

# Mortality of urban and rural young children with cerebral palsy in Bangladesh

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Bangladesh has a high child mortality rate. However, little is known about the outcome for young children who have cerebral palsy (CP). Ninety-two children with CP with a mean age of 3 years 3 months at entry into the study were followed for up to 3 years as part of an intervention study. Eight children died: two of 49 (4%) from an urban area and six of 43 (14%) from a rural area. Extrinsic factors such as infections and drug reactions preceded all the deaths, but those who died were mostly severely malnourished and among the more severely disabled of the total group. Eighty-nine percent of rural children in the study were from low-income families. Intervention programmes for severely disabled children in developing countries must include primary health care and feeding programmes as well as rehabilitation services to address both the needs of the child and empowerment of the mother and the family.

Most children with disabilities live in developing countries. A large epidemiological study of children with disabilities aged 2 to 9 years in Bangladesh indicated a prevalence rate of 6.8% for all grades and types of disabilities (motor, vision, hearing, cognition, and epilepsy) and of 1.5% for serious disabilities (Khan and Durkin 1995). Little is known about the long-term survival and death rates of children with disabilities. This paper considers the death rate in young children with cerebral palsy (CP) who were followed for up to 3 years.

With a total population of over 120 million in Bangladesh, 55.9% of whom are less than 18 years of age (UNICEF 1998), vast numbers of disabled children remain unaccounted for in the health and educational sectors. However, there are indications of positive change: a slow but steady reduction in child mortality rates (e.g. 247 per 1000 in 1960 to 112 per 1000 in 1996); diminishing family sizes; and increasing numbers of children being brought to child development and neurodisability services in hospitals and community clinics (Khan 1998).

Bangladesh is a tropical country where 81% of the population live in rural areas and survive on agriculture. This rural population has very limited access to disability services, most of which are concentrated in the capital, Dhaka. Mothers of rural-based children seem to be more stressed than their urban counterparts (McConachie et al. 1998). Yet within rural communities disabled people often find a fruitful niche for themselves which is not stigmatizing (Kisanji 1995). In Bangladesh in 1988, in the extreme circumstances of a very severe flood, no difference was found after 5 months between children with and without disabilities in mortality or morbidity in rural areas (Durkin et al. 1993). Notably, it is in the urban-slum population of developing countries where children are subjected to the most inhuman living conditions (Khan 1997). If equitable services are to be developed making the best use of limited resources, death and survival of children with disabilities in both urban and rural communities have to be understood.

The Bangladesh Protibondhi Foundation (BPF) ('protibondhi' means disabled in Bengali) has developed neurodisability clinics, special education schools, home-based therapy manuals, and community-based rehabilitation services in Bangladesh since 1984. It runs two centres, one urban and the other rural. The urban programmes are within Dhaka. The rural programmes are in Dhamrai, 50 km north of Dhaka, where the main source of income is from cultivation of agricultural land; 90% of houses have straw or bamboo roofing material. Child development clinics in both centres are run by a group of professionals including paediatricians, psychologists, and therapists aided by community health workers.

A prospective study of children with CP was conducted by the BPF in both urban and rural populations between 1993 and 1995 to evaluate the functional outcomes of therapy and health interventions. During the course of the study a number of children died. In this paper the various demographic and clinical features of the original study population are presented together with descriptions of the subset of children who died. The objective of the study is to ascertain the natural history of CP among urban and rural populations of young children in Bangladesh, so that long-term survival strategies can be developed and integrated within ongoing and future services.

## Method

### CHILDREN

Ninety-two children aged between 1 year 4 months (16 months) and 5 years 7 months (67 months) with CP were followed for up to 3 years from both the urban (49 children) and rural (43 children) centres of the BPF. The children were enrolled consecutively as their parents sought disability services, over a period of 1 year. Those with overt visual or hearing disability were excluded. It was possible to obtain a complete follow-up of the 92 children because health and therapy services were offered, and thus families were contacted by the research team from time to time. The different services children received included primary health care offered to the whole family; involvement in a stimulation group with their mothers, held daily (urban) or weekly (rural) in speech, occupational and physiotherapy; or training of their mothers to use at home a pictorial manual giving advice on positioning, daily living activities, and language stimulation. Evaluation of the comparative outcomes of intervention is in preparation.

