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Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh

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Abstract

Given the numbers of disabled children in Bangladesh and the lack of trained professionals, innovative forms of service delivery are required. The Bangladesh Protibondhi Foundation has developed an outreach parent training service based at two centres, one urban and one rural. Mothers are shown how to use pictorially based Distance Training Packages (DTP), which they take home. This paper presents findings concerning factors which seem to affect mothers' attendance with their children at DTP advisory sessions. The study followed 47 children with cerebral palsy, aged between 2 and 5.5 years, over a period of around 18 months. The main factors predicting higher attendance were the child's sex (i.e. boys were brought back more often), particularly in the rural area, and lower adaptation to the child reported by the mother. The problems described by mothers in using the DTP advisory service were economic (such as transport costs), cultural (such as mothers not being permitted out alone), and medical (such as the child having repeated fits). The implications for future service development are discussed.

Keywords: developing countries, early intervention, cerebral palsy, disability, community-based rehabilitation

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Introduction

Bangladesh has a population of 120 million people, with almost half under the age of 18 years. An epidemiological study conducted in the late 1980s showed a high prevalence of developmental disabilities: nearly 7% of 2–9-year-old children. The prevalence of serious disability was found to be 1.6%, that is, around half a million children under 10 years (Khan & Durkin 1995). There are few schools offering special education and very sparse services to children < 5 years. There is no systematic paediatric training of therapists, and doctors mostly lack understanding of disabling conditions in children, the stresses on their families and the possibilities of improvements in children's skills. Given demographic factors such as poverty, a largely rural population and poor links between areas of the country, inventive approaches are required in order to provide services.

The setting for the present study

The Bangladesh Protibondhi Foundation (BPF) has developed an outreach parent training service based at its two centres, one urban and one rural, for parents who bring their children for advice from all over Bangladesh. Over an 8-year period, the Foundation staff developed pictorially based Distance Training Packages (DTP) promoting physical, daily living, speech and language, and cognitive skills. The skills, positions, simple aids and activities depicted are based on sources such as Levitt (1982), Werner (1987), the Derbyshire Language Scheme (Knowles & Masidlover 1982) and the Cognitive Skills section of Portage (Shearer & Shearer 1972). Parents are trained for 1–2 h on each occasion of contact, and take home pictorial manuals as a reminder of activities. The training method involves demonstration, teaching and then observing the mother handle her child with reference to the ideas and activities pictured in the package booklets. The trainers are special education teachers with additional in-service training in physiotherapy or speech and language therapy (hereafter 'therapists'). Preliminary studies involving matched groups of children have suggested an equally beneficially effect in terms of progress in motor skill development comparing DTP with a classroom group offered daily (Zaman & Balo 1990).

The paper presents findings about factors which may affect use of the DTP service in Bangladesh by families of young children who have cerebral palsy.

Methods

Sample

Children aged between 1.5 and 5.5 years, with mild, moderate or severe cerebral palsy, were enrolled in the study as their parents brought them to a BPF centre for advice. The sample of 47 children included 24 from the urban area, and 23 rural, aged from 22 to 66 months (mean 40.5 months).

Measures

Socio-demographic characteristics

The Household Form was used to collect information about the child's family circumstances including income, land ownership, family structure, parents' ages and educational level. This is a standard interview format developed for the earlier epidemiological study (Durkin *et al.* 1991).

Child characteristics

Neurodevelopmental assessment included neurological examination, a detailed history, measurement of height and weight, and a summary rating of level of severity of various areas of functional disability in the child (adapted from WHO 1981).

Children's adaptive skill levels were assessed using the Independent Behaviour Assessment Scale, which was developed and standardized in Bangladesh (Munir, Zaman & McConachie 1999).

Maternal characteristics

Maternal stress was measured using the Self-Report Questionnaire (20 items answered yes/no) validated for use in primary care screening of adults in four developing countries (Harding *et al.* 1980).

