# Prevalence and causes of blindness and severe visual impairment (BL/SVI) among children in Ntungamo district, Southwestern Uganda: A key informant cross-sectional population survey

Arunga S, Onyango J, Ruvuma S, Twinamasiko A

Mbarara University of Science and Technology (MUST), Mbarara, Uganda

**Corresponding author**: Dr Simon Arunga. Email: arungasimon@gmail.com

# **ABSTRACT**

**Objective:** To estimate the prevalence and causes of blindness and severe visual impairment among children in Ntungamo district South-western, Uganda.

**Methods:** This was a cross sectional community survey using the key informant method; approximately 200 village health team members were carefully selected and trained to screen for severe visual impairment using a torch, 6 meter string and a 6/60 E chart. They did house to house screening for severe visual impairment and blindness among children below 16 years in the whole district. Identified children were referred to a rendezvous point within the community to be examined further by the ophthalmologist. Data was collected using the standardized WHO childhood blindness data collection form. Proportions and causes of severe visual impairment and blindness were determined. Clinical and social characteristics were described.

**Results:** A total of 59 children were identified, 15 with severe visual impairment and 44 with blindness. Mean age was 6.5 years (95% CI 5.3-7.4) and 59% of the children were male. The prevalence of blindness and severe visual impairment was 0.02% (95% CI 0.01-0.03). Causes were analysed by anatomical site, aetiology and specific diagnosis. Majority of the anatomical causes were due to cornea (18%) and lens (17%) abnormalities. With respect to specific diagnosis, 30% was cataract and cataract surgery complications and corneal scar. Overall, 72% of the blindness and severe visual impairment was due to avoidable causes.

**Conclusion**: Prevalence of severe visual impairment and blindness was relatively low in this population. Lens and corneal abnormalities were the leading cause of blindness. Most of the cases of visual impairment and blindness were avoidable.

### INTRODUCTION

It is estimated that there are about 1.4 million blind children in the world and that about one child goes blind every minute<sup>1</sup>. Three-quarters of the world's blind children live in the poorest regions of Africa and Asia<sup>2,3</sup>. Although there are fewer blind children than adults, the number of years lived with blindness is much higher for children. More than half of blindness in children is avoidable (either preventable or treatable); majority of the children who become blind have a lifetime of visual disability ahead of them with all the associated emotional, developmental impact onto the child's life. The World Health Organization's VISION 2020 initiative, "The Right to Sight" recognises this; urgency and control of blindness in children is one of the five priorities of its VISION 2020 programme<sup>2,4</sup>.

The causes of Blindness/Severe Visual Impairment (BL/SVI) in children worldwide are variable and differ between and within countries depending on access to and availability of health facilities<sup>3</sup>. Therefore, in order to reduce BL/SVI in children, it is important for different settings to determine the magnitude of the problem and specific aetiologies that lead to childhood BL/SVI. This is important for appropriate planning and efficient

allocation of resources for prevention and treatment of childhood blindness.

Population based surveys are ideal methods of estimating the prevalence of childhood blindness. However, blindness in children is relatively rare and carrying out population studies requires a large sample size which is logistically and economically costly. For instance in one study conducted in India and over 4000 children were examined but only seven children were identified with blindness<sup>5</sup>. Other methods used from available data on the prevalence of BL/SVI in children are from studies carried out in schools for the blind, community based rehabilitation programs, hospital-based studies, and registers of the blind children. Although these targeted findings on childhood blindness are convenient, they have the potential of bias and findings may not be representative of the general population. In the recent years Key Informant Method (KIM) has been used in estimating the magnitude of childhood blindness in the population and has been found very successful in Bangladesh, Malawi, Ethiopia and other parts of Africa<sup>6-8</sup>. This method involves the use of trained community volunteers known as Key Informants (KI) to actively search for blind children in the community of an estimated population of children. KI test Visual Acuities (VA) of suspected blind children by use of counting fingers at 6 metres. Those children who fail the test are brought forward to be examined by specialized eye workers. A number of studies have demonstrated that KI can recruit a large number of children quickly and the children identified are more representative of all children from the community and this method is feasible in African settings<sup>6-9</sup>.

Uganda is one of the least developed countries in Eastern Africa with limited access to ophthalmic care. Population based data on the prevalence and causes of childhood blindness is limited, the purpose of this research was to find out the magnitude and causes of childhood blindness and visual impairment using a Key Informant Method (KIM) in rural South Western Uganda to address this knowledge gap.

