 (54.5)	5 (16.1)	6.24 (2.02–19.24)
Absent	20 (45.5)	26 (83.9)	P = 0.001
Cell phone			
Present	26 (59.1)	8 (25.8)	4.15 (1.52–11.33)
Absent	18 (40.9)	23 (74.2)	P = 0.004
Reimbursement for	• travel		
Present	20 (45.5)	2 (6.5)	12.08 (2.56–56.98)
Absent	24 (54.5)	29 (93.5)	P = 0.001
Donor support for	follow-up		
Present	17 (38.6)	3 (9.7)	5.88 (1.54-22.36)
Absent	27 (61.4)	28 (90.3)	P = 0.005
Educational placen	ient of childrer	1	
Meet teachers			
Yes	11 (25.0)	1 (3.2)	10.0 (1.22-82.15)
No	33 (75.0)	30 (96.8)	P = 0.01
Meet parents			
Yes	37 (84.1)	23 (74.2)	1.83 (0.59-5.75)
No	7 (15.9)	8 (25.8)	P = 0.29
Refer to school			
Yes	31 (70.5)	26 (83.9)	0.37 (0.11-1.26)
No	13 (29.5)	4 (16.1)	P = 0.10
Refer to annexe			
Yes	19 (43.2)	8 (26.7)	2.09 (0.76-5.71)
No	25 (56.8)	22 (73.3)	P = 0.15
Refer to mains			
Yes	31 (70.5)	16 (53.3)	2.09 (0.79-5.49)
No	13 (29.5)	14 (46.7)	P = 0.14
Children at sch	ools for the b	lind assessed	l before enrolment
Yes	15 (34.1)	8 (25.8)	1.49 (0.54-4.11)
No	18 (40.9)	7 (22.6)	"no"+"don't know"
Don't know	11 (25.0)	16 (51.6)	Combined
Educational ref			
Yes	26 (59.1)	22 (71.0)	0.66 (0.25–1.79)
No	16 (40.9)	9 (29.0)	P = 0.41
Rehabilitation	referral possib	ole for other	disabilities
Yes	27 (61.4)	19 (61.3)	1.0 (0.39–2.58)
No	17 (38.6)	12 (38.7)	P = 0.90

The coverage of the CEHTF survey was fairly good (87% of African facilities, 58% of South Asian facilities); however, we cannot provide information on how different or similar the responding facilities were from the non-responding facilities.

Compared with the previous survey of CEHTF in SSA,¹⁵ the current assessment demonstrates that the staffing complement and infrastructure has improved greatly in the past 6 years. That said, the staffing and infrastructure findings from the SSA CEHTF were not as supportive of good-quality child eye health services as compared with the South Asian CEHTF. We cannot explain the differences except to note that South Asian CEHTF have, by and large, been established longer and have greater donor support for services provided at follow-up.

Similar to the previous work by Agarawal and colleagues,¹⁵ having a Coordinator is associated with having effective follow-up mechanisms such as

 Table 3
 Association between providing low-vision devices and referring to mainstream schools

	Refer children to mainstream schools			
	Yes	No	- Odds ratio (95% CI) P-value	
Provide	high+(magnifying)	spectacles		
Yes	43 (95.6)	20 (80.0)	5.37 (0.96-30.12)	
No	2 (4.4)	5 (20.0)	P = 0.04	
Provide	hand magnifiers			
Yes	43 (95.6)	18 (69.2)	9.56 (1.85-49.47)	
No		8 (30.8)	P = 0.002	
Provide	stand magnifiers			
Yes	35 (89.7)	16 (64.0)	4.92 (1.32-18.39)	
No	4 (10.3)	9 (36.0)	P = 0.013	
Provide	telescopes			
Yes	35 (85.4)	12 (52.2)	5.35 (1.62-17.60)	
No	6 (16.4)	11 (47.8)	P = 0.004	
Donor/g (all CEH	overnment support ITF)	available for low-a	vision services	
Yes	28 (62.2)	6 (23.1)	5.49 (1.84-16.39)	
No		20 (79.9)	P = 0.001	
	overnment support Asia CEHTF)	available for low-a	vision services	
Yes	18 (81.8)	2 (22.2)	15.75 (2.35-106.23)	
No	4 (18.2)	7 (77.8)	P = 0.002	
	overnment support CEHTF)	available for low-a	vision services	
Yes	10 (50.0)	4 (23.5)	3.25 (0.78-13.48)	
No	10 (50.0)	13 (76.5)	P = 0.10	

having a tracking register, using cell phone contact for follow-up, and providing reimbursement for travel. There are costs associated with hiring and training a Coordinator, and as noted in our study, CEHTF with a Coordinator are 5.9 times more likely to have donor support.

Approaches to follow-up are generally inadequate at most facilities and there is little external support for followup. The most common follow-up approach was cell phone contact, (still less than half of facilities), followed by tracking (about one-third) and reimbursement. Approaches to follow-up were weakest in Africa even though there is little difference in donor support between SSA and South Asia. Distances and the indirect costs associated with returning for follow-up remain the main challenges reported by the personnel within CEHTF; this suggests that more proactive efforts at providing support for transport are needed.

Most facilities offered spectacles for children and most also had low-vision devices, although in only about half of the facilities were there mechanisms to support provision of spectacles or low-vision devices for children, particularly in SSA.

Most facilities reported discussing educational placement with parents, but few also discussed it with teachers; referral to mainstream schools without involving the classroom teachers is less likely to lead to successful educational placement.

Referring children with low vision to mainstream school environments, although preferable, may not be possible in all settings, particularly where there are no supportive mechanisms for these children. Nevertheless, the fact that 52% of CEHTF and 75% of CEHTF in SSA and South Asia, respectively, refer children to the mainstream schools, indicates that educational attainment opportunities for these children are growing. Most CEHTF reported minimal contact with schools for the blind, as less than one-third of CEHTF knew if children were screened prior to admission to these schools. In the end, providing both the low-vision services and the educational environment will be critical to ensure that children attain the best possible visual and educational outcomes.

Our findings, although limited by the responses received by the CEHTF, particularly those in India, provide valuable insights into how follow-up management is being currently provided in SSA and South Asia. There is considerable scope for improvement of service delivery; this will require investment by government and donors. Given the significant cost¹⁶ associated with surgical interventions, the effort to obtain good-quality follow-up is minimal.^{17–19}

Summary

What was known before

- Initial work in Tanzania identified reasons for poor follow-up.
- There is limited information on educational placement following sight-restoring or sight-improving surgery in children.

What this study adds

- Systematic literature review on follow-up of children with ocular surgical management in developing countries.
- Determines current practices regarding follow-up for clinical, optical, low vision, rehabilitation, and educational placement among children receiving surgical services at Child Eye Health Tertiary Facilities.

Conflict of interest

The authors declare no conflict of interest.

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Supplementary Information accompanies this paper on Eye website (http://www.nature.com/eye)