Psychosocial Effect and Economic Burden on Parents of Children with Locomotor Disability

Ananya Ray Laskar, Vimal K Gupta, Dharmendra Kumar¹, Nandini Sharma and Megha M. Singh

Department of Community Medicine, Maulana Azad Medical College, Delhi, ¹Institute for Physically Handicapped (IPH), Delhi, India

ABSTRACT

Objective. To assess the social and financial burden on parents of children with locomotor disability.

Methods. A cross-sectional study was conducted in the Institute for Physically Handicapped (IPH), Delhi, where parents of 100 locomotor disabled children of age group 6 to 15 years were interviewed to estimate the socioeconomic burden of caregiving their children.

Results. The study observed that the parents of the disabled children were severely burdened in terms of financial burden and mental health.

Conclusions. There is an urgent need for support activities for such families at a national level in order to curb the huge economic and social burden of care-giving. Counselling should be an integral part of rehabilitation for such families.

[Indian J Pediatr 2010; 77 (5) : 529-533] E-mail: ananya.ray.laskar@gmail.com

Key words: Financial burden; Family interaction; Insurance coverage; Locomotor Disability; Social burden

Locomotor disability accounts for the highest proportion (51%) among disability in India, as per 58th round of NSSO survey 2002.¹ Such children and adolescents are faced with a lifetime of functional limitations and their caregivers have to cope with their special needs.² Moreover, the social security systems targeting the caregivers of differentlyabled children are not well developed in India. Therefore, disability adversely affects not only the child, but the entire family. The distress caused to the parents may result in an adverse effect, on their routine activities and interpersonal relationship.³ In this context, it has been observed that that parental distress and disruption of family functioning, hampers child’s cognitive, behavioural and social development.⁴

Only few studies in India have focused on this aspect. The present study was done with the objective of assessing the psycho-social and economic burden of parents of children with locomotor disability. Insight into their health-related needs would provide valuable inputs for the development of new strategies to sustain caregivers in their vital roles.

Correspondence and Reprint requests : Dr. Ananya Ray Laskar Department of Community Medicine, Maulana Azad Medical College, Delhi-110002, India. [DOI-10.1007/s12098-010-0064-7] [Received September 10, 2009; Accepted January 22, 2010]
Exclusion criteria: i) Disabled children not accompanied by any parent, ii) multiple disabilities iii) disabilities other than locomotor such as visual, hearing or mental disability iv) parents who were not staying with their disabled child.

Sampling Frame: All new subjects who fulfilled the inclusion criteria and were willing to participate, were enrolled in the study.

Study Instrument:

i) Social burden of parents was assessed by using the Social Burden Scale. It consists of 24 items, arranged in 6 categories namely, financial burden, disruption of the routine family activities, family interaction and leisure, affect on physical and mental health. The scale has been validated for the Indian population. The reliability score has been found to be above 90% for 20 items and between 87 to 89% for the other four. During the interview, the rating for each category was given on a three point scale as perceived by the patient viz. (a) Severe burden -2, (b) Moderate burden -1 and (c) No burden -0

The final score was expressed as the average score of all items in each of the 6 categories. ii) Parents of these children were further interviewed with a semi-structured questionnaire to find out the reasons for their perceived burden. iii) OPD and Hospital records were reviewed to estimate treatment costs.

Ethical considerations: The study was approved by the Ethical Review Committee of Maulana Azad Medical College, New Delhi. An informed consent was taken from all the parents, before they were interviewed.

Statistical Analysis

Data were entered in MS Excel and analyzed using SPSS version 12 software. The results were expressed as percentages and chi-square (χ²) test was used to test significant difference between the categorical variables.

RESULTS

During the study period, 329 fresh cases in the age group of 6-15 years were registered in the OPD of IPH. Of these, 100 were selected based on the completeness of records, fulfilment of inclusion criteria and consent to participate. Majority of the subjects were of urban origin (58%) and belonged to lower or upper lower income groups (83%). 72% belonged to nuclear families while the rest to joint families. The mean family size was 3.19 and the median per capita income of the subjects was 2450 per month. Literacy status among mothers was poorer (29% illiterate and 42% primary education) than the fathers. Among the causes of locomotor disabilities diagnosed, 51% of the cases attributed to post polio residual paralysis, followed by CTEV (13%).