# **MATERIALS AND METHODS**

Study design overview: In a community based cross sectional study, Key Informants (KI) were trained; and, used to identify children who are blind, or with SVI, from the population of children in Ntungamo district; through house to house search. The identified children were then examined by a clinical team at selected cluster centres. Diagnosis of visual problems among children brought forward by KI was confirmed during clinical examination. Comprehensive data was collected using the WHO childhood blindness collection tool.

Study area: The study was conducted in Ntungamo district. Ntungamo district is the most central and fairly representative of the south-western region. The district has a total of 489,320 people of which, 50% are children below 16 years of age<sup>10</sup>.

*Study population*: All children below 16 years of age residing in Ntungamo district at the time of the study.

Sample size: The study assumed a prevalence of 0.8/1000 which is middle of the range of estimates for Africa<sup>8</sup>, a precision of 20% and a confidence of 95%; the required sample size was found to be 8000 children; It was assumed that since the KI would be doing house to house screening, all the children in Ntungamo district at the time of the survey would be screened.

Case definition: Children aged  $\leq 15$  years presenting VA of less than 6/60 in better eye residing in Ntungamo district for at least the last six months.

*Inclusion criteria*: Children were eligible to participate if they fulfilled the following criteria;

- (i) They were aged 15 years or below at the time of the study
- (ii) They had vision less than 6/60 in the better eye
- (iii) Their families had been living in Ntungamo for the last 6 months
- (iv) Their parents willingly consented to participate in the study.

Exclusion criteria: Children were excluded if;

- (i) Their age could not be ascertained at the time of the study.
- (ii) They were unaccompanied with no one to consent on their behalf

Key Informant (KI) identification and selection: The KI were village volunteers. They were identified and selected from their respective villages with the help of the office of the District Health Officer, Ntungamo district. They were taught how to measure VA of any suspected child less than 16 years by reading the E chart at 6 metres and given an examination kit to start identifying blind children in their respective areas in a house to house search.

All children age ≤15 years who were not able to read the 6/60 E chart were registered and referred to an assessment centre for eye examination. Young children who could not read but identified or suspected by their parents to be blind were also recorded and referred for eye examination. Their vision was not tested at this point but was later tested with formal optotypes for preverbal children by a low vision orthoptist.

On agreed dates, KI with the identified children assembled at cluster assessment centres for eye examination. Presenting distance VA was measured in each eye separately and then in both eyes together using E optotype at 6 metres<sup>11</sup>. Children who came wearing spectacles were tested for the distance vision when wearing glasses. For children not able to be tested using the optotypes for various reasons, Cardiff acuity cards were used, employing the standard staircase method<sup>12</sup>. Other tests like ability to fixate and following of light were also used to reach a judgment whether the child was sighted or not.

Data was collected using the WHO/PBL questionnaire for childhood blindness survey. Socio-demographic data and relevant ophthalmic, medical, obstetric and family histories was elicited by the ophthalmologist. Ocular surface examination was assessed using a torch and magnifying loupe. Cycloplegic refraction was performed using retinoscopy and trial lenses, except when it was considered clinically inappropriate for example in dense cataract or very young children. The posterior segment of the eye was examined using indirect ophthalmoscopy. Children identified who needed treatment were treated on site. However, those who needed further assessment and treatment were referred to a specialised eye hospital.

Data entry and analysis: Data was directly entered into the designed database of the WHO childhood blindness software for analysis of eye examination records, cleaned in excel spread sheet and simple tabulation descriptive analysis done using STATA 11.

*Ethical consideration*: Ethical approval was sought from Mbarara University of Science and Technology Institutional Review Committee, and Uganda National Council of Science and Technology No 09/11-14. The district health officer and the chief administrative officer

of Ntungamo district gave permission to carry out the study. Parents of the referred children were provided with information about the study in the local language. Those who accepted to participate in the study were requested to sign or thumb print a consent form.

Limitations of the study: Although an effort was made to try and make an exact diagnosis of the possible cause of BL/SVI, this was entirely clinical; the study had no resources to conduct further investigations. The study lacked intra ocular pressure measuring equipment, therefore, congenital glaucoma was only clinically screened. However, none of the examined children had clinically overt features of congenital glaucoma.

