Epidemiology of eye diseases among children with disability in rural Bangladesh: a population-based cohort study

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ABBREVIATIONS

KIM	Key informant method
LMIC	Low- and middle-income country
SCC	Shahjadpur Children's Cohort
SVI	Severe visual impairment
WHO	World Health Organization

AIM To describe the epidemiology of eye diseases among children with disability in rural Bangladesh.

METHOD We established a population-based cohort of children with disability using the key informant method. Children younger than 18 years with disability (i.e. physical, visual, hearing, speech, epilepsy) were included. We used detailed ophthalmological assessments following World Health Organization (WHO) protocols by a multidisciplinary team including an ophthalmologist, optometrist, physician, and physiotherapist. Visual impairment, blindness, and severe visual impairment (SVI) were defined by following WHO categories.

RESULTS Between October 2017 and February 2018, 1274 children were assessed (43.6% female; median [interquartile range] age 9y 10mo [6y–13y 7mo]). Overall, 6.5% (*n*=83) had blindness/SVI, and 5.6% (*n*=71) had visual impairment. In the group with blindness/SVI, 47% (*n*=39) had cortical blindness; of those, 79.5% (*n*=31) had cerebral palsy (CP). The other main anatomical sites of abnormalities in this group included lens (13.3%, *n*=11), cornea (10.8%, *n*=9), and optic nerve (9.6%, *n*=8). In the group with visual impairment, 90.1% (*n*=64) had refractive error. Overall, 83.1% (*n*=69) and 78.8% (*n*=56) of those with blindness/SVI and visual impairment had avoidable causes. Most children with blindness/SVI and visual impairment lacked access to education.

INTERPRETATION The burden of blindness/SVI/visual impairment is high among children with disability in rural Bangladesh, mostly due to avoidable causes. Overrepresentation of CP and cortical blindness in the group with blindness/SVI and refractive error in the group with visual impairment highlights the need for integration of ophthalmology assessment, eye care, and refraction services in comprehensive health care for children with disability including CP in rural Bangladesh.

The global burden of childhood disability is approximately 93 million, of whom 85% live in low- and middle-income countries (LMICs).[1] Childhood blindness and visual impairment are a major public health concern, with an estimated 1.4 million children having blindness globally, thus contributing substantially to the burden of childhood disability.[2] Children with eye diseases are considered one of the most vulnerable groups, largely owing to difficulties with social participation and the length of disability-adjusted life years.[3] Visual morbidity among children is often both a cause and a consequence of disability. Several studies have demonstrated the effect of visual impairment contributing to poor motor, cognitive, and emotional development of children, which further exacerbates the burden.[4,5] Children with disability are more vulnerable to visual morbidities such as visual impairment and blindness.[6] Furthermore, blinding eye diseases and associated ophthalmic manifestations are often associated with other impairments: for example, one of the common causes of congenital cataract in LMICs is congenital rubella syndrome which is associated with hearing impairments and congenital cardiac anomalies.[7] Recent estimates from Bangladesh have reported an incidence of 0.99 per 1000 live births, corresponding to approximately 3292 cases of congenital rubella syndrome annually, which is a substantially higher burden than global estimates.[8,9]

The causes of blindness have changed markedly over the years, particularly in high-income countries.[10] However, several avoidable causes continue to prevail in LMICs where some 90% of worldwide blindness occurs.[11] In addition to infectious diseases such as rubella underlying the burden of childhood disability,[12] the lack of good perinatal care in LMICs such as Bangladesh also contributes substantially to the burden of visual disorders and neurodevelopmental disabilities such as cerebral palsy (CP).[13,14] The reported prevalence of CP in Bangladesh is markedly greater than global estimates, which is largely representative of findings from high-income countries.[14] CP is the most common type of physical impairment in children and is commonly associated with disorders of visual function, often occurring due to damage to the central visual pathway (i.e. cerebral visual impairment).[15] Comorbidities commonly observed among children with CP, including impairments of vision, intellect, and epilepsy, often stem from the same underlying pathology.[15,16] Furthermore, several antiseizure medications have been reported to result in various abnormalities of vision.[17]

Exploration of the burden of visual problems among children with disability in LMICs is imperative for optimal use of limited resources. Despite the magnitude of the problem, there are no population-based data on the burden of eye diseases among children with disability in LMICs such as Bangladesh. This study aimed to describe the burden of eye diseases among children with disability in a rural subdistrict of Bangladesh.

What this paper adds

- Blindness/severe visual impairment (SVI) and visual impairment prevalence was 6.5% and 5.6% among children with disability in rural Bangladesh.
- Most blindness/SVI among children with disability was due to potentially preventable/treatable causes.
- About a third in this cohort had cortical blindness and cerebral palsy.
- Among children with disability, mild to moderate visual impairment was caused by refractive error in the majority of cases.
- Most children with blindness/SVI and visual impairment had no access to formal schooling in rural Bangladesh.

