WORLD VIEW

The key informant method: a novel means of ascertaining blind children in Bangladesh

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Background: Most information on the causes of blindness has come from examining children in special education. To obtain a more representative population-based sample of children, a novel method was developed for ascertaining severe visually impaired (SVI) or blind (BL) children by training local volunteers to act as key informants (KIs).
Objective: To compare the demography and cause of blindness in children recruited by KIs with other ascertainment methods.
Method: Children with SVI/BL were recruited in all 64 districts of Bangladesh. Three sources for case ascertainment were utilised: schools for the blind (SpEdu), community-based rehabilitation (CBR) programmes and KIs. All data were recorded using the standard WHO/PBL Eye Examination Record.
Results: 1935 children were recruited. Approximately 800 KIs were trained. The majority of the children were recruited by the KIs (64.3%). Children recruited by KIs were more likely to be female (odds ratio (OR) 1.6, p<0.001), of pre-school age (OR 14.1, p<0.001), from rural areas (OR 5.9, p<0.001), be multiply impaired (OR 3.1, p = 0.005) and be suffering from treatable eye diseases (OR 1.3, p = 0.005) when compared with those in SpEdu. Overall a child with an avoidable causes of SVI/BL had 40% (adjusted CI 1.1 to 1.7, p = 0.015) and 30% (CI 1.0 to 1.7, p = 0.033) higher odds of being ascertained using the KIs compared with SpEdu and CBR methods, respectively.
Conclusion: Using this innovative approach has resulted in one of the largest studies of SVI/BL children to date. The findings indicate that KIs can recruit large numbers of children quickly, and that the children they recruit are more likely to be representative of all blind children in the community.

The epidemiological investigation of rare diseases is challenging; very large sample sizes are required for surveys to provide precise estimates of prevalence, and even larger samples are needed to provide reliable information on causes. These challenges apply to the epidemiological study of blindness in children, where the estimated prevalence varies from 3/10 000 to 15/10 000 children in different countries.[1]

Bangladesh is one of the poorest and most densely populated countries in the world. The country has eight special schools for blind children and 69 integrated schools (together described as SpEdu) which educate blind children alongside their sighted peers. Although national epidemiological data on the causes of blindness in children would be of value to inform policy and planning control strategies, no such data were available for the country which has over 50 million children. To address this information need, a nationwide study was carried out.[2]

We have developed a novel method for identifying children who are blind in the community, by training local volunteers to act as key informants (KIs). KIs are people who live and/or work in their local community, who have a social role through their vocation, and who are, therefore, likely to know the local context as well as the people about whom information is being sought. KI surveys have been described as an alternative to population-based studies in evaluating community-based programmes,[3] needs assessments,[4] studies of mental health[5] and AIDS programmes.[6] The aims of this paper, which uses data from the national study of blindness in children in Bangladesh,[2] are to compare the demographic details and the causes of blindness in children recruited using different methods of case ascertainment—the KI method, recruiting children from SpEdu and recruiting children from community-based rehabilitation (CBR) programmes.

SUBJECTS AND METHODS

Children aged 0–15 years with severe visual impairment or blindness (SVI/BL) were eligible for inclusion. Ethical approval was obtained from the ethics review committee of BNSB Eye Hospital in Bangladesh.

Definitions and classifications

The World Health Organization (WHO) categories of visual impairment were used[7] where SVI is defined as a presenting visual acuity of <6/60 in the better eye, and BL as a presenting visual acuity of <3/60 in the better eye.

Classification of causes

The WHO classification system[8] was used to identify (1) the main anatomical site of abnormality and (2) the main underlying aetiology of SVI/BL for each eye, and then for each child. Causes were than categorised as preventable, treatable or unavoidable. Preventable causes were conditions which could have potentially been prevented through simple health promotion, prevention and education at community and household levels. Treatable causes were conditions where surgical, medical or optical interventions could have preserved or restored sight (eg cataract surgery). Avoidable causes were the sums of treatable and preventable causes, and unavoidable causes were all those that could not have been prevented or treated.

