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Infectious Causes of Childhood Disability: Results from a Pilot Study in Rural Bangladesh

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Summary

Purpose: To identify the contribution of infectious aetiologies to major childhood disabilities in Bangladesh.
Methods: Active community-based survey was conducted for severe childhood disability using the Key Informants Method between September 2011 and March 2012 in a rural sub-district of Bangladesh.
Results: We screened 1069 children and identified 859 with severe disabilities. The mean age of the disabled children was 8.5 year and 42.9% were girls. The major forms of impairments/conditions were cerebral palsy ($n = 324$, 37.7%), hearing impairment ($n = 201$, 23.4%), physical impairment ($n = 147$, 17.1%), visual impairment ($n = 49$, 5.7%), cerebral palsy with epilepsy ($n = 39$, 4.5%) and epilepsy ($n = 41$, 4.7%). Congenital rubella syndrome was identified in 1.1% ($n = 9$). 7.1% disabilities resulted from clinically confirmed infections, and another 10.8% originated from probable infections; thus a total of 17.9% disabilities were related to an infectious origin.
Conclusions: Infectious diseases appear to be one of the major causes of severe childhood disability in rural Bangladesh.

Key words: Disability, infection, key informants method, Bangladesh.

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Introduction

According to the World Health Organization (WHO), there are over one billion people with disabilities in the world, of whom between 110 and 190 million experience significant difficulty.[1] However, reliable data on the prevalence of disability is lacking for most developing countries. Often, there are discrepancies between government estimates and surveys carried out by non-government agencies. For example in Bangladesh, government surveys show that 1.6% of the population are disabled while non-government surveys puts this estimate at ~9%.[2] Clearly, the magnitude of disability may be grossly underestimated.[3] As the WHO world report on disability contends that we need 'robust evidence helps to make well-informed decisions about disability policies and programmes' and understanding the numbers of children with disabilities and their circumstances 'can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate'.[1]

Global data suggest that infection is a leading cause of chronic, developmental disability in children.[4] A systematic review on childhood disability in low and middle-income countries suggests that the commonest causes of hearing impairment (the most frequently studied disability) are meningitis, measles and congenital rubella.[5] Infections are also prominent among the underlying causes of other disabilities including intellectual impairment.[5]

Infections also contribute to disability during early childhood. For example, one of the common causes of hearing impairment in developing countries is due to chronic suppurative otitis media (CSOM).[6] Moreover, other childhood infections including, inter alia, congenital rubella syndrome, and pneumococcal, meningococcal and *Haemophilus influenzae* type b (Hib) meningitis/sepsis can lead to disability: all of these are potentially preventable by vaccines. However, systematic studies to identify each infectious cause and their contribution to total disease, economic and other burdens in disability are lacking.

Characterizing both the aetiology and the impact of disability are important steps toward limiting or preventing long-term disability. Determining the causes of disability provides an opportunity to identify aetiologies amenable to early treatment and or prevention (e.g. by vaccination). Unfortunately, reliable data on the causes of disability in resource poor countries, including Bangladesh, are limited.

Research on the preventable infectious causes of childhood disability may provide a realistic hope to bring about an appreciable change in the overall prevalence of disability. In this pilot study we aimed to evaluate the capacity of a sensitive method called Key Informants Method (KIM) to identify infectious causes of severe disabilities among Bangladeshi children. KIM is a novel method for identifying disabled children in the community. It involves 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 are being sought.[7] Validation study of the KIM to identify children with disabilities showed that KIM was highly sensitive (~98%) in detecting children with visual impairment, hearing impairment, physical impairments and epilepsy. KIM is considered as an effective and low-cost method to identify children with disability in a low-income setting.[8]

Methods

An active community-based survey for severe childhood disability conducted from September 2011 until March 2012 using KIM. Children aged <18 years were included in the study in a rural sub-district of Bangladesh (Shahjadpur) with a child population of 189 203.