METHOD

We conducted a population-based epidemiological survey of eye diseases among children with disability living in a rural subdistrict (Shahjadpur) of northern Bangladesh. The study site (Shahjadpur) has 296 villages, 123 576 households and a population of 561 076 (child population 232 037 in 2011).[18] The study site is representative of rural Bangladesh in terms of sociodemographic characteristics (e.g. population age–sex distribution, housing, water, and sanitation characteristics).[18]

Study participants and ascertainment method

We established the first population-based cohort of children with disabilities, namely Shahjadpur Children's Cohort (SCC), in the study area. A child was eligible to participate if they were younger than 18 years at the time of assessment and had at least one form of disability (e.g. physical impairment and/or speech impairment and/or hearing impairment and/or vision impairment and/or epilepsy) as per the definitions adopted.

We used the key informant method (KIM) where we trained local volunteers (known as key informants) to identify children with moderate to severe disabilities from their communities and bring them to medical assessment camps for confirmed diagnosis and services provided by a trained medical team. The KIM is a valid method and has been widely practised in several studies in resource-poor settings such as Bangladesh where healthcare accessibility and records are limited.[19,20] A total of 130 key informants received structured training for 1 day on major categories of disability (e.g. epilepsy, physical, visual, hearing, and speech impairment) and reduced social stigma around disability. Participatory methods with flip charts were used for training. The key informants were given 4 to 6 weeks (depending on the geographical areas to cover) to identify children with suspected disabilities and share their contact information with community mobilizers (paid project staff).

Establishment of SCC

To identify the children with disability and establish the SCC, the key informants first retraced children with specific disabilities from two other cohorts previously established using KIM by our research team in the study area, which were as follows.

Childhood disability survey in Shahjadpur

This was an active community-based survey that identified children with severe disability using KIM between September 2011 and March 2012. The study cohort had 859 children with visual, hearing, and physical impairment, and epilepsy in Shahjadpur (i.e. the SCC study site).[12]

Bangladesh cerebral palsy register

This was the first population-based register of children with CP in an LMIC, established in 2015. This register uses KIM to identify children with suspected CP from the community.[14,21] As of December 2016 the Bangladesh Cerebral Palsy Register had 816 children with CP registered from Shahjadpur (inclusive of 412 children previously identified as part of the Childhood Disability Survey in Shahjadpur study).[12,14]

Within the same time period (i.e. 4–6wks after key informant training) the key informants also identified new children with suspected disabilities who were not included in those previously established cohorts. Once the key informants completed identification/retracing of children with disability from their communities, they shared the information with community mobilizers. The community mobilizers, with support from the key informants, assisted the listed children and their primary caregivers to attend the medical assessment camps held in their locality.

Medical assessment camps

Medical assessment camps were conducted with a multidisciplinary assessment team including an ophthalmologist, paediatrician, physiotherapist, optometrist, and community rehabilitation worker. The assessment was completed in following two steps.

Clinical assessment for documentation of any disabling impairment

A paediatrician and a physiotherapist assessed each participating child (i.e. a child with at least one form of disability listed by key informants), reviewed available medical records, and collected detailed clinical history for confirmed diagnosis and documentation of the type and severity of any disabling impairment (physical, hearing, speech, visual, epilepsy). The standard definitions of different disabling impairment adopted in this study are summarized in Table S1 (online supporting information).[12,21–26]

Ophthalmological assessment and diagnosis of visual impairment

After assessment by the physician and physiotherapist, each child underwent detailed ophthalmology assessment by an ophthalmologist and an optometrist for identification/assessment and documentation of their visual impairment status. The World Health Organization (WHO)/prevention of blindness form for examination of blindness and low vision among children was used for comprehensive assessment.[25] Coding was done following the WHO instruction manual.[26]

The presenting distance visual acuities were assessed using a Snellen 'E' chart following standard protocols. For younger children we used Cardiff acuity cards, employing the standard staircase method. Additionally, in some very young children we also used, for example, response to light, pupil response, ability to follow a target, and cover and uncover tests when required. Documentation was also made if an assessment was not conducted owing to the severity of impairment and/or the young age of a child. Near vision was also tested following standard protocols.

Documentation of visual loss

The WHO International Classification of Diseases definitions and classifications were used to categorize any visual loss among children with disability in our cohort. Blindness was defined as presenting visual acuity (i.e. with glasses if normally worn) of less than 3/60 in the better eye, severe visual impairment (SVI) as presenting visual acuity of less than 6/60 but better or equal to 3/60 in the better eye, and visual impairment as presenting visual acuity of less than 6/18 but better or equal to 6/60 in the better eye.[25–27]

Assessment of refractive error

All children were assessed for refractive error. Refraction was performed using retinoscopy and trial lenses. Identification of refractive error was done by an optometrist with a multiple pinhole and/or corrective lenses after refraction. Diagnosis of refractive error was made if the acuity improved to 6/18 or better with refraction and/or multiple pinhole.[26] Children who required advanced treatment (including surgical, medical, or optical treatment) were referred to collaborating eye hospitals in Sirajganj district, Bangladesh.