### MEASURES

Average family income was determined by taking into account monthly wages earned and also production of crops and their selling value. A monthly income of less than taka (Tk) 4000 (1US\$=Tk45 approximately) was categorized as 'low'; a monthly income of Tk4000 to 8000 was categorized as 'middle'; and a monthly income of more than Tk8000 was categorized as 'high'. The gross national product (GNP) per capita of Bangladesh is Tk9900 (US\$220), but as more than three-quarters of the population live below the poverty line and the cost of living is low, a lower banding of income was used.

Comprehensive neurodevelopmental assessments were done by paediatricians for all 92 children. These included a history of the chief complaints or worries the care-provider had concerning the child, birth history, family history, milestones of development, functional observation, general physical and neurological examination, and examination of

vision and hearing. The Medical Assessment Form, which has been standardized in Bangladesh for an epidemiological survey of childhood disability, was used for this purpose (Zaman 1990, WHO 1992). CP was classified into the following types: tetraplegia, diplegia, hemiplegia, dyskinetic CP, ataxic CP, and miscellaneous (Neville 1993). A summary sheet was used to record the main impairments and level of disability in gross motor, fine motor, vision, hearing, speech and cognitive functions, and seizure disorders. A modified version of the WHO criterion of recording impairments and disabilities, and grading severity of each type of disability was used (WHO 1981). Disability was graded into mild, moderate, and severe categories.

Adaptive behaviour was tested in every child by one psychologist using the Independent Behaviour Assessment Scale (IBAS) (Munir 1987). This test was developed and standardized within Bangladesh for children from both urban and rural populations, taking into account cultural norms and practices in both settings as well as sex differences. The strength of the test lies in describing the abilities of children even if they are not enrolled within a formal educational system or exposed to any formal preschool activities. Each child was assigned scores in four categories: gross and fine motor functions, communication skills, socialization skills, and daily living activities. Subscores and total score were calculated and age-matched with locally developed norms into five functional grades: high, moderately high, average, moderately low, and low. An average score suggested age-appropriate adaptive behaviour.

Nutritional status was ascertained by calculating weight-for-age *z* scores for the children and comparing them with those of the US National Health Center for Health Statistics reference population (NCHS growth charts 1976). Mild, moderate, and severe grades of malnutrition were recorded.

### PROCEDURES

All mothers whose children died during the course of the study were interviewed by a paediatrician either at the centres or in the child's home (1 child only). One mother spontaneously informed the centre. Others were brought to the centre by a community health worker.

All data records were precoded and entered into the D-base 3-plus software program (Ashton Tate 1986).

## Results

Mean age at entry into the study was 3 years 3 months, with the mean age at enrolment in the rural group being significantly higher ( $t=2.98$ ,  $P=0.004$ ) (Table I) than in the urban group. The male:female ratio was 2.3:1 for the total population in both urban and rural groups. Most children (70%) in the total study population were from low-income families. In the urban group a substantial number (47%) came from middle and high-income families, whereas the majority in the rural group (89%) were from low-income families. Furthermore, within the low-income group, 16% (8 children) of urban and 58% (22 children) of rural families were very poor, i.e. with incomes of less than Tk2000 per month. Most rural mothers had no literacy skills (58%) compared with the urban mothers (21%). Of the substantial number of urban mothers who had attended more than basic secondary school (36%), about 10 (20%) were college graduates.