Definitions and classifications

Clinical definitions. We classified children using major disability categories (e.g. visual impairment, hearing impairment, epilepsy, cerebral palsy and physical impairment) according to the International Classification of Functioning, Disability and Health (ICF).[9] WHO categories of visual impairment were used, where severe visual impairment (SVI) is defined as a presenting visual acuity of <6/60 in the better eye, and blindness (BL) as visual acuity of <3/60 in the better eye.[10] Hearing impairment was defined as a deficit above 30 decibel (dB) in both ears. Diagnosis of epilepsy was based on the history of tonic–clonic seizures. In consultation with a Paediatric Neurologist, active epilepsy was considered in those who had one or more unprovoked seizures in the previous 3 months. Cerebral palsy (CP) was defined as 'a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour and/or by a seizure disorder'.[11] Physical impairment was defined as a dysfunction of the musculoskeletal and/or neurological body systems that affects the functional ability of the child to move or coordinate movement. Disabling physical impairment was identified as those with significant (moderate/severe) disability of 6 months duration (or from birth if younger), affecting function such that the child was not able to easily perform one or more of the Washington Group short set of daily activities.[12]

Determining the probability of an infectious aetiology for the presenting disability was based on clinical history and examination findings. In addition, hospital discharge records were reviewed where available. A validated clinical case definition (e.g. WHO or CDC, definition of an infectious condition) was used to identify an infectious syndrome.[13,14] A confirmed infectious cause was considered when there was sufficient clinical history (including previous medical records) and examination findings to suggest that the particular disability/impairment had a causal relation to a particular infection (e.g. disability from polio, post meningitis, encephalitis sequelae, hearing impairment from CSOM). For example, the WHO case definition for a clinically confirmed case of congenital rubella syndrome (CRS) was applied, which requires fulfilment of $\geq$ two major criteria or one major and $\geq$ one minor criteria, in the absence of any other obvious cause (major criteria: sensorineural hearing impairment, congenital heart disease, pigmentary retinopathy, cataract, congenital glaucoma. Minor criteria: purpura, splenomegaly, microcephaly, developmental delay, meningoencephalitits, radiolucent bone disease, jaundice with onset within 24 h of birth).[15] A probable infectious cause was an estimate based on the published literature for any particular group of disability/impairment. The probable cases do not have sufficient information to establish a causal relationship.

Case ascertainment

KIM survey. Details on KIM survey have been described in an earlier validation study.[8] For this study, two trained community mobilizers (CMs) identified KIs in the study area who were then trained on common childhood disabilities in a day-long workshop. After the initial training, KIs were given 4–6 weeks to find and list children with the specific impairments in their local community and were informed of the date and venue of the KIM medical assessment 'camps'. During the study period, approximately 180 KIs were trained in the study area (about one per village) and their participation was voluntary without material reward throughout the process.

Medical assessment camps
We conducted eight medical assessment camps. The specialized medical assessment team comprised two paediatricians, an ophthalmologist, an otolaryngologist, an audiometrist, a physiotherapist and a counsellor. Each assessment camp usually lasted 2 days. Team members were trained in using standardized data collection forms. All the children referred by the KIs were examined to assess their physical condition and diagnose any specific physical disability. Families were provided appropriate advice, information and counselling and referral services. Retrospective diagnosis of the infectious aetiologies was based on a set of clinical and laboratory criteria obtained by detailed history (including antenatal, peri-natal and postnatal history) and examination.

Data instruments and statistical analysis
The clinical history and examination form was the principal data collection instrument, consisting of demographic details, income category, parent's perception of impairment, activity limitations, school attendance, rehabilitation, clinical history and examination findings followed by referral recommendations. Data analysis was done using the Statistical Package for the Social Sciences (IBM SPSS Statistics 19 INC, Somers, NY).

Ethics approval
This study was approved by the Bangladesh Medical Research Council (BMRC) ethics committee (BMRC reference number BMRC/ERC/2007-2010/728).

Results

In total, 1069 children were examined of which 859 (80.3%) were diagnosed with severe disabilities. The mean age of the disabled children was 8.5 years (median 8 years; ranged 1 month to 18 years) and 42.9% (369) were girls.

The major form of impairments/conditions were cerebral palsy 37.7% (324), hearing impairment 23.4% (201), physical impairment 17.1% (147), visual impairment 5.7% (49), epilepsy 4.8% (41), cerebral palsy with epilepsy 4.5% (39), cerebral palsy with hearing impairment 3.7% (32), cerebral palsy with visual impairment 1.5% (13) and CRS 1.1% (9); see Table 1.

We found that 7.1% (61) disabilities resulted from clinically confirmed infections, and another 10.8% (93) originated from probable infections thus a total of 154 (17.9%) children with disabilities are thought to have an infectious origin.