Documentation of the anatomical site of abnormality

Anterior and posterior segment examinations were done following standard guidelines. All structural abnormalities were recorded for each eye separately. Detailed definitions and criteria in the WHO coding instructions[25–27] were used to select one major site of abnormality for each eye. For instance, cataract was defined as central lens opacity reducing visual acuity. As per WHO guidelines, one site, either in the right or left eye of the child, was selected to represent the major site. Prioritization was given for the treatable abnormality and then for the preventable abnormality if the main sites differed between eyes.[25–27]

Determination of the causes of visual loss

The WHO classification system was followed to categorize the anatomical site and underlying aetiology of blindness/SVI.[25–27] Preventable, treatable, and unavoidable causes of blindness/SVI were established on the basis of history, and clinical and ophthalmological assessment. Preventable causes constituted conditions that could have been possibly avoided through simple interventions in households or in the community such as health promotion, prevention, and education. Treatable causes consisted of conditions where sight could have been restored or preserved through surgical, medical, or optical interventions (e.g. glaucoma or cataract surgery). Avoidable causes included all the treatable and preventable causes, while the rest were considered unavoidable. Preventable, treatable, and unavoidable categories were mutually exclusive for diagnosis and subsequent analysis.[25–27]

Underlying aetiology

The aetiology of visual loss was determined for each eye and for every child. Efforts were made to determine the time at onset and the insult leading to visual loss on the basis of family history, ocular history, clinical findings, and diagnosis. Hereditary, intrauterine, perinatal/neonatal factors, and postnatal/infancy/childhood factors were used as the categories according to the WHO guidelines.[25–27] If the aetiology was unknown, it was also documented.

Ethical considerations

Research ethics approval was obtained from the ethics review committee of the Asian Institute of Disability and Development (AIDD HREC southasiairb-2017-8-01), and the Bangladesh Medical Research Council (BMRC/NREC/2016-2019/468). The study was conducted with adherence to the guidelines provided in the Declaration of Helsinki. Informed written consent was obtained from the primary caregiver of each child who participated in the study.

Statistical analysis

A χ^2 test, Fisher's exact test, and a binomial test were used to measure significant variations in proportions. A Shapiro–Wilk test was used to assess the distribution of continuous data (e.g. age, income, expenditure), and a

Mann–Whitney *U* test was used to compare the median values of two groups. A level of $p<0.05$ was considered significant throughout the analyses. All analyses were done using SPSS version 26 (IBM, Armonk, NY, USA). The point prevalence of disability among children younger than 18 years at the study site (Shahjadpur) was estimated using the following formula: (total *n* of children with disability aged younger than 18y recruited in the SCC divided by the total *n* of child population aged younger than 18y living in the study site) × 1000.

The prevalence of different forms of disability (e.g. physical, hearing, speech, visual, and epilepsy) at the study site was also estimated similarly. The total number of child population aged younger than 18 years living in the study site (i.e. the denominator) (according to the latest Bangladesh Population and Housing Census report[18]) was used to calculate the prevalence. Additionally, the prevalence of blindness/SVI or visual impairment among children recruited in the SCC was estimated using the following formula: (total *n* of children with blindness/SVI or visual impairment among children recruited in the SCC divided by the total *n* of children recruited in the SCC) × 100.

For each estimated prevalence, a 95% confidence interval (CI) was calculated using the Wilson score method with the Epitools online calculator (Ausvet, ACT, Australia).[28] For any missing data, the valid percentages were used; the respective numerator and denominator were presented for all subgroup analyses throughout the results section.

RESULTS

Between October 2017 and February 2018, 52 assessment camps were conducted in the 14 unions of Shahjadpur. A total of 1274 children with confirmed disability were included in the study to form the SCC.

Sociodemographic details of study participants

The sociodemographic characteristics of the study cohort is outlined in Table 1. The median (interquartile range [IQR]) age of the children in the SCC was 9y 10mo (6y – 13y 7mo); 43.6% (*n*=556) were female. The overall housing structure, maternal and paternal educational levels, and maternal occupation were significantly lower among children in the SCC compared with the regional average ($p=0.001$, $p<0.001$, $p<0.001$, and $p<0.001$ respectively). The median (IQR) monthly family income was 7000 (6000–10 000) Bangladeshi taka (≈US$83 [71–118]). Overall, 78.7% (*n*=997 out of 1267) of families had no savings or were in debt in the preceding month of the survey, which indicates their economic vulnerability.