Case ascertainment methods
Recruitment through schools (SpEdu)

Systematic attempts were made to identify all schools providing education to blind children through (1) the Resource Directory of the International Council for the Education of the Visually Impaired,[9] (2) by liaising with international and local non-governmental organisations (NGOs), and (3) records from the Ministry of Social Welfare. All eight special schools and the 69 ''resource centres'' for the integrated education of blind children in the country were visited. All children present on the day of the visit were examined by the ophthalmologist.

Recruitment from CBR programmes

All programmes catering for people with blindness were identified by networking with NGOs involved in disability or eye care, the Ministry of Social Welfare and other government departments. In addition, the study ophthalmologist also made specific inquiry during his visit to each district and through networking with local organisations to identify any other relevant local CBR programmes that had not been listed. Among the 507 subdistricts in the country, only 21 had active CBR programmes for SVI/BL children. All 21 CBR programmes in the country were visited.

Recruitment by KIs

The purpose of using KIs was to recruit blind children not enrolled in special schools. In each district, project officers identified approximately 15 local KIs during their preliminary visits. All the KIs were local volunteers and they did not receive any financial incentive. Two groups of KIs were most active and effective in this study (1) field workers and officers of the Directorate of Social Welfare of the Government of Bangladesh, and (2) field workers of various NGOs working in health, disability and social development projects at the community level. In addition, there were KIs who were school teachers, social workers, community leaders, religious leaders (Imams), local journalists and college students. In each district, the project officer, usually with support from the local administration and NGOs, organised a 1-day briefing meeting for the KIs to explain the overall purpose of the study, and why blind children were being ascertained. The KIs were shown how to measure vision in school-aged children using ''finger counting'' at 6 m. For young children, the KIs were told to observe the eyes carefully and look for any obvious abnormalities (eg, any abnormal looking eye including a white opacity in the central part of the front of the eye which could be due to a corneal scar or cataract). KIs were also encouraged to find and refer children whose mothers suspected them to have a ''serious eye or vision problem'' even if there did not appear to be anything obviously wrong with their eyes. The KIs were encouraged to network as widely as possible after the training so that children in remote rural areas would also be identified. The KIs did not give up their usual jobs and they were expected to disseminate what they had learnt during the training by talking to people they came across during their everyday activities. On the day of the training, they were also informed of the date and place where the eye examination would take place, so they could inform parents. The KIs were told that all the children they thought were blind would be examined by an ophthalmologist, and that all those who might benefit from treatment (medical, surgical or optical) would be referred to a collaborating eye hospital. After training, the KIs spent approximately 2–3 weeks in their communities, listing all children they ''suspected'' to be blind. These lists were given to the project officer who compiled a single list for each district. Approximately 800 KIs were trained throughout the country.

Eye examination and data recording procedure

A detailed description of the methods has been published previously.[2] Socio-demographic data, and ophthalmic, medical and family histories were recorded before visual acuity measurements, refraction and ophthalmic examination. All data for each child were recorded on the WHO/PBL Eye Examination Record for Children with Blindness and Low Vision, in accordance with the coding instructions.[8]

Statistical analysis

An analysis of demographic variations between children ascertained by the case ascertainment methods was conducted. Logistic regression analyses with univariate and adjusted models were used to compare the KI method of case ascertainment with ascertainment from SpEdu and from CBR programmes with respect to age, gender, division, rural/urban dwelling, visual acuity, the presence of additional impairments and the causes of SVI/BL. All tests were two sided and the results are quoted as odds ratios (OR) with CI at the 95% level.

RESULTS

A detailed description of the anatomical and aetiological causes of childhood blindness in this national study has been reported previously.[2] The majority of the 1935 BL/SVI children were recruited by KIs (n = 1245, 64.3%), followed by recruitment from SpEdu (n = 394, 20.4%) and CBR programmes (n = 296, 15.3%).

