

# Childhood blindness and low vision in Uganda

KEITH M. WADDELL

## Abstract

**Purpose** To examine the causes and outcome of subnormal vision starting in childhood in Uganda, to aid in planning for its avoidance and for rehabilitation.

**Methods** All those seen having subnormal vision with onset from birth to 15 years (total 1135) (schools 1983–97; community 1988–97) were included in the study. Clinical examination was performed and a World Health Organisation (WHO) form completed, with analysis by its computer program. Main outcome measures were visual acuity, signs of eye pathology, outcome of treatment and refraction and low vision assessment.

**Results** By WHO category 14.8% had visual impairment, 6.5% severe visual impairment, 63.2% were blind and 15.2% were too young to test. The acuities and causes were similar in school and community groups, excepting cortical visual impairment and multiple impairment, which are much commoner in the community. Cataract was the largest cause of visual impairment (30.7%) and surgical outcome was unsatisfactory. Visual loss following corneal ulceration was the second commonest cause of subnormal vision (22.0%).

**Conclusions** Cataract and corneal damage cause half of all subnormal vision, which is avoidable for both. Cataract surgery needs to be upgraded. To prevent corneal visual loss, primary health care should continue to be expanded, especially measles immunisation and nutrition care; rubella immunisation should be added. Special education needs to be greatly expanded. Public perceptions need changing if results are to be improved and help offered to more than the present minority.


**Key words** Childhood blindness, Childhood low vision, Cataract, Measles, Rubella, Cortical visual impairment

The childhood blindness situation in Africa is unacceptably bad. There are estimated to be 250 000–400 000 blind children on the continent,<sup>1</sup> and much of the blindness is avoidable. However, population-based studies

on which to make this estimate are few,<sup>2,3</sup> and data have been collected in a non-standard way. To plan for improvement, total numbers in a country and details of causes are essential, but are mostly unrecorded. Recently a standardised form and computer program have been developed (WHO/PBL Eye Examination Record for Children with Blindness and Low Vision) for recording and analysing subnormal vision.<sup>4</sup> These have been applied to children in schools for the visually impaired in several African and other countries.<sup>5,6</sup> The advantage of using special schools is that data can be rapidly acquired, but the children at such schools are a biased group. Many children in Africa never go to school and so the economically disadvantaged or multiply impaired may be left out. Also schools may be unevenly sited and not reveal ethnic or geographical variations.

There is also a lack of data showing time trends, as most studies have been at one point in time. Previously the major cause of visual impairment in Africa was corneal damage, especially from measles and vitamin A deficiency.<sup>1</sup> This is avoidable and with improved primary care in recent years its dominance should have diminished, but this has not yet been well documented. In addition cross-sectional studies give little insight into the outcome of treatment or rehabilitation, or into the cultural and economic barriers to improving these.

There is thus a need for a wide sample from a whole country followed over a period, including children who have not been to school. This paper reports a personal series of children and young people in Uganda born between 1951 and 1995 having subnormal vision with onset between birth and 15 years of age. They come from both the community and special schools and were seen between 1983 and 1997, often repeatedly. They are analysed for the frequency and outcome of the causes, for differences between the school and community groups, for trends over time and for regional variations. The implications for the development of services for prevention, treatment and education are discussed.

K. Waddell   
Box 4008  
Kampala  
Uganda  
Tel: +256 41 200222  
Fax: +256 41 200486

## Patients and methods

For the past 14 years the author has carried out mobile eye work at multiple sites around Uganda, seeing patients referred by paramedical eye workers for consultation and treatment. The aim is to make services accessible to the people. Schools for the blind have also been repeatedly visited. Records exist of all those seen, the onset of whose subnormal vision dates from childhood (15 years or under), starting in 1983 for special schools, and in 1988 for the community. All were either seen in childhood, or if seen later had a clear history of childhood impairment and compatible signs. The data have been transferred to the new WHO form. Previously there had been no attempt to document the problem, and the great majority of those affected had never before seen a doctor or been treated, even into adult life.

The places of special education ('schools') were 17 annexes to normal primary and secondary schools scattered around the country. In addition there are students in one university and three teacher training colleges that are fully integrated. Two vocational schools were also visited. The community patients were seen at 44 sites in all regions, covering most of the country except part of the north owing to civil strife there. Some patients were seen once only but others were followed repeatedly for up to 14 years. When surgical or medical treatment was possible it was carried out, and spectacles and low vision devices supplied. Whenever possible, education in a suitable school or vocation was facilitated.

