

Predictors of Stress in Mothers of Children With Cerebral Palsy in Bangladesh

Reaz Mobarak,¹ MBBS, DCH, MSc, **Naila Z. Khan**,¹ MBBS, FCPS, PhD, **Shirin Munir**,² MSc, PhD, **Sultana S. Zaman**,³ PhD, and **Helen McConachie**,⁴ MPhil, PhD
¹Child Development Center, Dhaka Shishu (Children's) Hospital, ²Kalyani Special School, Bangladesh Protibondhi Foundation, ³University of Dhaka, and ⁴University of Newcastle

Objective: To identify the stress experienced by mothers of young children with cerebral palsy in Bangladesh and to determine predictive factors.

Methods: We recruited 91 mothers of children with cerebral palsy ages 1.5 to 5 years as they sought services at an urban and a rural center for their children. Mothers were interviewed with the Self-Report Questionnaire and other family background and child behavior measures. The children were examined by a pediatrician and by a psychologist.

Results: Out of 91, 38 (41.8%) mothers were at risk for psychiatric morbidity. Significantly associated factors included living in the rural area within a poor family, with a relatively older child. The strongest predictor of maternal stress in multivariate analysis was child behavior problems, especially those related to burden of caring.

Conclusions: Ensuring practical help for mothers and advice on managing common behavior problems are important components of intervention, as they may directly help to relieve stress on mothers of young disabled children in developing countries.

Key words: *child disability; developing countries; maternal stress; behavior problems; poverty.*

Disability in a child affects not only the child's life but also the family's life (Beresford, 1994; McConachie, 1991). The parents, other members of the family, relatives, friends, and even neighbors of a child with disabilities may all experience stress to a varying extent. In particular, everyday problems in caring for a child with disabilities, such as sleep and behavior difficulties, have a significant impact on

maternal stress levels (Quine 1986, 1991; Sloper, Knussen, Turner, & Cunningham, 1991; Sloper & Turner, 1993).

In developing countries, the pressure is even greater. The majority of families are already living under difficult conditions, with few resources and little access to appropriate services. In countries like Bangladesh, the situation is worst for women, who comprise the poorest and most vulnerable population even among the hard-core poor (Sen, 1997). Thus, mothers of children with disabilities are likely to be doubly disadvantaged in developing countries

All correspondence should be sent to Naila Z. Khan, Child Development Center, Dhaka Shishu Hospital, Sher-e Bangla Nagar, Dhaka 1207, Bangladesh. E-mail: zakhan@bangla.net.

(Ong, Afifah, Sofiah, & Lye, 1998; Singhi, Goyal, Pershad, Singhi, & Walia, 1990). This study examines factors associated with stress in mothers of children with serious physical disabilities. These contributory factors should be addressed in planning services for both the child and the family.

Most children with disabilities live in developing countries. In Bangladesh the prevalence of disability in a population of children ages 2–9 years from both urban and rural populations was estimated to be 70/1,000 for all grades of severity and 22/1,000 for serious disability (Khan & Durkin, 1995). Appropriate rehabilitation services are lacking for the vast majority. To make the best use of the few center-based services available, programs depend heavily on training mothers in skills to help their child to develop (McConkey, 1995; O'Toole, 1989). However, there is evidence that economic and cultural barriers restrict mothers from accessing such services (McConachie et al., in press) and that for some mothers the stress level may even rise during the course of attending such programs (McConachie et al., in press). We must understand the sources of stress before we can reduce them.

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 centers, one urban in Dhaka and the other rural 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 centers are administered by a group of professionals including pediatricians, psychologists, and therapists aided by community health workers.

A study of children with cerebral palsy (CP) was conducted by BPF in both urban and rural populations between 1993 and 1995 to evaluate an outreach program using Distance Training Packages (DTPs). This involves short training of mothers to manage their child at home, with pictorial manuals as reminders of the training. During the study extensive information was collected for each mother on socioeconomic status, adaptation to the child's problems, levels of stress, and support received from the family and community. The aim of this article is to identify the degree of stress experienced by mothers of young children with cerebral palsy and

to examine associated factors including child characteristics and family characteristics that reflect poverty.

Method

Participants

Ninety-one mothers were enrolled into the study as they sought disability services for their child: 49 were enrolled from the urban program, and 42 from the rural program. The children's ages ranged from 1.5 to 5 years. Diagnosis of CP in the child was carried out by a developmental pediatrician. Every mother was interviewed by a psychologist, who also assessed the child. In order to gain parents' consent to participation in the research measures, they were told that the intervention programs were being evaluated and oral consent to participation was taken. Written consent was not obtained because of low levels of literacy of women in Bangladesh (UNICEF, 1997). The study protocol was approved by the Ministry of Social Welfare, Government of Bangladesh.