Over one-third of children with hearing impairment (35.8%) and 6.1% of the visually impaired children had an infectious aetiology. Tables 1 and 2 shows major groups of disabilities and their infectious aetiologies.

Among the disabled children, 4.9% (42) had significant diseases during pregnancy and 17.8% (153) had their onset of disability at <12 months of age. An acute illness was considered as the apparent cause of disability by the family in 19.5% (168) of the children.

Most of the disabled children were from poor families, 72.7% (625) had a monthly family income of less than US$65 (<5000 Bangladeshi Taka).

TABLE 1
Causes of disabilities and infectious aetiologies

Impairments/disease	Total	Clinically confirmed infectious causes	Probable infectious causes[a]
Cerebral palsy	**324**	–	24
Cerebral palsy with epilepsy	**39**	–	10
Cerebral palsy, epilepsy, visual and/or hearing impairment	**4**	–	1
Cerebral palsy with hearing impairment	**32**	–	8
Cerebral palsy with visual impairment	**13**	–	3
Epilepsy	**41**	–	10
Hearing impairment	**201**	41	31
• Chronic suppurative otitis media (CSOM)	41	41	–
• Congenital bilateral hearing impairment	155	–	31
• Other (e.g. Conductive hearing loss)	5	–	–
Congenital Rubella Syndrome	**9**	9	–
• Congenital heart disease with congenital hearing impairment	1	1	–
• Congenital hearing impairment with congenital cataract	7	7	–
• Congenital heart disease with congenital cataract	1	1	–
Visual impairment	**49**	3	–
• Congenital cataract/pseudo/aphakia	3	–	–
• Corneal opacity	15	3	–
• Refractive error	21	–	–
• Microphthalmos/anophthalmos	3	–	–
• Other (e.g. Glaucoma, optic atrophy, retinal dystrophy)	7	–	–
Physical impairment	**147**	8	6
• Microcephaly/Congenital infections (2 with movement disorder, 2 with delayed speech and one each with intellectual disability and xerophthalmia)	6	–	6
• Post meningitis/encephalitis sequelae (all with difficulty walking, limb weakness and one with bilateral hearing impairment)	4	4	–
• Post polio sequelae	4	4	–
• Club foot	22	–	–
• Cleft lip/palate	11	–	–
• Trauma/burn	13	–	–
• Erb's palsy/Birth trauma	29	–	–
• Other congenital deformity	21	–	–
• Other (e.g. Hydrocephalus, scoliosis)	37	–	–

[a]Estimation based on published literature (7.5% of cerebral palsy, 25% of cerebral palsy with either epilepsy, hearing or visual impairment, 25% of epilepsy and 20% of those with congenital bilateral hearing impairment are estimated to have an infectious cause).

Interestingly 74.1% (639) of the families had a mobile phone.

Only 21.1% (182) of the disabled children were attending regular schools and just 0.2% (2) were attending special schools. Among the fathers of the disabled children, 36.7% (315) were illiterate and only 22.5% (194) completed primary or higher education. Among the mothers of the disabled children, 33.6% (289) were illiterate and only 22.6% (195) finished primary or higher education.

Discussion

We present pilot data from a childhood disability study in a rural subdistrict of Bangladesh that includes data on probable infectious aetiologies, based on history, clinical findings and with estimates. There are limited contemporary data on the contribution of infectious aetiologies to major childhood disabilities at the community level.

Our study shows that about one in six (17.9%) disabled children may have an infectious cause, and

TABLE 2
Major groups of disabilities and infectious aetiologies

Impairments/disease	Total	Clinically confirmed infectious causes (n)	Probable infectious causes (n)	Total infectious causes (n)	Total infectious causes (%)
Cerebral palsy	324	–	24[a]	24	7.4[a]
Cerebral palsy with epilepsy	39	–	10[a]	10	25.6[a]
Cerebral palsy, epilepsy, visual and/or hearing impairment	4	–	1[a]	1	25.0[a]
Cerebral palsy with hearing impairment	32	–	8[a]	8	25.0[a]
Cerebral palsy with visual impairment	13	–	3[a]	3	25.0[a]
Epilepsy	41	–	10[a]	10	25.0[a]
Hearing impairment	201	41	31[a]	72	35.8
Congenital Rubella Syndrome	9	9	–	9	100.0
Visual impairment	49	3	–	3	6.1
Physical impairment	147	8	6	14	9.5
Total	859	61	93	154	17.9

[a]Estimates based on published literature.