The WHO categories of visual loss were used,<sup>7</sup> criteria for inclusion being an acuity of less than 6/18 or a field of less than 10° in the better eye. For children too young to test formally, those with eye lesions or visual behaviour predicting an acuity definitely worse than 6/18 were included – probably most were much worse than this level. For those whose acuity improved after surgery to 6/18 or better, the previous worse acuity was taken for analysis so as not to eliminate those who had been blind for much of their childhood. Refractive errors were excluded unless they had other features and the subject could not be refracted to 6/18 or better. Sixty-eight children have been included in a previous report.<sup>5</sup> The form was modified to include fields for year of birth and of becoming blind (starting with 1951) so that time trends could be examined. The latter field proved not usable for analysis owing to lack of documentation and uncertain recall. In this semi-literate culture dates are often estimates, but cases were only included if origin in childhood was undoubted. The other fields were marked in accordance with the coding instructions. The whole group was taken for analysis, unlike other studies<sup>6</sup> which used only 'severe visual impairment' and 'blind' categories; this was to avoid excluding the 'not testable' community group. Data were analysed with the computer program of the form and with EpiInfo 6.

## Results

### Characteristics of the sample

A total of 1135 children and young people were documented (697 males, 438 females), of whom 443 (39%) (279 males, 164 females) were first seen in places of education, and 692 (61%) (418 males, 274 females) were first seen in the community. They came from 26 ethnic groups which comprise most of the peoples of the country. Table 1 shows a summary of ethnicity with the total population of each group for comparison (1991 census). Fig. 1 shows the year of birth of the two groups.

### Frequency of abnormalities

Table 2 gives the frequencies of the major abnormality causing subnormal vision for each person, divided into school and community groups. The largest difference between the groups is with cortical visual impairment, and to a lesser extent with cataract/aphakia and phthisis/scar/staphyloma.

### Cataract

Cataract or aphakia was the largest group. Most were sporadic but 48 (13.8%) were familial, presumed genetic, and 23 (6.6%) were from rubella as judged by the presence of deafness, cardiac lesions or retinopathy. All except 26 (who declined or had partial opacities) had surgery. The standard operation was extracapsular extraction, aiming for spectacle correction, but 42 patients have had intraocular lens (IOL) implantation in 1994–7. Fifty-three patients with nuclear or lamellar opacities had optical iridectomies, pending IOL implantation. After the initial admission for surgery, 182 patients (52.3%) were never seen again by the surgeon even once. For these cases and for infants, final acuity is unknown. Of the rest, 27 people (7.8% of all cataracts) had a final visual acuity of 6/18 or better (including 6 iridectomies, 8 IOLs), and 43 (12.4%) an acuity between 6/24 and 6/60 (14 iridectomies, 3 IOLs). Most of these had either partial cataracts or had developed them in later childhood, and probably only one had total congenital opacity.

**Table 1.** Ethnicity of cases, compared with the total population in the 1991 census

Ethnic group	Cases; number (%)	Population ( $\times 10^3$ )
Banyankole/Bakiga	257 (22.6)	3 033
Baganda/Basoga	161 (14.2)	4 387
Lugbara/Madi	122 (10.7)	768
Iteso	113 (10.0)	1 000
Karamajong	103 (9.1)	346
Acoli/Langi	79 (7.0)	1 713
Batoro/Banyoro	52 (4.6)	983
Alur/Dyapadola	50 (4.4)	756
Bakonzo	46 (4.1)	362
Bagisu	25 (2.2)	751
Others/unknown	127 (11.2)	2 573
Total	1135 (100)	16 672