Age and gender, and visual acuity differences of the study population

The median age of the children was 132 (interquartile range (IQR) 96–168) months and, overall, there were more boys (n = 1220, 63.1%) recruited than girls. More than two-thirds of the children in the SpEdu group were aged between 11 and 15 years (n = 265, 67.26%) compared with 56.8% in the CBR group and 47.7% in the KI group. The vast majority of children aged 0–5 years were identified by KIs (247/297, 83.2%). Only 2.0% of children in the SpEdu group were aged 0–5 years, compared with 14.2% in the CBR group and 19.8% in the KI group (table 1). In the SpEdu group, 71.1% of the children were boys, compared with 60.8% in the CBR group and 61.0% in the KI group (table 1). A total of 140 children (35.23%) in SpEdu were congenitally blind compared with 112 (37.8%) in CBR programmes and 364 (29.2%) ascertained by the KIs. Children recruited by KIs had a higher proportion of SVI (9.8%) than children in the SpEdu group (4.8%). Of the children recruited from the CBR programnmes, 7.8% had SVI. A higher proportion of children with an infantile (postnatal to <1 year) age of onset of impairment was found by KIs (25.2% vs 11.7% in SpEdu).

Differences in anatomical cause and aetiology by ascertainment method are shown in table 2.

A comparison of preventable causes showed that the children in the KI group were less likely to have a preventable condition than children in the other two groups (table 2). Approximately one in four children (95% CI 23.5 to 28.5) in the KI group had a preventable condition compared with 34.5%, (95% CI 29.8 to 39.4) in the SpEdu group. The main difference in this preventable group was seen in differences in vitamin A deficiency, which was responsible for 22.8% of the poor vision in SpEdu, 18.9% in CBR and 15.7% in KI groups.

In contrast, children with treatable conditions were more likely to be identified in the KI group than by the other methods of case ascertainment. Bilateral untreated cataract was identified most commonly in the children ascertained by the KIs. Nearly one-third of the children (n = 393, 31.6%) in the KI group had BL/SVI due to untreated cataract. This compared

Table 1 Distribution by gender, age and division within the different methods of case ascertainment

	Special education n (%)	CBR n (%)	Key informants n (%)	Total n (%)
Gender p = 0.001*				
Boys	280 (71.1)	180 (60.8)	760 (61.0)	1220 (63.0)
Girls	114 (28.9)	116 (39.2)	485 (39.00)	715 (37.0)
Age (years) p = 0.001*				
0−5	8 (2.0)	42 (14.2)	247 (19.8)	297 (15.3)
6−10	121 (30.7)	86 (29.0)	168 (32.5)	611 (31.6)
11−15	265 (67.3)	168 (56.8)	594 (47.7)	1027 (53.1)
Visual acuity p = 0.008				
SVI	19 (4.8)	23 (7.8)	122 (9.8)	164 (8.5)
Blind	375 (95.2)	273 (92.2)	1123 (90.2)	1771 (91.5)
Dwelling p<0.001*				
Rural	344 (87.3)	287 (97.0)	1216 (97.7)	1847 (95.5)
Urban	50 (12.7)	9 (3.0)	29 (2.3)	88 (4.5)
Family history† p = 0.164				
Yes	91 (23.1)	76 (25.8)	259 (20.9)	426 (22.1)
No	303 (76.9)	219 (74.2)	982 (79.1)	1504 (77.9)
History of consanguinity‡ p = 0.77*				
Yes	62 (17.0)	56 (19.2)	222 (18.0)	340 (18.0)
No	302 (83.0)	235 (80.8)	1010 (82.0)	1547 (82.0)
Age of onset p<0.001*				
Congenital	139 (35.3)	112 (37.8)	361 (29.0)	612 (31.6)
Infantile§	46 (11.7)	56 (18.9)	312 (25.1)	414 (21.4)
1 to <5 years	135 (34.3)	94 (31.8)	363 (29.2)	592 (30.6)
5 to <16years	74 (18.8)	34 (11.5)	209 (16.8)	317 (16.4)
Disability p = 0.005*				
Yes	7 (1.8)	17 (5.7)	72 (5.8)	96 (5.0)
No	387 (98.2)	279 (94.3)	1173 (94.2)	1839 (95.0)
Total	394 (100)	296 (100)	1245 (100)	1935 (100)

*χ^2 test showing significant differences between the ascertainment methods in gender, age, visual acuity, dwelling, age of onset and disability. postnatal to <1 year.
CBR, community-based rehabilitation; SVI, severe visual impairment.

with 22.3% in the CBR group and 17.5% in the SpEdu children. Children who had had unsuccessful cataract surgery were equally distributed amongst the three ascertainment methods. Children ascertained by KIs were most likely to have an avoidable cause of visual loss. Unavoidable causes such as retinal dystrophies were found more commonly in the SpEdu children (14.7% in SpEdu, 10.8% in CBR and 10.7% in KI children) and congenital anomalies were least commonly found amongst the KI children (10.3% in KI, SpEdu in 12.4% and 15.5% in CBR children).