# **RESULTS**

General demographics: The baseline characteristics of the study participants are summarised in Table 1. The total number of children who were screened and referred to the rendezvous points by the Key Informants (KI) were 250 children. Of those, only 59 children were confirmed to be severely visually impaired or blind. Mean age was 6.5 years (95% CI 5.3-7.8 years range of 6 months -15 years. Majority of the children were male (59%). Majority of the children were classified as having visual acuity of perception of light and below in the better eye. However, 49 (83%) had some degree of functionality and were able to navigate on their own. About 64% of the school age going children (more than 6 years old) were not attending school. Almost 20% of the children had received cataract surgery.

**Table 1:** Baseline characteristics among SVI/BL children in Ntungamo district (n=59)

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Baseline characteristic	No. (%)	
Visual acuity		
6/60-3/60	15 (25)	
3/60-PL	40 (68)	
NPL	4 (7)	
Visual acuity functionality		
Yes	49 (83)	
No	10 (17)	
Education (*N=33 only children 6 years and above)		
In special schools	1 (3)	
In integrated schools	11 (33)	
Not in school	21 (64)	
History of surgery		
None	47 (80)	
Cataract	11 (19)	
Unknown	1 (1)	

Prevalence of Severe Visual Impairment or Blindness (SVI/BL): Table 2 shows a summary of the prevalence of SVI/BL by county and by sex. Out of an estimated population of 244,660 children below 16 years in Ntungamo district, 59 children were confirmed to be SVI/BL. This gave an estimated prevalence of 0.02 (95% CI 0.01-0.03). The prevalence of SVI/BL was noted to be highest in Ntungamo municipality. Overall by sex, the prevalence of SVI/BL was found to be higher among males compared to females.

**Table 2:** Prevalence of SVI/BL among children in Ntungamo district (n=59)

County	Estimated population under 16 years	Number of SVI/BL	Prevalence (%)	95% CI
Kajara	55,348	17	0.03	0.02-0.05
Ruhama	116,072	18	0.02	0.01-0.03
Rushenyi	63,813	13	0.02	0.01-0.03
Ntungamo municipality (MC)	9,427	11	0.1	0.05-0.2
Total	244,660	59	0.02	0.01-0.03
Prevalence by sex a	nd by county			
Kajara (male)	25,872	10	0.03	0.02-0.07
Kajara (female)	29,476	7	0.02	0.01-0.04
Ruhama (male)	55,281	9	0.02	0.01-0.03
Ruhama (female)	60,791	9	0.02	0.01-0.06
Rushenyi (male)	31,111	9	0.02	0.01-0.05
Rushenyi (female)	32,702	4	0.01	0.005-0.03
Ntungamo MC (male)	4,857	7	0.1	0.05-0.2
Ntungamo MC (female)	4,570	4	0.08	0.05-0.2
Total males	117,122	35	0.03	0.02-0.04
Total females	127,538	24	0.015	0.01-0.02

Causes of SVI/BL: Table 3, summarises the history and causes of SVI/BL among children in Ntungamo. Overall, 75% of the children had SVI/BL since birth. About 20% had a positive family history of blindness. Of those with a positive family history, 91% were in first degree relatives; majority being cataract. Among the children with SVI/BL, 53% had an associated disability; they were noted to have hearing impairment, mental difficulties, delayed milestones and other physical disabilities. Individual

eye analysis was used to determine the causes of SBI/BL. Anatomical classification of causes: cornea (18%) and lens (17%) were the leading causes of SVI/BL. By aetiological classification of causes, majority (41%) of the causes were noted to be intrauterine. By actual diagnosis, cataract and post cataract (17%) and corneal scar (13%) were the leading causes of SVI/BL. About 60% of those identified causes were potentially avoidable.

**Table 3:** History and causes of SVI/BL among children in Ntungamo district (n=59)

History/Cause	No. (%)
Age of onset	
At birth	44 (75)
By infancy	10 (17)
By five years	5 (8)
Family history of SVI/BL	
Yes	11 (19)
No	48 (81)
Affected relative (n=11)	
First degree	10 (91)
Second degree	1 (9)
Presence of a co-disability	
Yes	31 (53)
No	28 (47)
Anatomical ocular abnormality (n=118 eyes)	
Whole globe	17 (14)
Cornea	21 (18)
Lens	20 (17)
Retina	8 (7)
Optic nerve	13 (11)
Normal globe	39 (33)
Aetiological classification (n=118 eyes)	
Intrauterine	48 (41)
Hereditary	8 (7)
Neonatal/Perinatal	10 (8)
Postnatal	18 (15)
Undetermined	34 (29)
Potentially avoidable causes (n=118 eyes)	
Yes	71 (60)
No	47 (40)
Final diagnosis (n=118 eyes)	
Achromatopsia	4 (4)
Albinism	2 (2)
Others	5 (4)
Post cataract	8 (7)
Cataract	12 (10)
Corneal scar	15 (13)
Cortical blindness	16 (14)
Disc atrophy/coloboma	14 (12)
Refractive error	14 (12)
Keratoconus	6 (5)
Microphthalmos	14 (12)
Nystagmus	8 (7)