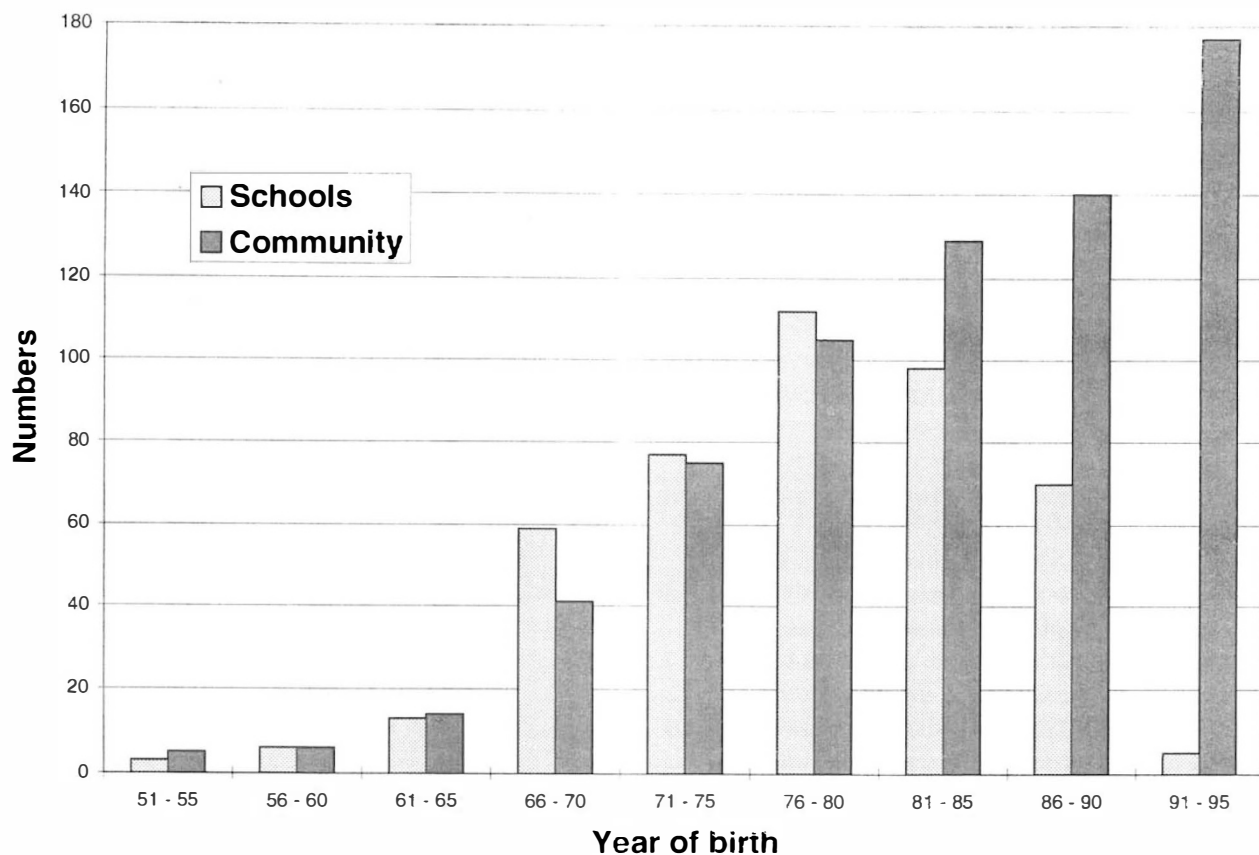


Fig. 1. Year of birth, comparing those seen in schools with those in the community.

#### Preventable corneal blindness

Corneal scar from ulceration, plus resulting phthisis or staphyloma, were taken together as the main corneal causes of visual loss (trachomatous scarring was not seen). This was the second largest cause of visual loss, and 199 (79.6%) of those affected were in the 'blind' category, so the loss is severe as well as common.

#### Buphthalmos and glaucoma

This was the third largest group, 46 having buphthalmos and 23 juvenile glaucoma. Thirty-seven had surgery, the rest presenting too late, and only 6 (1 buphthalmos, 5

glaucoma) were known to have retained vision better than 6/60. Three of these with glaucoma remained normal (6/18 or better) but were included as having fields of less than 10°.

#### Aetiology of visual loss

The sizes of the main groupings of causative factors of visual loss as defined by the WHO form are similar in schools and the community (Fig. 2) despite the wide differences in the age spectra. Table 3 shows a summary of the main abnormalities in each group. Conditions known to be genetic such as aniridia and pigmentary retinopathy were counted in the hereditary group even

Table 2. Frequency of major abnormality causing subnormal vision

Abnormality	Schools	Community	Total
Cataract/aphakia	96 (21.7)	252 (36.4)	348 (30.7)
Phthisis/scar/staphyloma	141 (31.8)	109 (15.8)	250 (22.0)
Buphthalmos/glaucoma	24 (5.4)	45 (6.5)	69 (6.1)
Cortical visual impairment	3 (0.7)	59 (8.5)	62 (5.5)
Retinal dystrophy	24 (5.4)	36 (5.2)	60 (5.3)
Optic atrophy	20 (4.5)	29 (4.2)	49 (4.3)
Microphthalmos	27 (6.1)	16 (2.3)	43 (3.8)
Uveitis	11 (2.5)	28 (4.0)	39 (3.4)
Other corneal opacity	8 (1.8)	26 (3.8)	34 (3.0)
Other retinopathy	18 (4.1)	15 (2.2)	33 (2.9)
Disc hypoplasia	20 (4.5)	11 (1.6)	31 (2.7)
Idiopathic nystagmus	5 (1.1)	14 (2.0)	19 (1.7)
Aniridia	10 (2.3)	7 (1.0)	17 (1.5)
Miscellaneous	36 (8.1)	45 (6.5)	81 (7.1)
Total	443 (100)	692 (100)	1135 (100)

Values are number (%).