Maternal adaptation to the child was measured using the Judson Scale (22 items rated on a seven-point scale; Judson & Burden 1980). Sample items include 'confident-unsure of myself'; 'know how much to expect of my child-don't know how much to expect'; 'not noticing any progress in my child-noticing great progress'.

Perceived support from family and community was measured using the Family Support Scale (18 items rated on a five-point scale for helpfulness; Dunst, Jenkins & Trivette 1984).

Qualitative information regarding attendance

At each occasion of meeting with a mother, the therapist (K or NA) kept notes on the interval since the previous contact and on the factors reported by mothers to affect their capacity to help their children and to come to the urban or rural base to access the service.

Procedure

The study was limited to those families who might be able to return on a regular basis, i.e. those living in Dhaka or within a 15-km radius of the rural centre. The assessment clinics are available 5 days a week in the urban centre and 1 day a week in the rural centre. On presenting at the centre, children were seen with their parents by the developmental paediatrician (SF). Children meeting the age and distance inclusion criteria for the present study were seen for completion of the maternal measures and child skills assessment by a psychologist (SM) not involved in delivery of the services. Then the family was allocated to one of the therapists. Parents were asked to bring their child monthly for a training session with the therapist and updating of advice. For the study period, the maximum DTP session attendance was nine sessions.

The study reported here formed part of a randomised controlled trial, the design and consent procedures for which are described in McConachie *et al.* (2000). Recruitment continued for 2 years and, in the rural area, was thought by community workers to include all eligible children. Strenuous attempts were made to follow up all the children enrolled in the trial.

Analysis

Differences on independent and dependent measures between the urban and rural groups were analysed using *t*-tests and χ^2 . Univariate analysis of the relationship between number of attendances and other variables utilized Spearman rank correlations and Mann–Whitney *U*-tests, because of the ceiling on number of attendances. Multiple regression analysis was used to explore the strongest predictors of children's attendance at DTP sessions.

Results

As would be expected, there were a number of significant differences between urban and rural groups in demographic characteristics. The rural families

tended to be poorer. The rural mothers were younger ($t = -2.23, P = 0.03$) and fewer had had any education ($\chi^2 = 10.71, P < 0.01$). In terms of child characteristics, the rural children were more likely to be severely malnourished ($\chi^2 = 11.24, P < 0.01$), on average older ($t = -2.03, P < 0.05$) and tended to be more able ($t = -2.00, P = 0.05$) than the urban children. Finally, there was a difference in mothers' adaptation to their disabled child, with more difficulty reported by rural mothers ($t = -3.98, P = 0.01$) (Table 1).

The attendance of the 24 urban and 23 rural mothers and children at the DTP service is given in Fig. 1. Half of the rural mothers receiving DTP were able to come to almost all of the suggested sessions. Two children who attended only once it was subsequently discovered had taken ill and died, and only two more were lost to follow-up. Of the urban mothers one-third came around monthly, another third came between three and seven times, and one-third came only once or twice. In all, eight were lost to the final follow-up.

Univariate analysis was performed, relating each of the variables to numbers

Table 1 Characteristics of the Distance Training Packages study sample ($n = 47$)

| | Mean | | No. (%) | |
|------------------------------|--------|--------|---------|---------|
| | Urban | Rural | Urban | Rural |
| Demographic | | | | |
| Income—taka per month | 7090 | 4252 | | |
| No land | | | 10 (42) | 14 (64) |
| Joint family | | | 12 (50) | 7 (32) |
| No education | | | | |
| Father | | | 3 (14) | 8 (36) |
| Mother* | | | 3 (14) | 13 (62) |
| Age (years) | | | | |
| Father | 37 | 33 | | |
| Mother* | 27 | 24 | | |
| Child | | | | |
| Age (months)* | 36.96 | 44.09 | | |
| Adaptive skills (IBAS total) | 109.08 | 160.82 | | |
| Boys | | | 17 (71) | 17 (74) |
| Severe physical disability | | | 12 (50) | 8 (35) |
| Severe malnutrition* | | | 6 (25) | 17 (74) |
| Maternal questionnaires | | | | |
| Family support scale | 16.33 | 13.55 | | |
| Self-report questionnaire | 4.88 | 7.09 | | |
| Adaptation to the child* | 108.83 | 91.32 | | |

*Urban/rural differences significant $P < 0.05$.