Cohort profile (types of impairment)

Table 2 summarizes the presence and types of different impairment among the children in the cohort (i.e. SCC; children with disability). Overall, 52.7% (*n*=672 out of 1274) of the children in the SCC had one impairment (of whom 4% [*n*=27] had only blindness/SVI or visual impairment) and the remaining 47.3% (*n*=602 out of 1274) had two or more different impairments (of whom 21.1% [*n*=127] had visual impairment in addition to other forms of impairment). When considered not mutually exclusive, physical impairment (including CP) was the most common form of disability (71.8%, *n*=915, 95% CI 69.2–74.2 [62.5%, *n*=796, 95% CI 59.8–65.1 and 9.3%, *n*=119, 95% CI 7.9–11.1]) among children in the SCC. Furthermore, 31.8% (*n*=400, 95% CI 28.9–34.0) were non-verbal, 30.6% (*n*=390, 95% CI 28.1–33.2) had hearing impairment (of whom 44.3%, *n*=173 had bilateral deafness), and 14.1% (*n*=179, 95% CI 12.2–16.1) had epilepsy. Overall, 6.5% (*n*=83) of children had blindness/SVI (of the 83 children with blindness/SVI, 39 had blindness and 44 had SVI) and 5.6% (*n*=71) of children had visual impairment. The proportion with blindness/SVI and visual impairment was comparatively higher among children with hearing impairment (15.6%, *n*=61), epilepsy (21.2%, *n*=38), and speech impairment (15.3%, *n*=61; Table 3).

Prevalence of different forms of childhood disability in the study site

Extrapolating data from the latest Bangladesh Population and Housing Census report,[18] there were 255 225 children aged younger than 18 years living at the study site (Shahjadpur) during the study period,[18] giving an estimated point prevalence of overall disability of 5.0 per 1000 children in Shahjadpur. Using the same denominator (i.e. 255 225 children aged <18y in 2018 in Shahjadpur), the estimated prevalence of major types of disability in Shahjadpur was as follows: physical impairment 3.6 per 1000 children (95% CI 3.4–3.8); speech impairment (non-verbal) 1.6 per 1000 children (95% CI 1.4–1.7); hearing impairment 1.5 per 1000 children (95% CI 1.4–1.7); epilepsy 0.7 per 1000 children (95% CI 0.6–0.8); visual impairment: 0.3 per 1000 children (95% CI 0.3–0.4); and blindness/SVI 0.3 per 1000 children (95% CI 0.2–0.3) (Table 2).

Main anatomical site of abnormalities for children with blindness/SVI and visual impairment

No structural abnormality of the globe was documented in most children (55.4%, *n*=46 of those with blindness/SVI and 90.1%, *n*=64 of those with visual impairment). Overall, cortical blindness was predominant among children with blindness/SVI whose globe appeared normal (84.8%, *n*=39). Of those children with cortical blindness in the group with blindness/SVI, 79.5% (*n*=31) had CP (67.3% [*n*=31] of the total *n* of children whose globe appeared normal in the group with blindness/SVI). Furthermore, the lens, cornea, and optic nerve were documented as the main anatomical sites of abnormalities among 13.3% (*n*=11), 10.8% (*n*=9), and 9.6% (*n*=8) children with blindness/SVI. Whereas most children in the group with visual impairment had refractive error (90.1%, *n*=64), of them 87.5% (*n*=56) were prescribed glasses as part of the study.

Table 1: Sociodemographic characteristics of children with disabilities in the Shahjadpur Children's Cohort (SCC), n=1274

Demographic characteristics	SCC, n (%)	Regional data, n (%)	p
Age			
Median (IQR), y:mo	9:10 (6:0–13:7)	N/A	N/A
0–4y	242 (19.0)	26.2[a]	
5–9y	415 (32.6)	31.8[a]	0.61[e]
10–14y	411 (32.3)	29.1[a]	
15–18y	206 (16.2)	12.7[a]	
Sex			
Female	556 (43.6)	48.2[a]	0.61[e]
Male	718 (56.4)	51.8[a]	
Main construction material of walls			
Hemp/hay/bamboo or other	40 (3.1)	1.4[b,c]	0.001[e]
Mud brick, tin or corrugated iron, sheet/wood	1144 (89.8)	71.6[b,c]	
Brick/cement	90 (7.1)	27.0[b,c]	
Main source of drinking water			
Improved source[d]	1272 (99.8)	98.7[b]	0.50[f]
Unimproved source[d]	2 (0.2)	1.3[b]	
Water treatment method			
Proper treatment[d]	163 (12.8)	4.2[b,c]	<0.001[g]
Improper treatment	1111 (87.2)	N/A	
Access to sanitation			
Improved[d]	918 (72.1)	65.1[b]	0.52[e]
Unimproved	356 (27.9)	32.3	
Maternal age, mean (SD), y:mo	33:10 (7:8)	N/A	N/A
Maternal education			
Illiterate	523 (41.1)	18.7[b]	<0.001[e]
Primary incomplete	185 (14.5)	23.2[b]	
Primary complete	331 (26.0)	7.7[b]	
Secondary incomplete	143 (11.2)	36.7[b]	
Secondary complete and higher	92 (7.2)	13.7[b]	
Maternal occupation			
Professional/technical	15 (1.2)	3.1[b]	<0.001[g]
Factory work/blue collar service/ semi-skilled/unskilled labour	75 (5.9)	19.6[b]	<0.001[g]
Business	13 (1.0)	3.2[b]	<0.001[g]
Agricultural/farming	7 (0.5)	2.6[b]	<0.001[g]
Homemaker	1161 (91.1)	N/A	N/A
Others	3 (0.2)	0.1[b]	0.137[g]
Paternal age, mean (SD), y:mo	40:2 (9:2)	N/A	N/A
Paternal education, n = 1270			
Illiterate	608 (47.9)	21.3[b]	<0.001[e]
Primary incomplete	135 (10.6)	30.4[b]	
Primary complete	231 (18.2)	7.0[b]	
Secondary incomplete	131 (10.3)	24.7[b]	
Secondary complete and higher	165 (13.0)	2.1[b]	
Paternal occupation			
Desk job	68 (5.3)	N/A	N/A
Blue collar job	474 (37.2)	N/A	
Business	234 (18.4)	N/A	
Agricultural/farming	310 (24.3)	N/A	
Unemployed	17 (1.3)	N/A	
Others	171 (13.4)	N/A	
Monthly family income in BDT (US$)[h], n=1271			
BDT, median (IQR)	7000 (6000–10 000)	N/A	N/A
Approximate US$, median (IQR)	83 (71–118)		
Monthly family expenditure in BDT (US$),[h] n=1270			
BDT, median (IQR)	7000 (5500–10 000)	N/A	N/A
Approximate US$, median (IQR)	83 (65–118)		