Measures

Mother's stress. This was measured with a 20-item Self-Report Questionnaire (SRQ, 20 item yes/no version; Harding et al., 1980) adapted from the General Health Questionnaire and validated through use in a number of developing countries. A study in Ethiopia suggested that the SRQ measured not only psychiatric complaints but minor behavioral illness also (Kortmann & ten Horn, 1988). Mari and Williams (1985) give a cutoff point for psychiatric morbidity >7 (sensitivity 83%, specificity 80%, total score range 0–20).

Mother's adaptation. Mother's adaptation to the child was measured with the Judson Scale (Judson & Burden, 1980), a 22-item maternal self-rating scale, rated 1–7, total score range 22–154, which has been used in several British studies of families of young children with disabilities.

Social support. Social support was measured with the Family Support Scale (FSS) (Dunst, Jenkins, & Trivette, 1984), which recorded availability and the mother's perception of helpfulness of 18 sources of informal and formal support, total score range 0–72; informal support, 0–52; formal support, 0–20.

Sociodemographic characteristics. Parents' age, education, number of siblings, composition of the household, land ownership, and so forth were recorded in the Household Form, which was developed for the Rapid Epidemiological Assessment of Childhood Disabilities (REA) study for use in Bangladesh (Zaman et al., 1990).

Child characteristics. Comprehensive neurodevelopmental assessments were done by the pediatrician for all 91 children. The Medical Assessment Form, which was used in the REA study, was used for this purpose (WHO, 1992; Zaman et al., 1990). In the summary sheet we used a modified version of the WHO criterion of recording disabilities and grading severity of each type of disability (WHO, 1980).

Adaptive behavior skills were tested in every child by one psychologist using the Independent Behavior Assessment Scale (IBAS) (Munir, Zaman, & McConachie, 1999). This test was standardized in Bangladesh for children from both urban and rural populations, taking into account cultural norms and practices as well as gender differences in both settings. The assessment samples behaviors in gross and fine motor functions, communication skills, socialization skills, and daily living activities. For this study, total scores were calculated and age-matched with locally developed norms into five functional categories based on 1 or 2+ standard deviations above/below the mean: high, moderately high, average, moderately low, and low. In analysis, IBAS total z scores were used as a continuous variable.

Child behavior problems were measured using a version of the Behavior Screening Questionnaire (Richman, Stevenson, & Graham, 1982), adapted for disabled children (Davis & Rushton, 1991) to include extended information on incontinence and habit problems. The BSQ was used previously in Bangladesh in a study examining the effects of flood upon children (Durkin, Khan, Davidson, Zaman, & Stein, 1993) and has been used in diverse cultures (Richman et al., 1982). Items are rated from 0 (no problem) to 3 or 4 (severe problem). The total score range is 0–149.

Analysis

Mothers' stress was taken as the main outcome variable. Univariate analysis used independent *t* tests with categorical variables and Pearson correlation coefficients with continuous variables. Child, fam-

Table I. Child and Family Characteristics (*n* = 91)

	<i>n</i>	%	<i>M</i>	<i>SD</i>
Child				
Male	63	69		
Severe gross motor disability	45	53		
Low level of adaptive behavior (>2sd below mean)	76	83		
Age (months)			38.9	12.7
No. of siblings			1.4	1.6
Family				
Urban	49	55		
Nuclear family	53	58		
Mother not educated	35	38		
<.5 acre land	64	75		
Mother's age			25.8	5.4
Household income in Taka per month			5,660	7,495

ily, and maternal variables found significantly related to stress were then entered into stepwise multiple regression. The distribution of scores on the SRQ was significantly skewed, and the square root was substituted in analysis. The analysis was then repeated with the raw scores, and a closely similar result obtained. The SPSSpc statistical software was used for analysis.

Results

Study Sample

Summary characteristics of the sample of children and families appear in Table I. The families are generally poor, with a mean level below the GNP per capita value for Bangladesh (9,900 Taka per month = \$220; \$1 = 48 Taka). The percentage of mothers who ever attended school is lower in the rural sample (42%) than in the urban sample (79%). The level of disability in the children is high, with around half having severe physical disability and four out of five having significantly low levels of adaptive skills.