The two largest categories of CP diagnosed among the 92

**Table I: Total study population by age, sex, socioeconomic status, and mother's education in rural and urban areas of residence**

	Urban <i>N</i> =49	Rural <i>N</i> =43	Total <i>N</i> =92
Mean age (y:mo)	2:11	3:7	3:3
(range)	(1:4 - 4:7)	(1:11 - 5:7)	
Sex			
Males (%)	34 (69)	30 (70)	64 (70)
Females (%)	15 (31)	13 (30)	28 (30)
Socioeconomic status			
Low income (%)	26 (53)	38 (89)	64 (70)
Middle income (%)	15 (31)	4 (9)	19 (20)
High income (%)	8 (16)	1 (2)	9 (10)
Mother's education			
Non-literate (%)	10 (21)	25 (58)	35 (38)
Primary school (%)	15 (31)	14 (33)	29 (31)
Secondary school (%)	6 (12)	3 (7)	9 (10)
>Secondary school (%)	18 (36)	1 (2)	19 (21)

study children were diplegia and tetraplegia (Table II). In the urban population, tetraplegia was the single largest category diagnosed, while in the rural population the largest category was diplegia. Hemiplegia was seen almost equally in both urban and rural groups, as was dyskinetic CP. Within the dyskinetic group the diagnostic subcategories were: (1) in the urban population – two children with choreoathetoid CP, one with athetoid CP, and one with dystonic CP; and (2) in the rural population – one child with choreoathetoid CP, and one with athetoid CP. No child was diagnosed with ataxic CP. The child classified with 'miscellaneous' CP was a boy aged 2 years 3 months with poor head control who was unable to sit with support and had brisk deep tendon reflexes.

Most children (83%) scored poorly on the total score of the IBAS, i.e. adaptive skills. Urban children were more likely to have a low level of adaptive skills than rural children. A substantial proportion of children had an average or above average score in the subcategory of communication skills within the IBAS, i.e. 31% and 37% in the urban and rural groups respectively, indicating the possibility of relatively good intellectual function.

Epilepsy was seen in 16% of the study population. Generalized tonic-clonic epilepsy was most common. The incidence of seizures was almost equally distributed between urban and rural groups.

The number of children with a severe degree of malnutrition was more than twice as great among the rural children (58%) as among the urban children (27%). The urban group also had a larger proportion of children with moderate and mild degrees of malnutrition compared with their rural counterparts. Overall, 93% of children were defined as malnourished in comparison with the US norms.

#### CHILDREN WHO DIED

A total of eight study children died during the 2 years of the study (Table III). Of these, two children (subjects 1 and 2) were from the urban group and six children (subjects 3 to 8) from the rural group. Thus, case fatality for the urban group was 4%, and 14% for the rural group. The median interval between the first contact with the disability service and death was 7 months (range 4 months to 10 months). Most deaths occurred in children with severe disabilities with tetraplegia with low adaptive functioning. Seven children had a severe degree of motor disability, while in the whole study group of 92 children only 48% were severely affected. Only one of the children who died had an average level of communication skills. Most (6 of 8) had a severe degree of malnutrition. Almost all children (7 of 8) came from low-income families.

Extrinsic factors such as infections and drug reactions seemed to precede all the deaths (Table III). Diarrhoea had occurred in half the children. One of them (subject 2) had been undergoing treatment for tuberculosis, and succumbed to infectious diarrhoea. Convulsions preceded three deaths (subjects 6, 7, and 8) accompanied by high fever in two, and by severe convulsions and loss of consciousness in one. Paracetamol poisoning was implicated as the probable cause of death in one child (subject 1). This occurred at a time when children had been dying from renal failure after ingestion of paracetamol syrup due to presence of a toxic diluent (Hanif 1995). The child died within 72 hours of ingestion of paracetamol syrup (taken for mild fever), and

without any previous history of kidney problems. Similarly, subject 5 died after a few days of taking cotrimoxazole, demonstrating all features of Stevens-Johnsons syndrome (Schaller and Wedgewood 1983).

Most mothers were non-literate (6 of 8). However, the mother of subject 1 – the child who died from probable paracetamol poisoning, i.e. an incidental cause of death – had graduated from secondary school. Only one other mother (the mother of subject 6) had some education (i.e. primary school). Her son had severe athetoid CP, was low functioning, and malnourished and from a very poor family. He died after an episode of severe convulsions.