BDT, Bangladeshi taka; IQR, interquartile range; N/A, not applicable; SD, standard deviation; US$, US dollars. [a]Census 2011. [b]Bangladesh Demographic and Health Survey, 2018. [c]National data for rural areas. [d]Improved source/appropriate water treatment method/improved sanitation was defined following the Bangladesh Demographic and Health Survey definitions. [e]χ^2 test. [f]Fisher's exact test (two-sided). [g]Binomial test. [h]US$1≈BDT84.5.

Additionally, the cornea was documented as the main anatomical site of abnormalities for 4.2% (n=3) of children with visual impairment. The details are shown in Table 4.

Underlying aetiology of blindness/SVI and visual impairment

Perinatal and neonatal factors predominated as the underlying aetiology for blindness/SVI (71.1%, n=59) and visual

Table 2: Prevalence of types of disability among children in the Shahjadpur Children's Cohort (SCC) and at the study site, *n*=1274

Presence of impairment	SCC, *n* (%)	Prevalence per 1000 children (95% CI)
Number of impairments		
One	672 (52.7)	2.6 (2.4–2.8)
Two or more	602 (47.3)	2.4 (2.2–2.6)
Type of impairment[a]		
Physical[b]		
No	359 (28.2)	N/A
Yes	915 (71.8)	3.6 (3.4–3.8)
Speech, *n*=1257		
No (verbal)	857 (68.2)	N/A
Yes (non-verbal)	400 (31.8)	1.6 (1.4–1.7)
Hearing		
No	884 (69.4)	N/A
Yes	390 (30.6)	1.5 (1.4–1.7)
Epilepsy		
No	1095 (85.9)	N/A
Yes	179 (14.1)	0.7 (0.6–0.8)
Visual		
No	1120 (87.9)	N/A
Blindness/severe visual impairment	83 (6.5)	0.3 (0.3–0.4)
Visual impairment	71 (5.6)	0.3 (0.2–0.3)

CI, confidence interval; N/A, not applicable. [a]Types of impairment are not mutually exclusive since multiple impairment was common among the study participants. [b]Includes cerebral palsy, birth defect, deformity, genetic disease, musculoskeletal dystrophy, trauma/injury-related impairment.

impairment (77.5%, *n*=55) among children in the SCC; whereas postnatal or infancy childhood factors were reported in 6.0% (*n*=5) and 8.5% (*n*=6) of children with blindness/SVI and visual impairment respectively (Table 5). Furthermore, among children with cortical blindness in the group with blindness/SVI, 64.1% (*n*=25) and 17.9% (*n*=7) had a history of cerebral hypoxia or injury and neonatal or postnatal convulsion respectively.

Preventable, treatable, and unavoidable causes of blindness/SVI and visual impairment

Among children in our cohort who had only blindness/SVI and visual impairment (i.e. who had no other impairment), 55.5% (*n*=15) and 29.6% (*n*=8) were due to preventable and treatable causes and 7.4% (*n*=2) were due to unavoidable causes. At the same time, among children who had blindness/SVI and visual impairment in addition to other impairments, 73.2% (*n*=93) and 7.1% (*n*=9) were due to preventable and treatable causes and 5.5% (*n*=7) were due to unavoidable causes. The specific causes are summarized in Table 6.

