



Socio-Economic Impact on Sri Lankan Families Managing A Child with Cerebral Palsy

KEYWORDS

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ABSTRACT

Cerebral palsy (CP) is a condition that limits a child's ability to move, maintain balance and posture. Dependency thus ensues, cause significant detrimental effects on the quality of life of CP children and their families. In a cross sectional descriptive study, socio-economic impact on Sri Lankan families managing a CP child was studied. An interviewer administered questionnaire was used to collect data 300 families with CP children were studied. The majority were from the low to low middle income groups. Significant negative socio-economic impacts on the families were identified in terms of the time spent on the child, economic loss due effects on employment, cost of managing the child, marital disharmony and effects on other siblings. A well-structured social welfare system is in need to support Sri Lankan families with CP children to minimize the negative socio-economic impact

Title Introduction

Cerebral palsy (CP) is a condition that limits a child's ability to move, maintain balance and posture. Developmental anomalies in the brain or an insult to the developing brain can cause CP [1]. Although by definition CP is a disorder of motor functions, affected children have problems related to intelligence, cognition, feeding, communication, co-ordination, emotions, behaviour, hearing, vision and activities of daily living as well [2]. Dependency thus ensues, cause significant detrimental effects on the quality of life of CP children and their families.

In Sri Lanka, like in most developing countries the responsibility of providing care for a CP child is mainly on immediate family members. Out of challenges and difficulties faced by these families, what is seen by the society is only tip of the ice berg. Most families suffer silently, without much assistance from the state or society. Increased awareness is been created about the need of a well-structured welfare system to support families with CP children, but such a system is still to operate in Sri Lanka.

Guyard et al reviewed the available literature on 'Impact on parents of cerebral palsy in children', have suggested further research before a complete model of, the CP child's impact on parents can be tested. [3] There are no data in medical literature on Sri Lankan set up. We hope results of our study will help to narrow the gap in medical literature, and improve the socio-economic conditions of families with CP children.

Method

Study setting and subject selection

A descriptive cross sectional study was carried at three hospitals in Sri Lanka, which are referral centres for CP children. CP children coming for treatment at these hospitals were selected on all-inclusive consecutive basis.

Study instruments and data collection

Data collection was from June 2014 to December 2015. A pretested, validated, interviewer administered questionnaire was used to collect data. Information about the child and the family were obtained from the accompanying parent. One investigator was assigned for data collection at

each site. Only CP children accompanied by mother or father were recruited. To avoid a child been included more than once, a red tag was issued to the parent after data collection and was inquired about it before recruitment. Precautions were also taken regarding this during data entering and analysis.

Permission and ethical issues

Permission to conduct the study was obtained from authorities of the three institutions. Informed written consent was obtained from parents prior to recruitment. All information received was treated confidential and used only for the study purposes. Ethical clearance was obtained from ethics and research committee of faculty of Medicine, University of Kelaniya.

Data analysis

Data analysis was done using statistical Package for social sciences (SPSS) version 16. Parents not living with the family were excluded, when number of hours spent by each parent with the child was analysed. When parents were separated, situation that prevailed in the family prior to separation was considered when appropriate.

Results

Characteristics of children

A total of 300 children were recruited. Out of this 154 (51.3%) were females. Age of children ranged from six months to 16 years, with a mean of 4.1 years and standard deviation 2.61.

According to the birth order 186 (62.0%) children in the study were first borns, while 74 (24.7%) and 37 (12.3%) were second and third child of the family.

Majority of children, 158 (52.7%) had quadriplegia, while 45 (15.0%) were diplegics and 67 (22.3%) were hemiplegics. Nineteen (6.3%) had hypotonia and 11 (3.7%) had dystonia.

Socio-demographic factors

Most parents were reasonably well educated. The majority, 57.3% mothers and 54.7% fathers had studied up to grades 6- 11. Thirty four percent mothers and 31% fathers

had studied up to grade 12 – 14. There was no significant difference in the level of education between mothers and fathers.

Out of 300 mothers 249 (83%) were housewives. One mother was abroad. Others (50) were employed in various sectors. Out of 300 fathers, three were dead. Seven were working abroad, and six were not employed.

Majority of the sample included low and low middle income families. In 159 (53%) families monthly income was less than 20,000 Sri Lankan Rupees (150US\$), with only 64 (21.2%) families had an income above 40,000 Sri Lankan Rupees (300 US\$)

Commitment of parents towards the child

Major burden caring for CP children was on the mothers. Two hundred and twenty mothers (73.6%) claimed spending 20- 24 hours of the day with the CP child. Majority of fathers spent less than 10 hours with the child. Breakdown of number of hours spent by parents are depicted in table 1.

Table 1.
Number of hours spent by parents caring for the child

hours	Number of	Mothers	Father
24	20-	220 (73.6%)	06 (02.1%)
19	15-	24 (8.0%)	03 (01.1%)
10	14-	23 (7.7%)	09 (03.3%)
09	05-	25 (8.4%)	154 (55.6%)
	< 5	07 (2.3%)	105 (37.9%)
Total*	Total	299 (100%)	277 (100%)

*One mother and 20 fathers are not living with the family and three fathers are dead.

One hundred and forty seven CP children in the study were hospitalized 1-5 times, 30 children 6 – 10 times and nine children more than 10 times during past year. Mother had to stay with the child during most of these hospitalizations. Table 2 gives number of days mother had spent in the hospital with the CP child during past year.