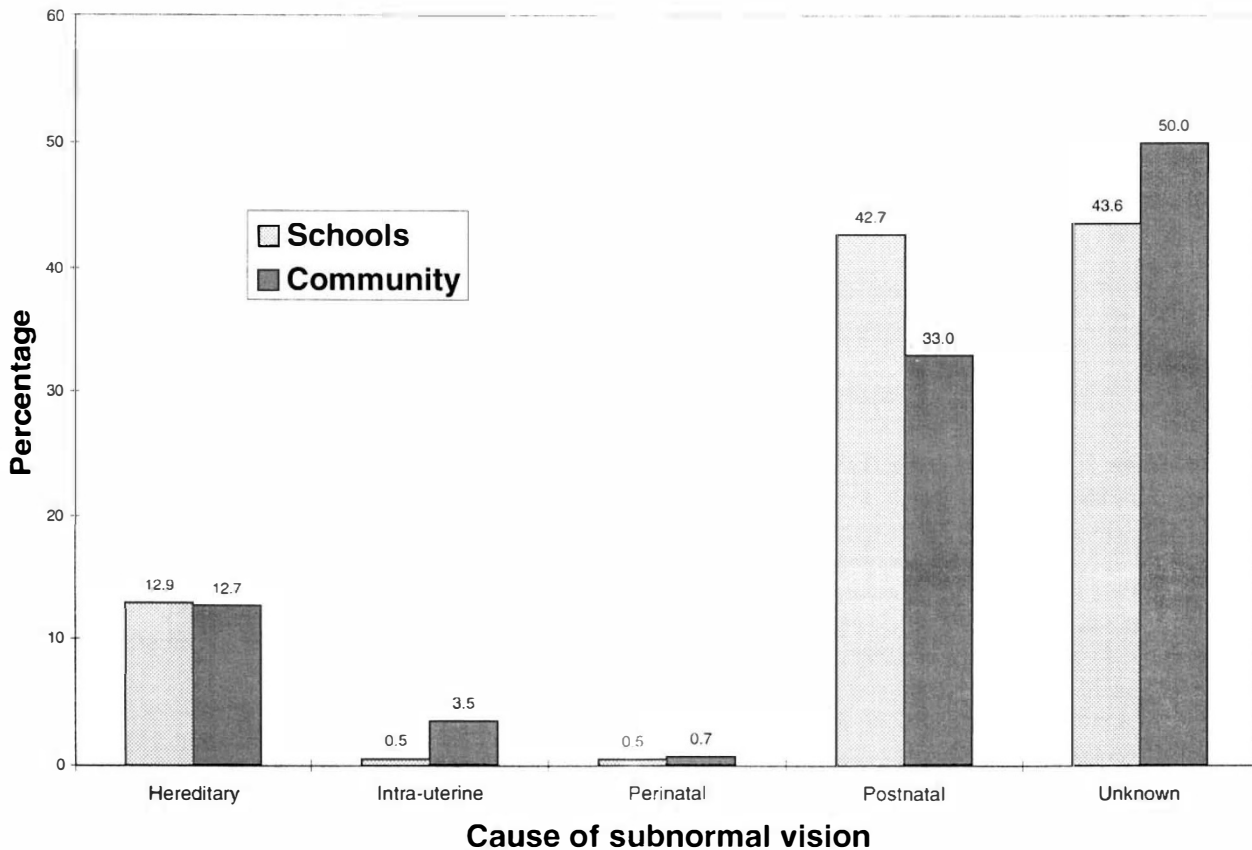


Fig. 2. Aetiological groupings of subnormal vision, comparing school and community groups.

in the absence of a family history. Retinopathy of prematurity was not seen and consanguinity was not reported.

#### Visual acuities

Table 4 shows the visual acuities by WHO categories for the two groups. The community sample had a large 'not testable' group as it contained very young children and some with learning difficulty. Table 5 shows the acuities of the five main causes of subnormal vision.

#### Multiple impairment

Impairments additional to visual were present in 91 children (8.0%; 79 in the community and 12 in schools). Cortical visual impairment (CVI) was associated with 31 of these, and rubella accounted for 19. Some children had

more than one impairment and these comprised hearing loss (22), learning difficulty (21), physical impairment (29), epilepsy (3), cardiac abnormalities (10) and assorted, mostly developmental delay (34).

#### Ethnic/geographic variations

Of the 103 people of Karamajong ethnicity (from the arid area in eastern Uganda) 83.5% were in the category blind, 72 (69.9%) from corneal causes, compared with 17.2% for the rest (odds ratio 11.1 95% CI 6.9–18.0). Other ethnic or geographic variations seemed random.