The estimated burden in terms of six categories are as follows:

(i) Financial Burden: Overall expenditure on disability had resulted in severe burden among 69% of the parents (Table 1). Out of these 69 subjects, majority (65%) of them were either daily wage earners or small traders. Financial burden in the form of loss of daily wages, requirement of frequent job change and loss of job, incurred in 35%, 6%, 1% of parents, respectively. Unlike the Government employees who could still avail of casual or medical leaves, the parents in private or unorganized sector were deprived of these benefits. The average non-recurring cost of treatment and rehabilitation was reported to be Rs. 6010 per yr while the direct recurring cost was Rs.4500 per yr. Median amount spent on transport, food, accommodation and making the house barrier-free etc. was Rs. 2610 per month, with an inter-quartile range of Rs 1360 to 5875. The amount incurred on accommodation was reported by attendants belonging to other states.

Significant association was found between rural & urban slum (combined) with severity of economic burden OR 20 [95% CI 4.12-131.97].

The financial burden made the parents more impoverished and indebted. More than half of the families had taken money from either local money lenders and 47% had to sell their assets to payback huge loans. Only 26% had correct information regarding Government-run schemes (in form of aids & appliances, subsidization of operation cost and educational benefits etc) and all of them were Government employees. A meagre 13% of the subjects had availed of financial benefits provided under the schemes like Assistance to Disabled Persons for purchase or fitting of Aids and Appliances (ADIP).

(ii) Routine family activities: 49% of the families felt they were moderately burdened, in terms of disruption of the routine family activities (Table 1). Most common reasons cited for the disruption were as follows: frequent visits by attendants to physiotherapy or occupational therapy, arrangement for the purchase of appliances or for corrective surgeries.

(iii) Family leisure: 38% felt that they were severely burdened, in terms of disruption of family leisure like watching T.V, going for movies, picnics, or leisurely travel (Table 1). The reasons highlighted were problems of commuting, feeling of embarrassment in visiting public places of recreation, consumption of holidays due to frequent visits to the rehabilitation centres (32%).

(iv) Family interaction: 70% of the parents were moderately burdened, in terms of disruption of family interaction within the family and outside (Table 1). An adverse effect on the marital relationship was more profound in nuclear families (73.4%) than joint families.
but no significant relationship was found. Frequent quarrels were reported in 55% of parents and in 34% of parents adverse effects on marital relationship was found. At the time of study two of the fathers had already separated from the family, leaving their wives alone to cope with problems of raising the disabled child. The extent of marital disharmony could not be fully gauged from the composite scores.

(v) Physical ill health: Physical health was moderately affected in 71% of the parents (Table 1), indicating that disability in the child may have an indirect bearing on the parent’s health and self-care. Parents reported of suffering from one or the other chronic ailments within the past six months of the study: 53% parents had musculoskeletal ailments; 12% suffered from hypertension; 5% had diabetes; 3% had tuberculosis and 2% died. They felt that “caring for daily routine activities of the disabled child demanded considerable time and attention hence, they could not pay due attention to their own health”.

(vi) Mental health: 56% of the parents felt that were severely burdened in terms of mental health (Table 1) and out of these 71% of them were mothers. Mothers were more adversely affected (67%) than the fathers (32%). 46% parents complained of sleep loss or altered sleep pattern; 32% had loss of appetite. They reported that they were over-anxious about their child or the family members constantly blamed them for the disgrace to the family. Only 13% of the parents sought help for psychological illness. There was a significant association between poor literacy status and mental health of mothers OR= 5.48 [95% CI 1.93-15.9].

TABLE 1. Proportion of Severity of Different Types of Burden and the Reasons Cited by the Parents

<table>
<thead>
<tr>
<th>S no.</th>
<th>Type of Burden</th>
<th>Severe (%)</th>
<th>Moderate (%)</th>
<th>No Burden (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Financial burden</td>
<td>69</td>
<td>31</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Disruption of the routine family activities</td>
<td>38</td>
<td>49</td>
<td>13</td>
</tr>
<tr>
<td>3</td>
<td>Disruption of family leisure</td>
<td>38</td>
<td>62</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Disruption of family interaction</td>
<td>5</td>
<td>70</td>
<td>25</td>
</tr>
<tr>
<td>5</td>
<td>Effect on physical health of the family</td>
<td>5</td>
<td>71</td>
<td>24</td>
</tr>
<tr>
<td>6</td>
<td>Effect on mental health of the family</td>
<td>56</td>
<td>30</td>
<td>14</td>
</tr>
</tbody>
</table>

The present study revealed that the parents have to bear huge financial liabilities, over and above that of rearing of a normal child. A community based survey at national level revealed that on an average the caregivers of disabled children bear Rs.5771 as non-recurring cost and Rs.4510 as recurring cost per annum, which is in line with the current study. A longitudinal study in US observed that 59.7% of the respondents had taken a leave from their employment or were on long term disability benefits, which corroborates with the findings of the study. Only a marginal proportion of parents, working in the Government sector had availed of the schemes for the disabled. Hence, there is an urgent need to popularize the existing benefits for the disabled and make them more user-friendly, particularly among the parents of the unorganized sector.