Table 2
Number of days mother spent in the hospital during past year.

Number of days	Number of mothers	Percentage
0	114	38.0%
1-10	80	26.7%
11-20	31	10.3%
21-30	33	11.0%
31-40	03	01.0%
41-50	05	01.7%
>50	34	11.3%
Total	300	100.0%

Adverse socio-economic effects

Only 140 (46.7%) CP children had siblings. Out of this 82 (58.6%) parents felt other children are neglected due to the CP child, and 79 (56.4%) admitted feeling guilty. Forty one (29.3%) parents admitted other siblings were complaining that they are being neglected. Most of the parents (88.5%) believed other siblings were supportive and helpful towards the CP child. Twenty (14.3%) parents ad-

mitted siblings demonstrated anger towards the CP child at times.

Sixty seven mothers (22.3%) and 22 (7.3%) fathers had left employment because of the child and 43 (15.7%) fathers had changed their employment. Eighteen mothers (6%) and six (2%) fathers abandoned higher education. The residence of 33 (11%) families had to be changed.

In 166 (55.3%) families, parents were feeling responsible for the child's condition; In 47 (15.7%) families parents were blaming each other for it. Marital disharmony due to child's illness was reported by 44 (14.7%) families and 13 (4.3%) parents got divorced or separated.

After the CP child, 172 (57.3%) parents avoided pregnancies. Out of this, 135 (78.5%) avoided a pregnancy because fear of a recurrence plus commitment towards the CP child. Commitment and fear alone was the reason in 31 families (18.0%) and six families (3.4%) respectively. Out of these 172 parents, 114 (66.3%) had only the CP child and 47(27.3%) did practice any form of contraceptives.

Parents were spending a significant proportion of their income on CP child's medication, transport, diapers and appliances etc. Table 3 depicts the approximate amounts spent by parents over a month.

Table 3
Monthly expenditure on CP child

Amount spent (SLR)	Number	percentage
0- 2,500	30	10.0%
2,500- 5,000	86	28.7%
5,000- 15,000	145	48.3%
15,000- 25,000	23	07.7%
25,000- 35,000	09	03.0%
>35,0000	07	02.3%
Total*	300	100.0%

140 SLR = 1US\$

Discussion

In Sri Lanka education and basic health facilities are provided free. People with chronic disabilities are given a monthly allowance of 3,000 Sri Lankan Rupees (22 US\$). Special schools, and normal schools with special classes are available for differently able children. However the extensive social welfare support for differently able children found in developed countries is not available in Sri Lanka. Yee et al have shown the quality and type of care received by CP patients are likely to determine the degree of handicap and effects on quality of life [4]

Caring for a CP child seems to cause immense pressure on parents, with serious consequences on wellbeing of the family, even up to total disruption of family life. Lack of proper understanding about CP cause a guilty feeling in parents, and leads to blaming each other. Apart from stress of caring the child, this too contribute significantly towards marital disharmony. Olawale et al have shown that proper understanding about CP will help families to cope better with the challenges [5].

Parents avoid further pregnancies though recurrences are

unlikely in most cases. Fear that CP child will get neglected and cost of bringing up another child are other main reasons to avoid pregnancies. Unfortunately a significant percentage of such couples have only the affected child. With time when parents can no longer support them, CP children need siblings for help. In Sri Lanka with an extended family structure, children are expected to look after their elderly parents. Most of the CP children are unlikely to do this. Thus parents need counselling regarding having siblings. Some parents who decided not to have more children were not practising a contraceptive method. Probably they may be avoiding sex as a precaution, which will contribute towards serious marital disharmony.

It is sad that a significant number of mothers and few fathers had carrier losses in terms of education and employment. This would have been prevented by a good social support with better socio-economic prospects to the family. Father's contribution towards care was low, while mothers spending most of her time with the CP child. Both parents should be encouraged to share the work load, so that mother can pay attention towards other children as well.

When CP children are hospitalized, mother usually stays with the child. During this period other siblings will be neglected with detrimental effects on their health and education. There are reported cases of child abuse occurring under such circumstances [6]. Parents focusing their attention on the CP child could cause feeling of insecurity, jealousy and anger among other siblings. Offering respite care in managing the CP children will help to ease this tension.

Another major concern for families with CP children is social isolation. Due to non-availability of respite care, they are unable attend social functions like weddings, religious activities, social gatherings etc. Some parents get adapted to it so that their entire world becomes the child, but for some this may be distressing. Continues psychological support for parents is thus important.

If accurately assessed the cost of managing a CP child can be surprisingly high. According to United States centres for disease control and prevention, the life time cost for a person with Cerebral Palsy born in 2000 is \$11.5 billion. This includes direct medical and non-medical costs plus indirect cost due to productivity loss [7]. According to our study, parents are spending significant amounts on management of their child with their limited income, which is already compromised by the child's condition. The disability allowance from government is hardly adequate to cover this. As government cannot handle this situation alone, there is a need to set up a mechanism supporting families with CP children. Currently few foundations exist in Sri Lanka to help families with CP children and support groups are also being established. However this study indicates that their achievements are far from ideal. Voluntary organizations and medical professionals should join hands to optimize the support activities for families with CP children.

Conclusion

Sri Lankan families with CP children suffer a lot in silence. The burden seen by the society is only the tip of an iceberg. A more organized and structured mechanism is in need to support these families.

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Conflicts of interest

All authors declare no conflicts of interest in publishing this paper.

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