#### Time trends

To examine changes in the frequency of causes over time, percentage prevalences were analysed at the end of each 5-year period (starting in 1965) for all who were still 15

Table 3. Abnormalities in each aetiological group

	Hereditary	Intra-uterine	Peri/neonatal	Postnatal	Unknown
Cataract/aphakia	48 (32.9)	23 (88.5)	0	5 (1.2)	272 (50.5)
Corneal opacity	0	0	1 (14.3)	261 (62.6)	22 (4.1)
Retinopathy	62 (42.5)	1 (3.8)	0	14 (3.4)	16 (3.0)
Optic atrophy/hypoplasia	0	0	0	43 (10.3)	37 (6.9)
Microphthalmos/aniridia/coloboma	17 (11.6)	1 (3.8)	0	0	56 (10.4)
Buphthalmos/glaucoma	0	0	0	0	69 (12.8)
Cortical visual impairment	0	0	3 (42.9)	44 (10.6)	15 (2.8)
Remainder	19 (13.0)	1 (3.8)	3 (42.9)	50 (12.0)	52 (9.6)
Total	146 (100)	26 (100)	7 (100)	417 (100)	539 (100)

Values are number (%).

**Table 4.** *Visual acuity in the better eye*

WHO category	Schools	Community	Total
No impairment field <10°	1 (0.2)	2 (0.3)	3 (0.3)
Visual impairment <6/18 to 6/60	72 (16.3)	96 (13.9)	168 (14.8)
Severe visual impairment <6/60 to 3/60	48 (10.8)	26 (3.8)	74 (6.5)
Blind <3/60 to no perception	320 (72.2)	398 (57.5)	718 (63.2)
Not testable, believed impaired or blind	2 (0.5)	170 (24.6)	172 (15.2)
<b>Total</b>	<b>443 (100)</b>	<b>692 (100)</b>	<b>1135 (100)</b>

Values are number (%).

years or under at those points. Fig. 3 shows the highly significant trends for corneal visual loss, which had a marked fall (chi-squared for linear trend 130.8), and for cataract and aphakia, which had a moderate rise (chi-squared = 15.8). Of the other conditions comprising over 5% of the total, two had highly significant trends, CVI showing a rise (chi-squared = 79.3, with 57 of the 62 cases (92%) being born after 1985) and retinal dystrophies a fall (chi-squared = 7.9). Buphthalmos/glaucoma showed no trend. The meaning of these trends is discussed below.

### Discussion

These results, though not fully population-based, give a clearer picture than before of childhood subnormal vision for a whole African country, and of those in both special schools and the community. They show proportions, but the total numbers are still uncertain as prevalence figures for Africa come from samples with very few affected children. A figure from Malawi was 1.1:1000 blind under 6 years old.<sup>8</sup> For Kenya it was 1:1000 blind and 2:1000 visually impaired under 20 years old.<sup>3</sup> The 1991 Uganda census gave 3076 children blind under 15 years, but its figure for all blind people was only 0.14% of the population, so this source of data is clearly incomplete. Taking a figure of 1:1000 for the 8.3 million under 16 years in the 1991 census, there would be about 8000 blind at any one time, together with the survivors of previous generations. This figure, though approximate, is much larger than the present sample, even though it covered much of the country over a prolonged period. So it seems likely that the majority of young people in Uganda with subnormal vision have never been brought to health units or schools, or have died early. Girls are

fewer than boys which is not explained by heredity, so girls seem to be given even less access.

### School and community subjects

Previous surveys around the world using only blind school students have raised the question of sample bias. The community group reported here had a different age structure from schools (Fig. 1). In this figure, the year of birth of the schools group reflects age of going to school; the community group was weighted towards younger children as they can present from birth. The steadily rising number of young children from the community reflects the author's increasing involvement in their care, and parents' increasing willingness to bring their child early. Despite differing ages of the two groups, the grades of visual acuity were similar in both groups apart from the 'not testable' group of infants in the community (Table 4). The broad groups of causative factors in the WHO form (Fig. 2) were also similar. The significance of these groups is that most factors except the genetic ones are potentially avoidable, but the limitation is the large group of unknown cause. In spite of these similarities, when the abnormalities are looked at individually (Table 2) there are differences. The major one is CVI, which is rare in schools and 12 times commoner in the community. Less striking is cataract/aphakia, with a higher percentage in the community, and corneal visual loss, which is higher in schools. Part of the reason for these differences may be the age structure, as cataract often starts earlier than corneal ulceration and its sequelae. The community contained most of the multiply impaired children, implying that these are seldom sent to school or do not survive to school age. The aetiology of the visual loss is often difficult to determine long after

**Table 5.** *Visual acuities of the commonest causes of subnormal vision*

WHO category	Cataract/aphakia	Cornea	Buphthalmos/glaucoma	CVI	Retinal dystrophy
No impairment field <10°	0	0	3 (4.3)	0	0
Visual impairment	57 (16.4)	28 (11.2)	5 (7.2)	0	16 (26.7)
Severe visual impairment	24 (6.9)	8 (3.2)	4 (5.8)	1 (1.6)	7 (11.7)
Blind	175 (50.3)	199 (79.6)	48 (69.6)	49 (79.0)	33 (55.0)
Not testable	92 (26.4)	15 (6.0)	9 (13.0)	12 (19.4)	4 (6.7)
<b>Total</b>	<b>348</b>	<b>250</b>	<b>69</b>	<b>62</b>	<b>60</b>

Values are number (%).