Table 4 summarises management and visual prognosis among children with SVI/BL. Majority (76%) of the eyes were classified as blind on presentation; after refraction or low vision device, vision could be improved in 19% of the eyes, with 7% achieving vision better than 6/18. Overall visual prognosis: vision would be improved in 72% of the children with SVI/BL. Among those, 23 (39%) of the children with SVI/BL needed some form of optical correction and 19% (32%) needed surgery.

**Table 4:** Management and visual prognosis of children with SVI/BL in Ntungamo district

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Management indicator	No. (%)		
Baseline unaided visual acuity (n=118)			
6/60-3/60	28 (24)		
3/60-PL	76 (64)		
NPL	14 (12)		
Visual acuity after refraction or with low vision			
device (n=118)			
Better than 6/18	8 (7)		
6/18-6/60	14 (12)		
6/60-3/60	6 (5)		
Worse than 3/60	90 (76)		
Visual prognosis (n=59)			
Can improve	42 (72)		
Stable	17 (28)		
Management decision (n=59)			
Optical correction	23 (39)		
Medical	5 (8)		
Surgical	19 (32)		
None	12 (21)		

### **DISCUSSION**

Prevalence of SVI/BL: It is estimated that of the 45 million people who are blind worldwide in 2000, 1.4 million are children from middle-income and low-income countries, the majority of whom live in the poorest regions of Africa and Asia<sup>13,14</sup>. Although the prevalence of childhood SVI/BL is generally low, its significance is in the fact that children who are blind have a whole life time of disability ahead of them. This is much different from other blinding conditions like age related cataract where the life expectancy of blindness is about 5 years. In this population, the overall prevalence of SVI/BL was found to be generally lower (0.02% 95% CI 0.01-0.03) compared to a similar study in the Eastern part of Uganda which found a prevalence of 0.07 (95% 0.05-0.09)9; prevalence was also lower than what is estimated for sub Saharan Africa of 0.08; and, from a number of selected KI studies [Ethiopia: 0.06%, Malawi: 0.09% and Ghana: 0.07%)]8,9. In comparison with a proxy estimate of childhood blindness using the under 5 child mortality rate; the under-five mortality rate for Ntungamo is estimated to

be 135/1000 live births; this gives a childhood blindness prevalence of 0.07%, which is much higher than what we found<sup>15</sup>. However, the under-five mortality estimate is less accurate than an actual survey. Ntungamo has been one of those areas that have benefited a lot from the various outreaches for eye health screening and treatment; over the last five years, Mbarara University Department of Ophthalmology and Ruharo Eye Centre have conducted a number of outreaches in these areas. Perhaps, the lower level of SVI/BL in this area reflects the successes of these programs.

By looking at prevalence across the different counties; it was more or less the same. However, prevalence of SVI/BL was much higher in Ntungamo municipality compared to the other counties. There was the implied sex difference in prevalence of SVI/BL: it was almost twice as much in males than it was in females. Again, this was not statistically significant. In this population, there were more males than females (59%) compared to a similar study in Eastern Uganda which had more females than males (51%)9. A number of studies have noted a gender inequality for prevalence of a number of blinding conditions such as trachoma, cataract, congenital cataract and glaucoma, where, females are more affected than males<sup>16</sup>. Causes of SVI/BL were classified by anatomical site, by time of onset (aetiological classification) and by whether they were avoidable or non-avoidable. Anatomically, the leading causes of SVI/BL were cornea (18%) and lens (17%). This was in agreement with a number of studies done in Uganda and Africa<sup>7,9,17-22</sup>. Of the lens pathologies noted, cataract accounted for 60% making it the leading cause of SVI/BL. In one of the examination sites, we met a family of three siblings whose father was also diagnosed with cataract. He had refused to take them to hospital for fear of them losing even the little navigation that they had after surgery. These fears in the community may not be completely baseless as the second most common lens pathology noted was post cataract surgery complications. Paediatric cataract is not as straight forward as adult cataract; a lot still needs to be done even after the operation including, amblyopia therapy, refraction and use of pseudophakic correction. Even when all is done, outcome is not predictable; most post cataract studies particularly in Africa have reported poor outcomes<sup>23,24</sup>. We met a 2 year old who had undergone cataract operation in both eyes; she had received pseudophakic spectacles; however, she could not use them because they were too big and heavy. These and many other barriers to paediatric cataract services still make this problem prevalent. Now in Uganda, paediatric teams have been established including a paediatric ophthalmologist, a paediatric anaesthetist and a paediatric low vision expert. The impact of these teams is yet to be felt, in future, a study to assess this may provide valuable additional information about this situation.