Table 4: Main anatomical site of abnormality among the children with blindness/SVI and visual impairment in the Shahjadpur Children's Cohort, *n*=154

Main anatomical site	Blindness/SVI *n*=83, *n* (%)	Visual impairment, *n*=71, *n* (%)	Total, *n*=154, *n* (%)
Whole globe	5 (6.0)	1 (1.4)	6 (3.9)
Phthisis	1	0	1
Anophthalmos	2	0	2
Microphthalmos	1	0	1
Glaucoma	1	0	1
Congenital nasolacrimal duct obstruction	0	1	1
Cornea	9 (10.8)	3 (4.2)	12 (7.8)
Scar	8	3	11
Keratoconus	1	0	1
Lens	11 (13.3)	1 (1.4)	12 (7.8)
Cataract	8	0	8
Aphakia	2	1	3
Pseudophakia	1	0	1
Uvea	0 (0.0)	0 (0.0)	0 (0.0)
Retina	0 (0.0)	1 (1.4)	1 (0.6)
Dystrophy	0	1	1
Optic nerve	8 (9.6)	0 (0.0)	8 (5.2)
Atrophy	8	0	8
Other, not listed	1 (1.2)	1 (1.4)	2 (1.3)
Ptosis	1	1	2
Not examined (believed blind)	3 (3.6)	0 (0.0)	3 (1.9)
Globe appears normal	46 (55.4)	64 (90.1)	110 (71.4)
Cortical blindness	39	0	39
Nystagmus	2	0	2
Refractive error	2	64	66
Amblyopia	1	0	1
Unknown	2	0	2

SVI, severe visual impairment.

Sociodemographic characteristics, rehabilitation, and educational status of children in the SCC

Most sociodemographic characteristics (e.g. age distribution, male:female ratio, source of drinking water, access to sanitation, parental occupation, and monthly family

Table 3: Presence of visual impairment among children with different forms of impairment in the Shahjadpur Children's Cohort

Types of impairment[a]	Present (*n*)	*n* (%) with visual impairment[b] Blindness/SVI *n*=83	Visual impairment *n*=71	No visual impairment *n*=1120	p^c
Physical[d]	915	52 (5.7)	54 (5.9)	809 (88.4)	0.12
Speech (non-verbal)	400	35 (8.8)	26 (6.5)	339 (84.8)	0.06
Hearing	390	36 (9.2)	25 (6.4)	329 (84.4)	0.02
Epilepsy	179	19 (10.6)	19 (10.6)	141 (78.8)	<0.001

SVI, severe visual impairment. [a]Types of impairment are not mutually exclusive and multiple impairments were common among the study participants. [b]Row percentages were calculated. [c]χ^2 test (two-sided). [d]Includes cerebral palsy, birth defect, deformity, genetic disease, musculoskeletal dystrophy, trauma/injury-related impairment.

Table 5: Underlying aetiology of blindness/SVI and visual impairment in the Shahjadpur Children's Cohort, n=154

Aetiology of visual loss	Blindness/SVI, n=83, n (%)	Visual impairment, n=71, n (%)	Total, n=154, n (%)
Hereditary disease	2 (2.4)	5 (7.0)	7 (4.5)
Intrauterine factor	1 (1.2)	0 (0.0)	1 (0.6)
Perinatal/neonatal factor	59 (71.1)	55 (77.5)	114 (74.0)
Postnatal/infancy childhood factor	5 (6.0)	6 (8.5)	11 (7.1)
Unknown	16 (19.3)	5 (7.0)	21 (13.6)

SVI, severe visual impairment.

Table 6: Preventable, treatable, and unavoidable causes of blindness/SVI and visual impairment in the Shahjadpur Children's Cohort, n=154

	Blindness/SVI, n=83		Visual impairment, n=71		Total (blindness/SVI/visual impairment), n=154	
Cause/aetiology	Only blindness/ SVI, n (%)	Blindness/ SVI and other impairments, n (%)	Only visual impairment, n (%)	Visual impairment and other impairment, n (%)	Only blindness/ SVI/visual impairment, n (%)	Blindness/ SVI/visual impairment and others, n (%)
n	20	63	7	64	27	127
Preventable	10 (50.0)	47 (74.6)	5 (71.4)	46 (71.9)	15 (55.5)	93 (73.2)
Cerebral hypoxia/injury	8	33	5	32	13	65
Epilepsy	0	0	0	3	0	3
Febrile convulsion	0	1	0	1	0	2
Neonatal convulsion	0	10	0	10	0	20
Neonatal jaundice	0	1	0	0	0	1
Neonatal septicaemia	0	1	0	0	0	1
Typhoid fever	1	0	0	0	1	0
Meningitis	0	1	0	0	0	1
Drugs	1	0	0	0	1	0
Treatable	7 (35.0)	5 (7.9)	1 (14.3)	4 (6.2)	8 (29.6)	9 (7.1)
Cataract	6	3	0	0	6	3
Glaucoma	1	0	0	0	1	0
Congenital cataract and glaucoma	0	0	0	1	0	1
Congenital epiphora	0	0	0	2	0	2
Viral conjunctivitis	0	1	1	1	1	2
Diabetes	0	1	0	0	0	1
Unavoidable	2 (10.0)	2 (3.2)	0 (0.0)	5 (7.8)	2 (7.4)	7 (5.5)
Anophthalmus	1	0	0	0	1	0
Chromosomal disorder	1	0	0	0	1	0
Down syndrome	0	1	0	5	0	6
Congenital blind eye	0	1	0	0	0	1
Unknown	1 (5.0)	9 (14.3)	1 (14.3)	9 (14.1)	2 (7.4)	18 (14.2)

SVI, severe visual impairment.

income) of children with blindness/SVI and visual impairment were similar to others in the SCC (i.e. children without blindness/SVI and visual impairment). No significant difference was observed in terms of access to rehabilitation services between children who had blindness/SVI and visual impairment and others in the cohort (63.6%, n=98 vs 65.3%, n=731 respectively never received any rehabilitation services; p=0.69; Table S2, online supporting information). However, among children with blindness/SVI and visual impairment who never received rehabilitation services, 66.1% (n=37) never received them because of a lack of awareness among caregivers about the service need. Furthermore, among those who had received rehabilitation services, 35.1% (n=39) of children received assistive devices (of whom 31 received their required devices) and most received services from non-government organizations (69.2%, n=63).