Level of Stress

Mothers' mean level of stress on the SRQ was 6.40 (*SD* = 4.92). The number above cutoff for potential psychiatric morbidity (>7) was 38 out of 91 (41.8%). The internal consistency of the scale with this sample was acceptable (alpha coefficient = .849).

Table II. Relationship of Continuous Variables With Maternal Stress ($n = 91$)

	<i>n</i>	<i>r</i>	<i>p</i>
Child variables			
Age	91	.22	.04*
Behavior scale total	87	.40	.00*
Adaptive skills total	91	.02	.86
Number of siblings	58	-.01	.94
Family variables			
Mother's age	87	.09	.40
Household income	86	-.26	.02*
Maternal adaptation total	89	-.31	.01*
Family support scale total	88	-.10	.34
Informal sources of support	88	-.14	.20

*Significant correlation with maternal stress.

Associations With Maternal Stress

Univariate analysis showed significantly greater stress in rural than in urban mothers (mean SRQ scores for rural mothers was 7.76 [$SD = 5.81$]); urban mothers 5.14 [$SD = 3.64$]; $t = 2.46$, $p = .02$). There was also a significant association with land ownership: those who had at a maximum half an acre of land were more stressed than those who had more land (mothers with little or no land mean SRQ score 7.01 [$SD = 5.30$]; those with more land mean score 4.81 [$SD = 3.37$]; $t = 2.08$, $p = .04$). Similarly, household income was negatively correlated with level of stress (see Table II). Other family characteristics (e.g., mother's age and education, father's age and education, type of family, number of siblings) showed no significant relationship with stress. However, scores on maternal adaptation to the child were significantly negatively correlated with maternal stress. The level of support perceived by mothers from informal and formal sources was not significantly related to stress; this may be explained by the relatively low internal consistency of the scale (FSS alpha coefficient = .626) or by the generally low levels of helpful support received (FSS mean = 15.65, $SD = 7.69$). Of the child characteristics studied, gender was not related to stress, nor were any of the indices of severity of disability (physical function, level of adaptive skills). However, maternal stress was greater in older children, and in those with higher scores on the behavior problems scale.

The variables found significantly associated in the univariate analysis were entered in a multiple regression to examine the strongest predictors of maternal stress (see Table III). The main predictor

Table III. Regression Analysis to Determine Predictors of Maternal Stress

Variable	Coefficient	Standard error	95% Confidence Interval		<i>p</i> value
			Lower	Upper	
Behavior scale total	.74	.19	.25	1.22	.01
Constant	-6.14	3.48	-15.09	2.80	.14

Table IV. Behaviors Reported as a Problem by More Than 25% of Mothers ($n = 91$)

Behavior	<i>n</i>	%
Not independent	87	96
Not going to sleep	81	89
Night wetting	61	67
Day wetting	52	57
Soiling	44	48
Hyperactive	44	48
Miserable	35	38
Waking at night	31	34
Attention-seeking	25	27
Temper tantrums	24	26

was found to be the child's behavior problems score, with goodness of fit 75.46%. The associated demographic characteristics of the families dropped out of significance in the multivariate analysis.

The behavior scale items most often reported as problematic by mothers are presented in Table IV. The major impact is in terms of the child's lack of independence in daily living skills. One third reported at least some problem with sleep disturbance, and at least one half with continence. Interactional problems such as being miserable, attention-seeking, and temper tantrums were also reported by more than a quarter of mothers.

Discussion

The results demonstrate that a high proportion of mothers of children with cerebral palsy in Bangladesh suffer from stress. Behavior problems in these children were found to be the strongest predictor of maternal stress. The majority of the families had low income with very few resources; the lack of variation may explain why poverty indicators were related to stress in the univariate analyses, yet did not remain as significant predictors in multivariate analysis. These findings have important implications for planning services for children with disabili-

ities and their families in Bangladesh and other similar developing countries.

The study had a number of limitations. It is not clear how representative the study sample is of the general population of young children with cerebral palsy, and their mothers, in Bangladesh. The children were those whose parents sought services. The rural group of children are thought to be the more representative given continuing contact by the attached community worker with villages in the catchment area, and thus spread of information about the services available from the rural program. The design of the study is limited by being cross-sectional, with reliance on several self-report measures from the same informant (including the main independent and dependent variable), and use of measures of adaptation to the child and of family support, which have not been validated explicitly for use in Bangladesh. There is a particular need to develop a culturally appropriate measure of informal support, given its important mediating role in stress. Nevertheless, the pattern of results reflects theoretically predictable sources of stress for mothers of young disabled children and has implications for the nature of interventions.