The health-care demands of the disabled child such as frequent visits to physiotherapy or occupational therapy, arrangement for the purchase of aids or appliances, take a toll on the routine activities and leave little time for family leisure. The findings corroborate with that of another institution-based study, which observed significant disruption of routine activities and leisure in families of disabled children. Gathwala et al assessed the burden of parents of mentally disabled children, using the same scale and reported that 40% of the families had disruption of family routine and leisure. The difference in the magnitude of disruption could be due to the difference in the type of disabilities. However, the above findings are at variance with observations of some authors in developed countries. Langergren et al did not observe any significant disruption in the family routine. This may be perhaps due to differences in socio-economic conditions, cultural practices and attitudes of the parents as well as the society.

Majority of the parents (70%), were moderately burdened in terms of disruption of family interaction while 5% felt severely burdened. A study conducted among the mentally handicapped children using the same scale, reported a higher proportion (45%) of severely burdened families in relation to family interaction. Dupont et al assessed the sociopsychiatric aspects of families of mentally retarded children and observed that 87% of the parents had limited cultural interactions owing to various inferiority complexes suffered by them. It is clear from the above discussion that the family interactions are not as severely affected among physically disabled subjects as compared to mentally disabled ones.

The present study also revealed conflicts among the family members arising from the burden of rearing a disabled child. Often these conflicts lead to marital problems, as was observed in the study and corroborated by many other studies too. Singh et al observed significant correlation between social burden scores and marital adjustment (r = 0.32) in the families having a disabled child. Marital dissatisfaction may stem from the tension of having an abnormal child or sexual dissatisfaction. Hostility of husband was significantly higher in families with disabled children, according to

DISCUSSION
Gath et al. observed that the marital adjustment scores were influenced more by the social environment characteristics like family support, marital satisfaction and social support network. Whitney et al. highlighted the fact that mothers of disabled children were more likely to be separated or divorced. The burden of care-giving a disabled child if not shared equally by both parents, may mount to marital disharmony and hence indicating the need to establish counselling sessions for both parents and day care centres, to reduce the burden on parents.

Most of the parents (71%) perceived moderate burden on their own physical health. Although the physical illnesses cannot be directly attributed to the disability itself but they could arise out of self neglect. 60% parents of mentally handicapped children, reported being severely burdened as they felt that rearing a disabled child leads to neglect of their own health. Singhi et al. revealed that more than half of the mothers (58%) had physical illness such as back pain and loss of weight.

The present study highlighted the deleterious effect on the mental health of care-givers particularly that of the mothers. Singhi et al. found a significant correlation between the social burden scores and maternal health (r=0.58). Dupont et al. observed, 80% of the parents had sleep disturbances and 56% of the mothers showed significantly higher scores on scales of anxiety, phobia and depression than fathers. A community based study revealed that poor maternal health status was significantly linked to child’s maladjustment with an OR=1.7 (95% C.I:1.1-2.4). A qualitative research among such caregivers described the negative mental health consequences of long-term, informal caregiving. There is a dearth of such studies in India.

In the present study, only a meagre 13% sought professional help. Poor health-seeking behaviour among the parents of affected children, is not uncommon in developed countries as well. Monique AM et al. reported that only 8% of the respondents consulted a psychologist or psychiatrist, owing to economic constraints and found it difficult to stick to frequent clinic attendance.

The present study had few limitations. The ‘Social Burden Scale’ used in this study could provide us with the perceived burden and not an actual estimate. Moreover, a father’s perception may differ from that of the mother’s due to differential subjective reporting. Some sensitive information, like marital disharmony may even go unreported. Other family members if included, could have added some valuable information about the family environment. Lastly, there are more chances of recall bias, particularly, regarding the estimates of financial burden.

CONCLUSIONS

The present study points towards an urgent need for support activities for the physically disabled children at a national level, in order to curb the huge economic and social burden of care-giving. Sincere efforts should be made to strengthen the existing schemes for the disabled, with special focus on the parents working in the unorganized sector. NGOs, CBOs and District Disability Rehabilitation Centre can play an active role in popularizing and facilitating their utilization. Trained psychologist should be recruited in all national level institutes and counselling should form an integral part of rehabilitation. The introduction of health insurance schemes and day-care centres for disabled children should be given a serious thought too. All these initiatives will go a long way in bringing down the social burden associated with physical disability.

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Contributions: The conception of the topic was done by ARL, VKG and DK. DK and ARL reviewed the literature. All the authors contributed to the protocol making and designing of the study. NS and MMS contributed to the data analysis in addition to the first author. The final manuscript was prepared and edited by all the authors.

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