Association analysis
When comparing children in the KI group with those in the SpEdu group, there were several statistically significant findings (table 3). Differences in age of the children as well as gender, level of visual acuity, associated disability and causes were identified.

In comparing children identified in CBR programmes with those identified by KIs, again age differences were apparent. The odds of ascertaining a child 0–5 years old compared with 11–15 years old was 70% more using the KI method (95% CI 1.1 to 2.4, p = 0.007). Lens-related abnormalities had a borderline higher odds of being ascertained using the KI method (p = 0.036), resulting in a borderline significantly higher odds of ascertaining an avoidable cause using the KI method (adjusted OR 1.3 95% CI 1.0 to 1.7, p = 0.033). No other significant differences were found.

Time frame and cost of case ascertainment
Field work took approximately 1 year. The main cost included salary for four local staff, extensive local travel and subsistence for the project team, and office costs. Approximately, US$50 000 (£25 300) was incurred for case ascertainment and data collection. However, the majority of the cost would

have been incurred if only children in SpEdu had been recruited and examined. The authors estimate that 25% of the total cost and time was specifically needed for the 'add-on' KI component.

DISCUSSION
Large-scale population-based prevalence surveys would provide the most accurate data on the prevalence and causes of blindness in children. However, with a prevalence estimated to be about 8/10 000 children in Bangladesh, a very large sample (approximately 130 000 children, which would yield only 104 BL/SVI children) would be required to provide meaningful data on causes. Examination of children in SpEdu, with classification of causes using the WHO system, has been widely used to obtain data on causes, the advantage being that a relatively large number of blind children can be examined in a short period of time and at low cost.[10–25] However, data from these blind school studies are likely to be biased for the following reasons: some causes of blindness are associated with high mortality rates (eg, measles, vitamin A deficiency, meningitis, congenital rubella) and only the survivors would be in school; cultural attitudes may make parents reluctant to acknowledge that they have a disabled child, and the child remains unidentified; in some cultures blind children provide an income for the family from begging; children with multiple impairments, and pre-school age children usually cannot be catered for in special education; and, lastly, most schools are in urban areas and parents in rural areas may be reluctant to send their child far away.[26]

Some data are available from the Nordic countries which maintain registers of the blind which, due to their small populations, are likely to be reliable, certainly in terms of cause-specific incidence. Disease-specific registers (eg, for congenital anomalies), useful for studying conditions which have been

Table 2 Anatomical site of abnormality, underlying aetiology and cause by method of ascertainment (special education, community-based rehabilitation and key informant)

	SpEdu group	CBR group	KI group	Total
	n (%)	n (%)	n (%)	n (%)
Main site				
p<0.001*				
Whole globe	71(18.0)	45 (15.2)	137 (11.0)	253 (13.1)
Cornea	120 (30.5)	83 (28.0)	311 (25.0)	514 (26.6)
Lens	92 (23.4)	85 (28.7)	452 (36.3)	629 (32.5)
Uvea	5 (1.3)	7 (2.4)	26 (2.1)	38 (2.0)
Retina	65 (16.5)	33 (11.2)	147 (11.8)	245 (12.7)
Optic nerve	26 (6.4)	25 (8.5)	104 (8.4)	154 (8.0)
glaucoma	16 (4.1)	16 (5.4)	51 (4.1)	83 (4.3)
Other†	0 (0)	2 (0.7)	17 (1.4)	19 (1.0)
Total	394 (100)	296 (100)	1245 (100)	1935 (100)
Aetiology				
p=0.002*				
Hereditary	69 (17.5)	41 (13.9)	181 (14.5)	291 (15.0)
Childhood factor	151 (38.3)	86 (29.1)	356 (28.6)	593 (30.7)
Unknown	171 (43.4)	165 (55.7)	698 (56.1)	1034 (53.4)
Other‡	3 (0.8)	4 (1.4)	10 (0.8)	17 (0.9)
Total	394 (100)	296 (100)	1245 (100)	1935 (100)
Cause p=0.034*				
Preventable	136 (34.5)	78 (26.4)	323 (25.9)	537 (27.8)
Treatable	124 (31.5)	114 (38.5)	563 (45.2)	801 (41.4)
Unavoidable	134 (34.0)	104 (35.1)	359 (28.8)	597 (30.9)
Total	394 (100)	296 (100)	1245(100)	1935 (100)