Two fifths of the mothers were found to be above the cutoff point on the SRQ, which may indicate that they were at risk of clinically significant mental health problems. The percentage was considerably higher than the 13.9% found in primary care screening of adults in four developing countries by Harding et al. (1980) using the same instrument. The level of stress is also higher than the findings of a previous study done in Bangladesh (Durkin et al., 1993). Mothers of 127 children from the REA study were followed up 5 months after a major flood. The mean SRQ score for 38 mothers of children with some level of disability was 3.97 ($SD = 2.57$), as opposed to a mean of 6.40 in this study. The mothers of 89 children without disabilities had a mean score of 3.31 ($SD = 1.68$; $F = 11.57$, $df = 1$, $p = .089$) (unpublished data, N. Z. Khan). The disabled children in the flood follow-up had less severe levels of functional disability, which might explain some of the differences from this study; however, these observations may also suggest that the degree of stress on mothers of children with disabilities might have increased over the past few years. Further study is required to follow up these mothers to know to what extent they were actually at risk for mental health problems.

Behavior problems in children were the most

significantly associated with maternal stress. The most prevalent behavior problems were those that consumed a considerable amount of the mothers' time, that is, the burden of care related to lack of independence, sleep problems, bed wetting, soiling, and hyperactivity. Ong et al. (1998) also found that the level of stress in Malaysian mothers of children with cerebral palsy was modified by factors such as increased care-giving demands. The burden of caring for children that is expected at two or three years of age seemed in this study likely to lead to greater maternal stress in caring for older children. Interventions aimed at improving functional skills in activities of daily living (e.g., feeding, bathing, toileting) and posture are needed, along with behavioral management programs to help with sleeping, temper tantrums, and so on (e.g., Piazza, Fisher, & Sherer, 1997). Ideas on making low-cost aids to help in mobility and caring for children with physical disabilities have been introduced successfully in a number of developing countries (Werner, 1987). In addition, informal sources of support need to be sought for the mothers within the family. This would allow more time available for the child with disabilities, either because the mother gains help in completing family chores, or through other family members' involvement in helping the child to become more self-reliant (Craft, Lakin, Opliger, Clancy, & Vanderlinden, 1990).

Social factors such as land ownership and household income also had a negative relationship with maternal stress. Episodes of illness account for 21% of families in Bangladesh slipping further down the poverty scale (Sen, 1997). Having to care for a child with serious physical disability may also consistently erode the limited resources of the family. It costs money for these families to access services for their child, especially travel costs and money for medicine, aids, and so forth. More often than not this may end in tragedy, as indicated by the fact that a significant number of the most severely disabled children, especially from the poorest rural families and with severe malnutrition, died during the follow-up period of this study (Khan, Ferdous, Munir, Huq, & McConachie, 1998). Economic empowerment of such families may, thus, be an essential factor in successful interventions. Innovative programs to empower poor women through small micro-credit programs have been successful in Bangladesh (e.g., Grameen Bank) (Hashemi & Schuller, 1996). Strategies to include disabled people in savings and credit programs are now being made

(Ahmed, 1999). The Bangladesh Protibondhi Foundation has started micro-credit programs for families of children with disabilities in their rural project for the past 2 years. It may be important to identify mothers of disabled children as another specially vulnerable group to be beneficiaries of such types of credit facilities to start small businesses.

In conclusion, this study has highlighted factors predictive of stress in mothers of children with disabilities that are amenable to change with appropriate intervention programs. Although it may be difficult to completely change behavior patterns and care requirements in severely physically disabled children, the strain can be reduced. Low-cost mobility (and other) aids must be made available to these mothers to reduce their physical labor in caring for their children. Cooperation from other family members must be harnessed, and methods sought to economically empower the mother. The direct benefits from optimizing mothers' mental and physical health may be an important interven-

tion in helping children with disabilities in developing countries.

Acknowledgments

Funding was provided by the British High Commission (Aid Management Office) and the Canadian High Commission (Canada Fund for Local Initiatives), to whom we are grateful. Time for analysis and writing was funded by the British Council in Bangladesh, including an Academic Link Program between Dhaka Shishu Hospital and the Neurosciences Unit, Institute of Child Health, London. We thank the parents and children who took part in the study for their cooperation.

Received May 13, 1999; revisions received September 30, 1999, and November 14, 1999; accepted November 30, 1999

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