Additionally, we found significantly lower participation or enrolment at mainstream or special education services among school-aged children who had blindness/SVI and visual impairment compared with others in the cohort (75.4%, n=89 school-aged children with blindness/SVI and visual impairment were not attending any mainstream or special school compared with 58.2% [n=504] of children without blindness/SVI and visual impairment in the SCC; p<0.001; Table S2). The major causes for non-attendance among children with blindness/SVI and visual impairment were physical barriers in accessing the services, followed by parents' refusal to send their children to the educational institutions, and unavailability of special education services in the neighbourhood (45.1%, n=32; 33.8%, n=24; and 18.3%, n=13 respectively).

DISCUSSION

To the best of our knowledge, this is the first study reporting population-based data to quantify the epidemiology of eye diseases among children with disability in a rural subdistrict of Bangladesh. These novel data will serve as the mainstay for prioritization of this vulnerable group in ensuring eye care for children, which requires a coordinated approach through data linkages such as this in LMICs.

Our study findings suggest a substantially high prevalence of blindness/SVI among children with disability compared with the general population.[29] Similar findings have been previously reported among children with CP in rural Bangladesh[14] and children with intellectual impairment in India.[6,30] The WHO, in partnership with the International Agency for the Prevention of Blindness, launched the 'Vision 2020: the Right to Sight' initiative in 1999 with view to eliminating avoidable causes of blindness.[31] A successful Vision 2020 initiative would result in only 24 million blind persons in 2020 and 429 million blind person-years avoided.[32] National and international eye programmes are often targeted either to alleviate or treat children with blindness/SVI and visual impairment. However, children with disability as a group have not been previously considered as a target group for eye care programmes. Although epidemiological studies are crucial to systematically define the burden of eye diseases, develop targeted strategies for prevention of blindness and visual impairment, and achieve the goals of Vision 2020,[31] such data focusing on children with disability are limited in LMICs.

The causes of visual morbidity among children with disability in the SCC varied; a larger proportion had an avoidable cause of blindness/SVI. The proportion was higher than reported in studies conducted among children with visual impairment in Bangladesh (83.2% vs 69.2%)[33] and other LMICs.[27,34,35] More than two-thirds of the cases of blindness/SVI and visual impairment among children in the SCC were due to perinatal/neonatal and postnatal causes. Ensuring adequate prenatal, perinatal, and post-neonatal care could avert those conditions. Improving perinatal care through primary healthcare services in rural Bangladesh should be a priority to reduce the burden of preventable and treatable conditions of blindness/SVI/visual impairment in children. Furthermore, we found that nearly 16% of the children with hearing impairment had blindness/SVI or visual impairment. Similar observations were reported in another study conducted in India.[36]

Cortical blindness was predominant whereas corneal scarring, optic nerve atrophy, and cataract were the second most common cause of blindness/SVI among children in the SCC. Similar findings were reported among children with visual impairment in Bangladesh and Indonesia.[27,33] Most children with cortical blindness in the SCC had a prenatal and perinatal aetiology (e.g. hypoxia, convulsion) and/or CP. It is likely that most of them had cerebral visual impairment. Similar findings were reported in another institution-based study in the USA.[37] Considering these facts, cerebral visual impairment was probably the major cause of blindness/SVI, and the brain was the main anatomical site of abnormality that caused blindness/SVI, among children with disability in rural Bangladesh; whereas refractive error was predominant among children with mild-to-moderate visual impairment and those with no structural abnormality of the globe. Similar findings were observed in another study where 44% to 60% of children with intellectual disability, Down syndrome, or CP had refractive error.[6]

Global development of children with special needs such as those in our cohort depends on holistic care, which can be achieved through a comprehensive service delivery model for children with disability. There are broadly two key messages related to services for the two major groups identified in this study. First, for children with blindness/SVI with or without other disabilities: the high number of CP and cortical blindness in this group highlights the need for integration of 'ophthalmology assessment' and 'rehabilitation/specialized care needs for vision and function' in healthcare screening and a service plan for children with CP and other disabilities in rural Bangladesh. Second, for children with mild-to-moderate visual impairment with or without other disabilities: refractive error was the predominant cause of visual impairment, so the vision and refraction services should be made essential, available, and accessible to all children with disability in rural Bangladesh. A vast majority of children with disability and mild-to-moderate visual impairment in rural Bangladesh will benefit from correction of refractive error and the provision of glasses.