CVI, cortical visual impairment.

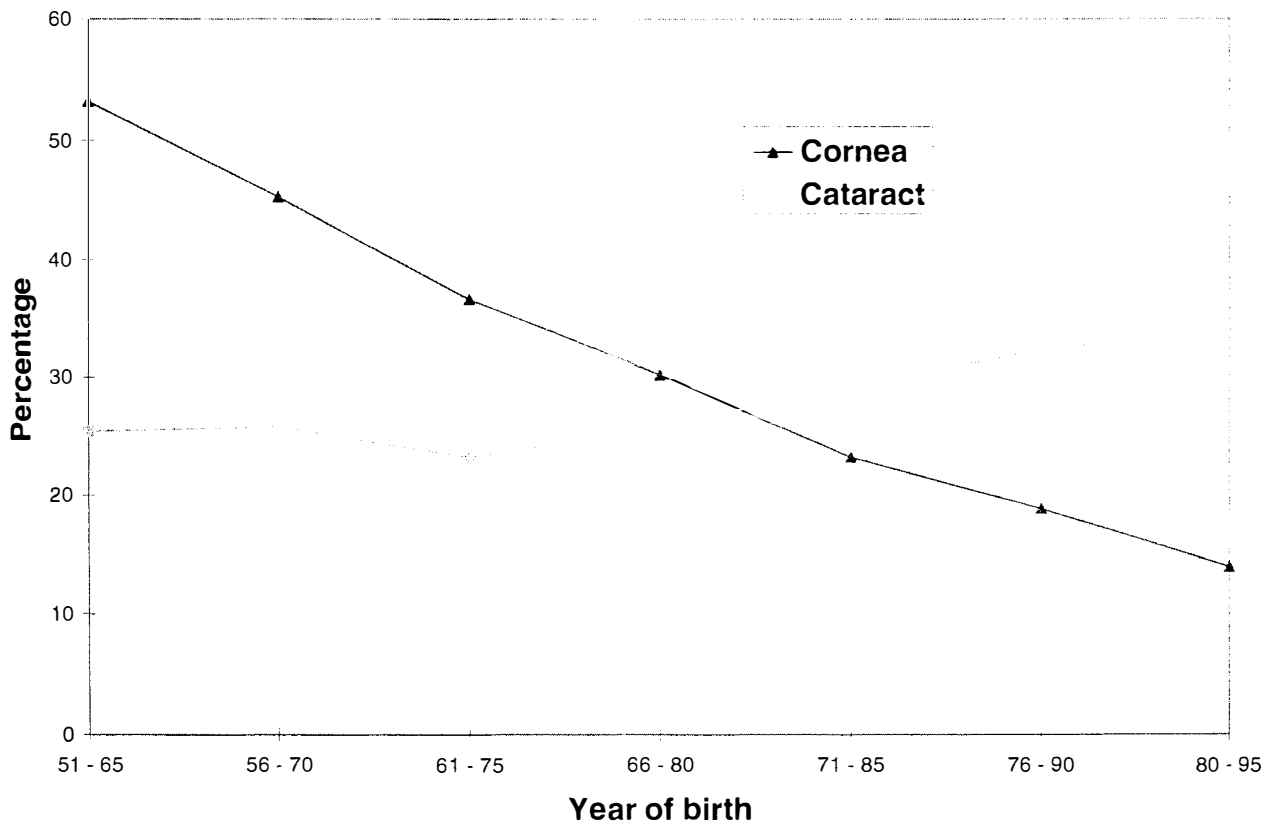


Fig. 3. Time trends for cataract and corneal visual loss: percentage prevalences of those still children at the end of each 5-year period.

the event. For example, there was only one observed case of neonatal gonococcal ophthalmia ending in blindness, but it is probably much commoner, being counted in retrospect in the postnatal onset group. Probably community cases, which can present closer to the onset, will give a more accurate diagnosis, especially of conditions ending in phthisis. With these reservations, it does seem that blind school surveys give a fair picture of overall childhood blindness and could continue to be used, being quicker to document.

### Cataract

The largest single cause of visual loss was cataract or aphakia, accounting for nearly a third of all cases. Thus a major target for reducing childhood blindness is an improved approach to management of cataract and a change in public attitude to it. Rubella caused at least 6.6% of these cases, and they also have other impairments. Many isolated congenital cataracts, especially with microphthalmos, may also result from rubella.<sup>9</sup> For prevention of blindness, rubella immunisation may be nearly as important as immunisation for measles, and needs to be introduced if the cost allows it.