*Pearson χ^2 test showing significant differences in site of abnormality, underlying aetiology and cause in the different case ascertainment methods.
†Includes children that had either no anatomical abnormality (n = 14) or no anterior segment abnormality, but the posterior segment was not examined (n = 5) because the child was too young, uncooperativeor or had multiple disabilities.
‡Perinatal, intrauterine.
CBR, community-based rehabilitation; KI, key informant; SpEdu, special education.

Table 3 Analysis of likelihood of ascertaining children with blindness and severe visual impairment in Bangladesh in 2001: comparison of case ascertainment by the key informant method with recruitment through specialised schools for blind children (n = 1639)

	Univariate analysis OR (CI)	Adjusted for age and gender OR (CI)	p Value
Age group			
11–15	1 (1)	1 (1)	
6–10	1.5 (1.2 to 1.9)	1.5 (1.2 to 2.0)*	0.001
0–5	13.8 (6.7 to 28.3)	14.1 (6.9 to 28.9)*	<0.001
Gender			
Boys	1 (1)	1 (1)	
Girls	1.6 (1.2 to 2.0)	1.6 (1.3 to 2.1)†	<0.001
Dwelling			
Urban	1 (1)	1 (1)	
Rural	6.1 (3.8 to 9.8)	5.9 (3.6 to 9.7)	<0.001
Visual acuity			
Blind	1 (1)	1 (1)	
SVI	2.1 (1.3 to 3.5)	2.5 (1.4 to 4.2)	<0.001
Additional impairment			
No	1 (1)	1 (1)	
Yes	3.4 (1.6 to 7.4)	3.1 (1.4 to 7.0)	0.005
Onset of visual loss			
Congenital	1 (1)	1 (1)	
Infantile‡	2.6 (1.8 to 3.8)	2.5 (1.7 to 3.7)	<0.001
≥1 year to <5 years	1.0 (0.8 to 1.4)	1.2 (0.9 to 1.6)	0.220
≥5 years	1.1 (0.8 to 1.5)	1.6 (1.2 to 2.3)	0.004
Cause: lens			
Non-lens	1 (1)	1 (1)	
Lens	1.2 (1.1 to 1.3)	1.2 (1.1 to 1.3)	<0.001
Cause: cornea			
Non-cornea	1 (1)	1 (1)	
Cornea	0.9 (0.8 to 1.0)	1.0 (0.8 to 1.1)	0.448
Preventable			
No	1 (1)	1 (1)	
Yes	0.7 (0.5 to 0.9)	0.8 (0.6 to 1.0)	0.09
Treatable			
No	1 (1)	1 (1)	1
Yes	1.3 (1.2 to 1.5)	1.3 (1.1 to 1.4)	<0.001
Avoidable			
No	1 (1)	1 (1)	1
Yes	1.3 (1 to 1.6)	1.4 (1.1 to 1.7)	0.015

*Sex adjusted; †age adjusted; ‡postnatal to <1 year of age.
SVI, severe visual impairment.

defined structurally, are less useful where the condition of interest is defined functionally (eg, visual loss). These registers, even in developed countries, are subject to under-reporting.[27] There are also studies of blind children ascertained through CBR programmes in India[28] and through active national surveillance schemes.[29][30] However, in developing countries, where a large proportion of the rural population do not have access to specialised health services and referral linkages are not effective, national surveillance may prove to be more difficult to establish, exposing the system to underascertainment.