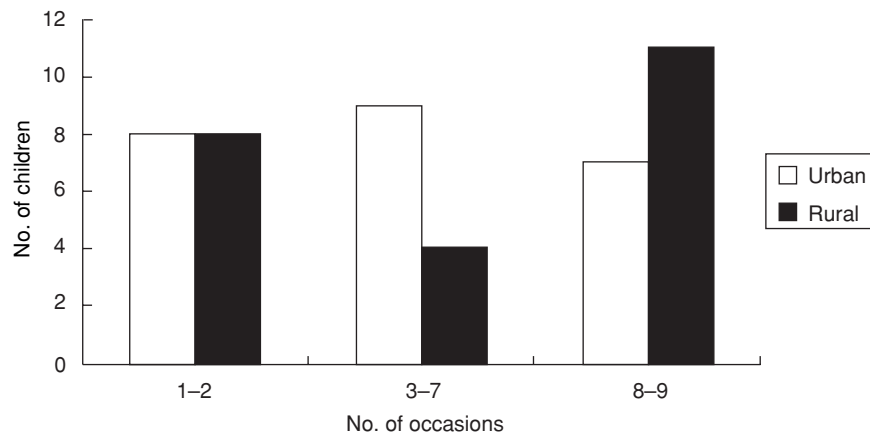


Figure 1 Attendance at Distance Training Package sessions.

Table 2 Significant predictors of number of attendances at Distance Training Packages service

| Predictors | Standardized Beta coefficient | t | P |
|-------------------------|-------------------------------|--------|-------|
| Adaptation to the child | -0.342 | -2.527 | 0.015 |
| Child sex | 0.308 | 2.279 | 0.028 |

of attendances at DTP sessions, involving both groups of children. Boys were more likely to be brought back repeatedly, particularly in the rural area (urban median: boys 4, girls 2; rural median: boys 8, girls 2; $U = 126$, $P = 0.02$) as were older children age ($r_s = 0.33$, $P = 0.02$). Repeat attendances were more likely where mothers reported higher stress ($r_s = 0.33$, $P < 0.03$) and lower adaptation to their child ($r_s = -0.37$, $P = 0.01$).

In view of the urban/rural differences, multiple regression analysis to predict the number of DTP sessions attended was conducted. At the first stage, groups of variables were entered separately, as follows: demographic, child characteristics, child measures of disability, and maternal questionnaire measures. Urban/rural dropped out of the analysis, along with all the demographic measures. Variables of statistical or clinical significance were entered in stepwise regression ($R^2 = 0.214$, $F = 5.856$, $P = 0.006$); only two were found to be predictors of number of attendances: maternal adaptation to the child accounted for 12% of the variance, and sex accounted for a further 9% of the variance (see Table 2).

Qualitative analysis

Many factors were reported by mothers as getting in the way of their attendance. Many of the reasons cited were economic (10 urban and five rural mothers), including travel costs particularly if living far from the centre. Some urban families went back to their village because of financial reasons; in Bangladesh contact between those who have moved to the city and their family village of origin is very close. There were also cultural reasons which prevented attendance, particularly in the city. Some mothers were not allowed out alone; many of these mothers were very young and their families feared for their safety. Other mothers had to meet traditional expectations of them in regard to a great deal of housework and care of children. Some families preferred to attend a religious healer with their child. Finally, there were medical reasons for non-attendance including the child becoming ill repeatedly (e.g. major convulsions).