Apart from cases caused by rubella, cataract is not preventable, but it is the prime condition for surgery and most patients had this. Aphakic correction has been mostly by spectacles, but a minority have since 1994 received lens implants, and this is planned as a major

way ahead. Half the patients were never seen again after surgery, so after-care and follow-up data are very incomplete. But enough is known to show that the visual results are unsatisfactory, only 7.8% being known to get normal vision, in contrast to the excellent results that are now possible even in congenital cases.<sup>10</sup> This applies to the community as well, so it is not just that the bad results are congregating in blind schools.

There are many reasons for the poor outcome. Surgery is often carried out in remote units without complex equipment. As mentioned above, half the patients are never seen again. Infants having extracapsular extraction often get later complications; a change to lensectomy might improve this. Many present late – it is common to find teenagers with unoperated congenital cataracts even though they have lived near an eye unit all their life. They are then densely amblyopic and surgery may be difficult if the cataract is degenerate. If operation was done early, baby-size spectacles have been hard to obtain or ignored by parents. For the same reasons contact lenses have no place. Even when spectacles are given, they are rarely brought for replacement, even if offered free. It is not all the parents' fault – they often come long distances with poor transport. Ophthalmologists are very few and unevenly spread: the surgeon may only pass by once in years (though paramedical eye workers are more accessible). But even when these restrictions do not apply, public perception often does not see the need for the meticulous follow-up that is required for success.

Patients are content to accept ambulatory vision, and this is hampering all attempts at improvement of the outcome.

As well as this need for education of the public, there is also a need to improve standards of surgery. Establishing a few centres of excellence could be done but will still be inadequate as they will be too far from many patients. Thus any techniques should be transportable to remote parts of the country in the same way as has been done for age-related cataract in the past 15 years in Uganda. Intra-ocular lenses will be one way around the problem of aphakic correction, but this is controversial in infants, and even in older children must be done cautiously for fear of unacceptable complications, given the scarcity of expertise and after-care. Many childhood cataracts are nuclear or lamellar. Often these children have fair functional vision and would be worse if aphakic without spectacles. But if untreated they struggle in school and in bright light. Mydriasis can help but is usually soon abandoned. Therefore 53 were treated with optical iridectomy, aiming for a narrow sphincter-preserving slit partly covered by the upper lid, thus using the pinhole effect. This improves their vision outdoors and for reading, usually allowing primary schooling, whilst not spoiling future lens implantation when this can be done to an acceptable standard. Those who in past years received a traditional inferonasal broad iridectomy were made worse, as were those made aphakic without correction.

### *Corneal visual loss*

In developing countries corneal ulceration leading to scarring and staphyloma or phthisis is a very common cause of visual loss (72% in East Africa<sup>8</sup>) and yet is largely preventable. Most often ulceration follows the complex of measles, malnutrition, vitamin A deficiency and herpes simplex during the first 3 years of life, often made worse by traditional eye medicines.<sup>11,12</sup> After the event it is difficult to separate the contribution made by vitamin A deficiency. In India this is considered to be high,<sup>6</sup> but overt xerophthalmia is not commonly seen in Uganda: only two cases were directly observed in this series. Measles is a much more obvious primary factor, emphasising the importance of immunisation, though it may be aided by its cofactors, including covert vitamin A deficiency. Giving high-dose vitamin A capsules to all children with measles is now standard. As countries develop they are expected to move towards the industrialised pattern in which corneal damage is rare.<sup>8</sup> In the past two decades primary health care including improved nutrition and the WHO Extended Program of Immunisation has advanced greatly in Uganda, though the full immunisation rate is still only 47%.<sup>13</sup> This study does confirm that a strong time trend towards decrease in corneal damage has occurred, though it is still far too common.

### *Buphthalmos and glaucoma*

The visual outcome of surgery for buphthalmos and glaucoma has been even poorer than for cataract, and it faces the same barriers to improvement. Juvenile glaucoma appears commoner in Africa than in the West (23 cases in this study) though population-based figures are not available. Being silent it often presents very late, and unless asymmetrical, when the better eye may be saved, the chances of preserving sight are slim. The frequency is not related to the occurrence of onchocerciasis, but appears to be a racial variant.