There were no reports of sibling deaths among the children who died. There were also no reports of sibling deaths among the surviving children.

#### Discussion

In developing countries, the mortality rates of children before the age of 5 years are still unacceptably high. Some gains have been made in Bangladesh: under-5 mortality rates have been declining, i.e. from 185 per 1000 in 1989 to 115 per 1000 in 1995 (UNICEF 1991, UNICEF 1998). This speaks favourably for the country's primary health care services. Paradoxically, the average calorie intake of the population has declined from 1940 kcal per day in 1988 to 1860 kcal per day in 1996 (Jahan 1996). In these situations, it is expected that many children with severe disabilities will succumb.

**Table II: Types of cerebral palsy, levels of adaptive behaviour, associated epilepsy, and degree of malnutrition of the total study population in urban and rural areas of residence**

	Urban N (%)	Rural N (%)	Total N (%)
<b>Types of CP</b>			
Diplegia	18 (37)	22 (51)	40 (44)
Tetraplegia	21 (43)	16 (37)	37 (40)
Hemiplegia	5 (10)	3 (7)	8 (9)
Dyskinetic	4 (8)	2 (5)	6 (6)
Miscellaneous	1 (2)	0 (0)	1 (1)
Total	49 (100)	43 (100)	92 (100)
<b>Levels of adaptive behaviour</b>			
Low	44 (90)	32 (74)	76 (83)
Moderately low	2 (4)	9 (21)	11 (12)
Average	3 (6)	2 (5)	5 (5)
Moderately high	–	–	–
High	–	–	–
Total	49 (100)	43 (100)	92 (100)
<b>Epilepsy</b>			
None	40 (82)	37 (87)	77 (84)
Generalized tonic-clonic	5 (10)	4 (9)	9 (10)
Myoclonic	4 (8)	2 (4)	6 (6)
Total	49 (100)	43 (100)	92 (100)
<b>Nutritional status</b>			
Severe malnutrition	13 (27)	25 (58)	38 (41)
Moderate	22 (45)	14 (32)	36 (39)
Mild	10 (20)	2 (5)	12 (13)
Normal	4 (8)	2 (5)	6 (7)
Total	49 (100)	43 (100)	92 (100)

especially when most of their families live below subsistence levels and disability services are so sparse and visits infrequent.

In this study, case fatality rates were more than three times higher in the rural children than in the urban children. There could be several reasons for this. From initial enrolment, differences were seen between the two groups in socioeconomic status of the family, maternal education, and nutritional status and adaptive behaviour of the children. Families of the rural children were poorer, most mothers were non-literate, and the children themselves more malnourished. Besides seasonal factors, family income and mother's education are two important factors which are significantly related to children's nutritional status in Bangladesh (Bairagi 1980). In this study the rural children as a group were older, included fewer cases of tetraplegia, and tended to have higher adaptive functioning than the urban group. This may suggest that a greater proportion of children with more severe physical disabilities with CP had already died than would have been the case in the urban area. This needs further verification by studies. In addition to malnour-

ished children being more susceptible to infections, poor rural families would not have the resources to get to and pay for health care services at short notice. Four of the six children who died from the rural group had had the least contact with disability services which may indicate that it is insufficient to provide only primary health care services without rehabilitation, as the latter ensures more frequent contact with the child and family.

From western studies we know that some factors are important in the long-term survival of individuals with CP. These are: degree of mobility, intellectual impairment, and epilepsy (Crichton et al. 1995). The first two factors seem to have influenced the deaths of most of the study children. Although none died in an epileptic seizure, convulsions had occurred before death in three children. Studies also report growth failure in children with severe four-limb CP (Stallings et al. 1993). Failure to thrive and limited balanced food resources may have contributed to the considerable risk of death within 2 years for severely malnourished children (nearly one in four in the rural group). Even in developed

**Table III: Clinical features and sociodemographic characteristics of the eight children who died during the 2 years of the study**