Using this innovative approach has resulted in one of the largest studies of blind children to date. This study also has the largest number of SVI/BL children recruited directly from the community, with almost two-thirds being ascertained by KIs, and these children would have been missed if more usual methods of case ascertainment had been used. Only 21 CBR programmes were active in Bangladesh, (there were no CBR programmes in Barisal, Khulna and Sylhet divisions) which emphasises the difficulty of community recruitment and yet highlights the success of the local volunteer acting with local knowledge and training. Recruitment of children for the study was done in a relatively short time period, with a small field team and without much additional cost.

There were some clear differences between the groups of children depending on how they were ascertained. Children identified by KIs were more likely to be younger, to have an equal gender distribution, to have multiple impairments and to be from rural areas. Children were also more likely to be

severely visually impaired rather than blind, which provides an opportunity for eye care programmes to employ KIs to find children early, before their sight deteriorates further and while the prognosis for sight-restoring surgery is good. A comparison of avoidable causes also reveals that significantly more children with avoidable causes were identified using the KI method than with either the SpEdu or the CBR methods (OR 1.6, p = 0.001 and OR 1.51, p = 0.031, respectively).

As no population-based studies have been undertaken anywhere which are large enough to determine the distribution of blindness in children by age, sex, place of residence and cause, one can only speculate how closely case ascertainment using KIs approaches the "truth" in the population. This is a complex area: many children are born blind from congenital anomalies, some of which are life threatening (eg, congenital rubella). In developing countries, the most common age for children who were born sighted to become blind is from approximately 6 months to 5 years, when they are susceptible to vitamin A deficiency, measles, malaria, meningitis and other acquired conditions which potentially cause blindness. Many of these incident cases of blindness will die, due to complications of the condition causing blindness, or from inadequate medical care, or possibly from neglect. Acquired blindness beyond the age of 5 years is relatively unusual. Taken as a whole, one

would therefore expect the age distribution to increase from birth until the age of 5, and then stay relatively stable thereafter.

Although some conditions are more common in boys than in girls (eg, X-linked retinitis pigmentosa and ocular albinism), these conditions are rare. One would therefore expect approximately equal numbers of boys and girls to be blind, unless there are gender differences in accessing services and a different mortality rate by gender. The finding that, comparatively, more girls than boys were recruited by KIs illustrates that parents may be more willing to acknowledge the presence of a blind female child, or to take a blind girl for assessment if facilities are provided locally, without charge and with the support of a respected local person.

One would also expect a higher prevalence, and different causes, in children from rural communities compared with children living in urban areas. The latter are less likely to be vitamin A deficient (apart from slum populations), more likely to have had measles immunisation, and, as there is better access to eye care services, children in urban areas may be less likely to be blind from treatable conditions. One would therefore expect a higher prevalence of blindness in rural areas, and a greater proportion of rural children to be blind from preventable and treatable causes. In developing countries, one would also anticipate more children to come from rural than urban areas relative to the population distribution, with children from rural areas being more likely to suffer from avoidable causes. The data presented in this study suggest that the KI method of ascertaining blind children may come closer to this speculative "truth." However, further studies are needed to validate the KI approach—for example, by comparing the findings either with those of a house to house survey of all children or with those of a random sample survey.

In societies that have gender inequality, as in Bangladesh, the primary caregiver for the child is typically the mother or grandmother. As the majority of KIs recruited in our study were men, there was potential for incomplete ascertainment. There was also some variation in the effectiveness of the KI method in different districts, which was due to the varying level of commitment to volunteering. Lack of cheap transport and long travel times were other challenges faced by the KIs. Before implementation of any method that has potential to generate a large number of cases, it is essential to establish watertight referral systems to paediatric care centres and to set up financial structures that can cover the expenses of eye treatments.

The success of the KI method lies in their knowledge and use of active social networks (contacts among government and NGO staff and local leaders, etc), and with suitable training we found that KIs were very capable of limiting the number of false-positive referrals. The KI method can also be extended to case ascertainment of children with other impairments or conditions (eg, hearing and speech impairments, epilepsy) which can be recognised by community members. It is hoped that KIs can be empowered to reduce social stigma, increase awareness and improve health seeking-behaviour among community members.

This novel method has the potential to identify the "difficult to reach" in developing countries, providing a mechanism for delivering services as well as providing population-based estimates of rare diseases and disability.

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