### *Cortical visual impairment and optic atrophy*

In the community group CVI was an important cause of visual loss (8.5%) and is often associated with multiple impairment. In the West it usually results from a hypoxic episode, but in Africa it usually follows a fever with impaired consciousness and convulsions. Malaria,<sup>14</sup> meningitis<sup>15</sup> and viral encephalitis<sup>16</sup> are known causes, and all are common in Uganda, but after the event it is difficult to be sure which was responsible. In the acute stage, experience suggests that encephalitis is the most frequent. The outcome is uncertain as patients often come from very remote areas and follow-up is inadequate. Some have been seen to improve but others not. The fact that few are seen older than 5 years and few arrive in schools is unexplained. Some may have recovered and others may be too handicapped. Probably also their impairment results in many being amongst the 14.7% of children in Uganda who die by their fifth birthday.<sup>13</sup> Optic atrophy may result from similar acute illnesses, and may co-occur with CVI, some children having features of both. These cases are a reminder of the heavy toll still taken by malaria, meningitis and encephalitis in Africa.

### *Uveitis*

Uveitis was not common (3.4%) but visual loss could be avoidable. No cases of juvenile chronic arthropathy were seen. A few had a history of injury in the other eye and so could be sympathetic uveitis. A few occurred during probable meningococcal septicaemia, either from direct infection or immune mechanisms. But most were unexplained, often sudden and causing blindness within days.

### *Regionalethnic variations*

Table 1 shows the sample was broadly representative of all the peoples of the country and so of all the regions. Frequencies of causes vary across the ethnic and geographic spectrum, but the reason appears to be mostly chance. An exception is the frequent corneal blindness amongst the Karamajong people. Drought with famine is recurrent in their home area (notoriously around 1980), and with their nomadic lifestyle and civil strife, health care is scarce. The figures illustrate the close link between lack of socio-economic development and this type of preventable blindness. Primary health care is

now going ahead in this area and the problem should diminish.

### *Time trends*

The method of analysis was chosen to give a series of views of the actual childhood situation at the end of each 5-year period over three decades (1965–1995). Each child is scored in up to four 5-year periods, and it is assumed they were blind the entire time and none died. Fig. 3 shows that the major trend with time is a strong fall in preventable corneal causes of visual loss. The size of the fall plus a plausible reason for it indicate that it is real. So despite Uganda's problems, primary health care seems to be making a real impact. Since corneal visual loss was long the commonest cause of childhood blindness in Africa, this is a major advance in blindness prevention. The rise in cataracts and aphakia was less striking; it may partly reflect increasing willingness to come for surgery, and may partly be just the reciprocal of the fall in corneal blindness, as the figures are proportions. CVI also showed a strong rising trend, most of those affected being born after 1985, but the rise may be only apparent, reflecting the author's activity. The fall in retinal dystrophies is probably because people born later have had less time to develop visual loss; as expected buphthalmos and glaucoma showed no trend. Other causes were not analysed, their proportions being too small.

### *Education and rehabilitation*

About 250 places are available in special education for the visually impaired, and about 30 in vocational schools. Segregation is avoided by the schools being annexed to normal ones, and they are usually residential because of distance. Some 15 students are in fully integrated education. There are clearly far fewer places than people who need them. In the past all visually impaired students have been taught Braille, even though many have enough vision for print education. Recently local making of low vision devices has made it possible for many more to learn to read.<sup>17</sup> Low vision assessment is now being undertaken for suitable children and devices given, and their use strongly encouraged. There has been a surprising resistance to this and preference for Braille, though workshops for teachers are now changing this. Only a very few of those guided towards special schools actually went and stayed, even when taken there and finance supplied. Cost is one problem; one child in secondary school may cost more than the per caput income of Uganda, which was \$170 in 1992/3,<sup>18</sup> though some special schools do have outside subsidies. Parents may be unable to afford to send normal children to school (though a programme for subsidised universal primary education started in 1997); families are large and an impaired child would be given lower priority. In a country where literacy is only 50%<sup>18</sup> and universal primary education is only beginning, people often question whether formal education is always

worthwhile. People with low vision but not blind can gain a livelihood without formal employment like many normal people do, but the blind cannot, or only with difficulty. In the extended family system they are cared for, but it is a dependent life. It is epitomised by the remark 'Who will marry her if she cannot collect firewood?' Besides, children with impairments need the self-esteem and relationships that come from education even more than do normal children. Social values are changing fast – illiteracy is acceptable now but in the lifetime of present children will become stigmatising. For all these reasons, formal education for all children with impairments is essential, and many more teachers of special education will be needed. The recently opened Uganda National Institute for Special Education is now active in training more teachers for children with visual and other impairments.

### *Planning future development of services*

To plan for improvements in treatment and education it is necessary to have figures from population-based studies with adequate numbers, so that the uncertainty is removed from projections of total numbers. In recent years community-based health care has been developed in Africa, reaching right down to village health workers. This offers the possibility of identifying all people with impairments in a defined area to provide firm data. It will also enable help and follow-up to be offered to the many children who at present languish at home. It should in addition help with changing public perceptions, because its keystone is community discussion and participation. We are now pursuing this avenue in Uganda.

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