Subject <sup>1</sup>	Age at first assessment (y:mo), sex	Approximate age at death (y:mo)	Type of CP (severity of motor disability)	Degree of malnutrition	Level of adaptive behaviour	SES	Associated problems	Incidents preceding death	Contacts with disability service
1	3:9, male	4:1	Tetraplegia (severe)	Moderate	Low	Middle	Microcephaly, GTC epilepsy, speech delay	Renal failure (possible paracetamol poisoning)	Frequent (12)
2	2:6, male	3:3	Tetraplegia (severe)	Severe	Low	Very low	Speech delay, squint	Pulmonary TB, developed bloody diarrhoea	Frequent (33)
3	5:0, male	5:6	Tetraplegia (severe)	Moderate	Low	Very low	Microcephaly, squint, speech delay	Severe diarrhoea	PHC (1)
4	2:6, male	3:1	Tetraplegia (severe)	Severe	Moderately low	Very low	Cataract left eye, undescended testes	Severe diarrhoea	PHC (1)
5	2:6, male	3:3	Tetraplegia (severe)	Severe	Low	Very low	Mild epilepsy, speech delay	Reaction to cotrimoxazole: (possible Stevens-Johnsons syndrome)	PHC (1)
6	5:0, female	5:4	Athetoid (severe)	Severe	Low	Low	Speech delay	Severe convulsions (possible encephalitis)	PHC (1)
7	1:10, female	2:8	Diplegia (moderate)	Severe	Moderately low	Very low	Speech delay	High fever, severe convulsion, severe diarrhoea	Occasional (2)
8	3:0, male	3:7	Tetraplegia (severe)	Severe	Low	Very low	Moderate hearing impairment, speech delay	High fever, convulsion	Occasional (2)

<sup>1</sup>Subjects 1 and 2 were from the urban group, subjects 3 to 8 were from the rural group; SES, socioeconomic status; GTC, generalized tonic-clonic; TB, tuberculosis; PHC, primary health care.

countries, only recently has the importance of nutrition of children with disabilities and of provision of parental support been recognized (Couriel et al. 1993). That the children probably died because of their severely disabling condition is also indicated from the fact that no deaths were reported in their siblings. Family support and personal motivation are other factors that are strong predictors of long-term survival in individuals who have CP (Mac Keith 1976, Werner and Smith 1982, Nosek et al. 1987). Poor and disempowered families will need extra social and community support to nurture their children with severe disabilities. Again, this may mean more regular contact of the disability services with the child and the family, including regular home visits.

Ninety-one percent of the children survived the 2-year study period, in spite of at least half of them being as disabled, malnourished, and low functioning as those who died. Moreover, most mothers of the surviving children were non-literate and with very little access to money and other resources. The intervention programmes may have made a direct contribution to the survival of these children. They aimed to improve motor functions, communication, and activities of daily living, depending to a large extent on improving the skills of the mothers in handling their children at home. Travelling to the centre may also have helped to build the mothers' confidence and mobility. However, these surviving children need to be followed-up further to determine long-term morbidity and mortality.

This study has provided a direction for planning intervention programmes for children with severe disabilities in developing countries like Bangladesh. It indicates the value of a holistic approach to disability services in developing countries where families have few resources for feeding the child, mothers have very little access to information on disability, and no disability services exist. Any service must include three important components: primary health care, feeding programmes, and rehabilitation. Since 1996, meals have been provided to all children in the rural programme of the BPF, and to those in the urban programme who cannot afford a nutritious meal everyday. Although the outcome has not been formally reported, attendance at the centres has become more regular and the number of enrolments has increased.

In conclusion, young rural children with CP had a higher mortality rate than those from an urban area. Those who died tended to be children of non-literate mothers from very low-income families, with lower adaptive functions and severe malnutrition. Those with the least contact with disability services were more likely to succumb. Intervention programmes for children with disabilities in developing countries must include both nutritional and disability rehabilitation and identification and empowerment of vulnerable mothers and families by home visits.

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