The other most common anatomical cause of SVI/BL was corneal pathologies. Of these, 71% was due to corneal scar mostly following trauma, probable history

of vitamin A deficiency and dangerous practises such as traditional eye medicine. This is still a prevalent problem in this community; traditional eye medicine has been shown to be linked to corneal blindness<sup>25-27</sup>. The second leading corneal pathology entity was keratoconus. This was mostly seen in young adolescents with a long standing history of allergy. Treatment for keratoconus is usually optical correction such as spectacles and contact lenses if vision can be improved with refraction, however, there may be need for surgery including corneal transplant surgery in very advanced cases such as the ones seen in this survey. Uganda does not have a regular corneal service.

Classification according to onset or aetiological causes; majority of the causes were noted to be intra uterine causes. Majority (75%) of the children were said to have been born with SVI/BL conditions. In this group, cataract was the leading cause of intrauterine conditions, and corneal blindness was the leading cause of postnatal conditions. Further classification done to indicate specific diagnosis showed cataract and post cataract (17%), cortical blindness (14%), corneal scar (13%), refractive error (12%) and microphthalmos (12%) to be the leading conditions. Most of the cortical blindness was attributed to a history of cerebral malaria and or a high grade febrile episode with convulsions (probably meningitis) in these children who had otherwise been reported to having good vision prior. Uganda is still one of the countries classified to be a hyper endemic malaria area; malaria is the leading cause of less than 5 year child mortality. It would be interesting to have a properly designed study to understand the effect of malaria and meningitis on vision in our settings. A number of children had microphthalmos, some with both microphthalmos and cataract. Although the study was limited in investigating this, the most plausible cause could be a probable congenital rubella syndrome. Uganda has no rubella vaccination program for women of child bearing age. A number of children were seen with high refractive errors, mostly high myopia. When asked why their children were not using spectacles, most parents reported cost as a barrier. Refractive services are still scanty in rural Uganda; the ministry of health with other partners have started a program to provide low cost spectacles particularly in children in Uganda.

By classification according to whether causes were avoidable, 72% of the causes of BL/SVI were avoidable. Other studies have reported similar results and the current findings are comparable to other key informant method in Africa, an average of 50-70% 9.28,29. This goes on to show that majority of the blinding conditions are potentially avoidable either by prevention or treatment. In the management of the children identified with SVI/BL, 39% needed optical correction, this included spectacles and low vision devices. With correction, vision improved in at least 19% of the eyes to better than 6/60. About 32% of the children with SVI/BL needed surgery due to mostly cataracts. It was encouraging to note that there was a chance vision could be improved in about 72% of the cases.

Similar to the study in Eastern Uganda, our study found that only a small number of children with SVI/BL (36%) were attending school. The barriers to this were not investigated, however, Uganda now offers free universal primary education; therefore, the barriers could largely be dependent on disability rather than cost.

# **CONCLUSION AND RECOMMENDATION**

The prevalence of SVI/BL seemed lower than suggested in previous studies. As it appears from the current and previous studies in Uganda, the leading cause of BL/SVI is likely to be from un-operated cataract and complication from cataract surgery. This needs to be addressed to all stake holders and logical steps taken to prevent BL/SVI from lens related pathologies. Also, there is still an unmet psychosocial support for the affected children particularly educational support. Planners there should focus on community-based approaches to ensure that blind children have appropriate rehabilitation services and educational placement. Planning will need to consider improving referral, surgical management and follow-up of children treated for eye conditions and scaling provision optical services and access of spectacles and visual aids.

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