Discussion

This study has demonstrated that attendance at an outreach parent-training service, based in centres run by a local voluntary organization in Bangladesh, was affected by a range of factors. Parents themselves report problems of distance and expense in travelling, as well as inhibitions on women travelling unaccompanied in the city. Analysis of measured information about the children and their families did not find that socio-demographic variables were related to attendance, but instead suggested that families were readier to bring male children for a service in the first place, and to bring them back repeatedly. In addition, mothers who reported themselves as less adapted to their child were more likely to return; in this study, the measure may have captured elements of what underlay the mothers' drive to help their child progress. Studies in both developed and developing countries have similarly found sex (Poland, Taylor & Hayes 1990; Westbrook, Silver & Stein 1998) and parental stress levels (Jensen, Bloedau & Davis 1990) to be associated with health service usage.

The study has limitations which may affect generalisability of the results. It is small in size. All of the participating families were volunteers in that they had found out the service for themselves, and they had given consent to the research. In addition, the qualitative analysis was limited to reports given by the mothers who returned, to explain long gaps since their last attendance,

and thus did not include an understanding of the opinions of the mothers who dropped out of the service altogether. Nevertheless, the study provides pointers to some of the issues of importance in attempting to develop the service further, which may apply also in similar circumstances in developing countries.

From analysis of change in outcome measures in the fuller trial study (McConachie *et al.* 2000), DTP appear generally beneficial for children and are low cost. However, the investigation in this paper of the process of service delivery suggests that they are not a sufficient answer. The problems experienced by Bangladeshi mothers in accessing centre-based services indicate that these are needed closer to home. There should also be the possibility of home visits by staff for frequently ill children, or where the mother is not allowed out alone. This may be particularly necessary in urban areas where in-laws are inclined to be restrictive; in the urban DTP group 50% were living in joint families. Medical support to therapists who are giving advice seems important, given high levels of malnutrition and low-grade infection in children in Bangladesh, which affect the children's ability to learn. Both in urban and in rural areas, girl children are likely lose out on early services if these cannot be taken to the home.

Mothers generally were reported by therapists to have a good level of enthusiasm for the services, except for one or two families who wanted a 'quick cure'. However, the present analysis was able to explain only a small proportion of the variance in predicting rate of attendance; thus, the service may not be providing what some families would want. Dale (1995) and other authors have stressed the importance of negotiation with parents over the style and content of professional services in order to meet their priority concerns. For example, House, McAlister & Naidoo (1990) describe their experience in Zimbabwe of expecting parents to want a programme of teaching their disabled children; however, on listening carefully to parents it seemed that the first priority was to find ways to change negative attitudes of neighbours and extended family members, such as providing accurate information about the causes of children's impairments (for example, that they were not a 'curse' for supposed maternal wrong-doing).

One constraint in developing the DTP approach has been the uncertainty over the timing of the next contact with a child and parents. As a result the therapists' style of working has tended to be 'method-led', suggesting several positions and activities from the booklets at one time. Where the service can evolve to be more home-based, or at local centres, then it will become easier to focus on a particular set of appropriate short-term goals decided upon in

consultation with parents. The goals may focus on the new skills which the family members would particularly like the child to acquire, or instead may address priority needs identified by the family, for example, for the father to gain employment or to find ways to reduce mothers' stress (McConachie 1994; Mobarak *et al.* 2000). This is not simply an issue for developing countries. Davis & Rushton (1991) have demonstrated the value of adopting a broad-based approach through their evaluation of the Parent Advisor model in an area of inner London, supporting parents who are worried about their children or a sick parent or how to pay bills, as well as about their child with a disability. The DTP service in Bangladesh has been offered from two school bases in order to make best use of scarce professional time. Recently, the service in the rural area has been extended through a pilot community-based rehabilitation programme, with advice to parents on child development activities combined with attention to wider needs of the family, including loans to families of disabled children so that they can start a small business (Khan 1998).

There is no blue-print for child disability services in developing countries. However, it seems likely that a broad base of community mobilization and support is required (Helander 1993) in order to create networks for stressed families, and to tackle issues of poverty and community attitudes, alongside offering advice to promote children's skills and parental adaptation.

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