Identifying and engaging an ophthalmologist and optometrist for the detailed ophthalmic assessment conducted as part of our study was challenging, thus demonstrating the need for training and development of health professionals in these settings. The healthcare workforce crisis and insufficient skill mix in Bangladesh emphasizes the need for capacity building of health professionals including optometrists, physiotherapists, special educators, and medical practitioners.[38] Similar barriers prevail in other LMICs where the community-based rehabilitation model is becoming increasingly popular.[39,40] A modified community-based rehabilitation model enriched by our study findings could potentially be the key to the development of a service delivery model for children with disability in Bangladesh and other similar settings.

It is important to recognize that children with disabilities experience inequalities; our findings indicate they are less likely to attend school, which would result in reduced employment opportunities and decreased productivity in adulthood.[41–43] Their disability also poses considerable psychological and social challenges for them and their families.[44,45] Hence, the impact of disability at an individual level is considerable and beyond limitations in access to care. Knowledge of the association between vision loss and socioeconomic factors is essential for public health planning.[46] A thorough understanding of the epidemiology of eye diseases among children with disability is important for clinicians, services, and policy-makers, and warrants a cross-disciplinary approach, as opposed to the traditional vertical programmes, to cater for the diverse needs of this particularly vulnerable group.

Through this study we established the first population-based cohort of children with disability in rural Bangladesh (i.e. the SCC) and formed the baseline to develop strategies for improvement of eye care services among children with disability in Bangladesh. As health systems evolve and we move towards the United Nations Sustainable Development Goals, the limited resources in LMICs need to be organized through an evidence-based approach to address the diverse needs of children with multimorbidity with a view to addressing the inequalities to truly ensure health for all.[47]

The findings have an important bearing on the management of children with disability in LMICs such as Bangladesh. Our population-based data have created scope for future longitudinal studies, with an opportunity to monitor the trend in need-based healthcare service provision and its impact on eye health for children with disability in rural Bangladesh. The study cohort can potentially serve as the sampling frame for future studies which will facilitate exploration of the natural course and risk factors of adverse outcomes among children with disability in an effort to prevent them. The findings highlight the need for eye care and could be used for advocacy at governmental, non-governmental, and international platforms for prevention, control, and management of eye care diseases among children with disability in rural Bangladesh.

Despite considerable efforts, our study had several limitations. First, we used the KIM for identifying children with disability from rural communities in Bangladesh. Although this method of case ascertainment has several apparent merits in low-resource settings and has been well documented and widely used globally,[19,48,49] it does not ensure full ascertainment.[19,20] Second, owing to age and other communication barriers (e.g. very young children, non-verbal, and/or intellectual impairment), different methods of ascertaining visual acuity were used; these were not directly comparable but complementary to assess children with varying levels of ability and age groups. Third, the commonly identified causes of blindness or visual impairment in our cohort (e.g. prenatal, neonatal factors) are often the cause of neonatal mortality, particularly in LMICs mortality among children, particularly in LMICs. It is therefore likely that the prevalence of blindness/SVI and visual impairment reported among children with disability in our study site was an underestimation of the true burden. Further studies are needed in similar settings to validate our findings. Fourth, the tool we adopted for visual assessment in our cohort emphasizes identification of preventable and treatable conditions over unavoidable conditions during population-based assessment of visual loss among children. Following the guidelines, we only documented one major abnormality causing the visual loss in children. Furthermore, for children whose globe appeared normal, diagnosis was made in the categories of refractive error, amblyopia, cortical blindness, idiopathic nystagmus, and normal vision, following the guidelines. Although there is a high likelihood that cerebral visual impairment was the major cause of blindness/SVI among children with disability in our cohort, It was likely that most children with blindness/SVI in our cohort had cerebral visual impairment. However, due to some inherent limitation of the study tool adopted,[25] we could not document that. Instead, they were probably grouped in the category 'cortical blindness' as the best suitable option. Furthermore, owing to insufficient data we could not identify the causes of blindness/SVI of two children whose globe appeared normal. Similarly, for children with visual impairment, most were likely to have varying degrees of vision loss due to multiple causes in addition to refractive error (e.g. refractive error and cerebral visual impairment considering the high number with cerebral hypoxia/injury and/or CP in that group). However, following the guidelines we only focused on highlighting the preventable and treatable conditions (e.g. refractive error), and those children may have been grouped in the category 'refractive error'. Therefore the findings need to be interpreted with caution, keeping the study limitations in mind.

In summary, this study of one of the largest population-based childhood disability cohorts in an LMIC has confirmed a high burden of blindness/SVI among children with disability in rural Bangladesh. It will form the basis for prospective observational studies and development of a model for community-based eye care services for children with disability in LMICs such as Bangladesh. Findings from our study will guide the development of effective, low-cost, and culturally appropriate solutions for comprehensive eye care programmes targeting children with disability and inform disability-inclusive development and policies which should be a national priority.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

SUPPORTING INFORMATION

The following additional material may be found online:

Table S1. Definition of different types of disability used in the study

Table S2. Comparison of demographic characteristic and rehabilitation status between children with and without visual impairment in the SCC

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