most of those causes are vaccine preventable. Through our study we have identified nine clinically confirmed CRS cases from a small geographical area (i.e. subdistrict) in Bangladesh. Global estimates of the burden of rubella suggest that the number of infants born with CRS in 2008 exceeded 110 000 which make rubella a leading cause of preventable congenital defects.[16] Interestingly, WHO CRS surveillance in Bangladesh did not report any CRS case from the country in the last decade, despite a high prevalence of rubella in this region. Among the WHO member states, Bangladesh was fourth by number of reported rubella cases (3245 confirmed cases) in 2012 and second two years running in 2009 (13 076) and 2010 (12 963).[17] Routine rubella immunization has been implemented in Bangladesh since September 2012. However, there is a strong need for sustaining routine immunization programmes and supplemental immunization activities including targeted campaigns for women of child bearing age to achieve high rubella vaccination coverage (≥80%).[18] It is also important to evaluate the current CRS burden in Bangladesh and the outcome of routine rubella immunization.

Our study identified four disabled children as a consequence of polio infection. However, all were aged ≥13 years. This reflects the likely success of the polio eradication program in Bangladesh in recent years.[19]

We have identified a large number of children disabled with cerebral palsy along with epilepsy and other major impairments (e.g. cerebral palsy with visual or hearing impairments). We could not retrospectively identify the infectious aetiology of cerebral palsy and epilepsy from history and clinical examination. The published literature suggests an infectious aetiology in 7.5% and 25%, respectively.[20–23] However, we contend that these estimates are conservative as intrauterine and perinatal infections play a major role in cerebral palsy and epilepsy-related disabilities.[24,25]

The relationship between poverty and infection is well recognized.[26] In our study we found that 72.7% of the disabled children had a monthly family income of <US$65. According to the UNICEF, in Bangladesh, 43% of the population were below the international poverty line (US$1.25 per day) during 2006–11.[27] A World Bank estimate shows that poverty headcount ratio at national poverty line for rural people in Bangladesh was 35.2% in 2010.[28] However, we found that this rate is almost double in those families with a disabled child. This is a worrying reflection of the vicious cycle of poverty, infection and disability.[26]

Interestingly, almost three-quarters of those families with disabled children had an active mobile phone. Mobile phones have been considered as an important tool in the advancement of both rural communication and the economy in Bangladesh.[29] A recent survey in Bangladesh showed that 73% of Bangladesh's rural households use mobile phones.[30] This could be an important tool in public health communications, education and disease surveillance in Bangladesh, especially as a reminder for vaccinations.[31]

It is estimated that >90% of children with disabilities in developing countries do not attend school.[32] Our study shows that only one in five (21.1%) disabled children attend the mainstream schools and just 1 in 500 (0.2%) attend special schools. According to UNICEF, primary school net attendance ratio in rural Bangladesh was 86% in 2006–11 when the adult literacy rate was 57%.[27] However, among the parents of the disabled children in our study, only 22.5% of the fathers and 22.6% of the mothers have completed primary or higher education. This also highlights the social inequity and relative lack of opportunity of the children and their families with a major disability.

Despite considerable effort, this study has several limitations. Our diagnosis is based on history and clinical examination. Many of the children's had multiple conditions/impairments and at times it was difficult to classify them in major groups. In this pilot study we have not done any serological tests for infectious aetiologies. Our reported proportion of infectious causes of childhood disability is, however, most likely an underestimation. During this pilot study it was not possible for us to collect a detailed immunization history of these children. Comprehensive information and measurement of their nutritional status and concurrent infections were not collected either. This pilot study gave us some valuable insights. Innovative approaches like testing for viral DNA (e.g. cytomegalovirus) in dried blood spot and using an oral swab for rubella antibody testing could be useful in this setting to confirm the infectious aetiology. The WHO guidelines for CRS surveillance among visually and hearing impaired children will also increase early diagnosis and treatment. More studies are needed addressing the limitations of the current study.

Conclusions

Infectious diseases are a major cause of severe disability in rural Bangladesh. Most of the families with a disabled child are living below the poverty line. Infectious diseases play an important role in the cycle of poverty, diseases and disability. Further population-based studies are needed to explore the effective interventions and preventive measure to reduce the burden of childhood disabilities in developing parts of the world. Targeted interventions are necessary to alleviate the barriers to rehabilitative services and maximize their opportunities to healthy living.

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