

Original Article

Level of maternal stress and its association with motor performance of children with cerebral palsy

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Keywords: maternal stress, motor performance, cerebral palsy

Abstract

Introduction

Cerebral palsy (CP) is a motor dysfunction seen among children due to an insult to the developing brain. Mother plays a major role in the family dynamics of Sri Lankan society and stresses experienced by mothers caring for such children are higher. The study attempts to describe the level of stress of mothers of children with cerebral palsy and associations with socio-demographic factors and motor performance of the child.

Methods

A descriptive cross-sectional study was conducted at the Lady Ridgeway Hospital and Navajewana Rehabilitation Centre, Tangalle. One hundred CP children and their mothers were enrolled and the Parental Stress Index was used to assess the level of stress. Socio-demographic data was collected using an interviewer administered questionnaire. Motor performance of the children was measured using the 30s walk test and section D & E of the Gross Motor Function Measure.

Results

Mean age of mothers was 33.4 years. Mean Parental Stress Index was 49.6 with 44% of mothers showing high stress levels. Level of stress was significantly associated with low income ($p < 0.001$) and female gender of the child ($p = 0.001$). Age ($p = 0.633$) and educational level of mother ($p = 0.501$) did not show any association. There was no relationship between maternal level of stress and motor performance of the child ($p = 0.947$).

Conclusion

Certain socioeconomic factors that increase the stress of mothers of CP children are identified. It is important to have programmes to provide some support to these mothers in order to alleviate such stress and improve the outcomes of home management of CP children.

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Received: October 2016, Accepted revised version: November 2016, Published: December 2016

Competing Interests: Author has declared that no competing interests exist

Introduction

Cerebral palsy (CP) is a group of permanent disorders of movement and posture that are attributed to non-progressive disturbances in the developing brain and affect 3.3 per 1000 births¹. There are several classifications of cerebral palsy but the common feature seen in all is lack of physical ability, affecting the function and health of the child. The most common early sign of CP is delay in reaching key development

milestones, such as gaining head control, rolling over, sitting, crawling and walking. The primary effect of cerebral palsy is defective muscle tone and gross and fine motor dysfunctions affecting balance, control, reflexes and posture².

Care giving is a primary role of parents and is usually a smooth function done with minimum effort. However, this role holds an entirely different significance when the child has functional limitations. Children with CP need expensive long term medical and family care. A multidisciplinary team has to be involved and the contributions may vary depending on the severity of the condition. Most often, the team would comprise of a paediatrician, physical therapist, occupational therapist, dentist, speech therapist, nutritionist, social worker, counselor and behavioural therapist. These health care workers focus on family-centered rehabilitation programs as most of the general hospitals with rehabilitation institutes are centered in and around main cities, at a distance from the patient. Hence, the parents are the most important stakeholders in continuing the rehabilitation programme³.

Every parent is under significant stress until their child is sufficiently grown, both physically and developmentally, to be independent. When a child is ill, parents, especially mothers, are more stressed. When it is a CP child the situation is entirely different. Parents are always worrying and stressed about the condition and the future of their child as there is always uncertainty regarding recovery. Although some mothers understand and accept their child's condition and adjust to it, all may not do so. Factors associated with these diverse responses are not fully understood. Such factors could include mother's personality, age, spousal support, social support, family income, number of children and educational level of parents. .

The physical therapist plays a key role in treating children with CP, and it is the commonest condition a pediatric physical therapists would treat⁴. Home-based therapy is important to achieve an effective outcome. The psychological status of the mother is directly related to the success of home-based physical therapy treatments. There could be an association between maternal stress and the level of motor performance of the child

It is estimated that CP affects over 40,000 Sri Lankan children⁵. In developed countries, 6 CP children per 1000 births are recorded and the figure is much higher in Sri Lanka, with around 12 to 15 children per 1000 births⁵. Therefore, cerebral palsy is a commonly prevalent illness among Sri Lankan children leading to a high degree of morbidity.

In the Sri Lankan family, the mother is the main care provider. Adverse psychological states in the mother could adversely affect family dynamics and lead to major social issues as well as issues in the provision of care to the child. Therefore, it is important to determine the level of stress in mothers caring for CP children and associated factors. Measures to alleviate such factors would help to improve the care and outcome of CP children. Therefore, this study was designed to identify the level of maternal stress and its relation to motor function in a group of Sri Lankan children with CP.

Methods

A cross-sectional, descriptive study designed to measure the maternal level of stress and its impact on the motor performance of children with CP was carried out at the Lady Ridgeway Hospital for Children in Colombo, Sri Lanka and the special school at Navajeewana Rehabilitation Centre in Tangalle, in the Southern Province. The study population included children aged between 6-12 years who were diagnosed with spastic diplegic CP and their mothers.

Inclusion criteria were mothers capable of reading and writing in Sinhala, Tamil or English as they had to complete a self-administered questionnaire and children able to follow simple verbal directions, walk independently, with or without a walking aid (levels I–III according to Gross Motor Function Classification System [GMFCS]), and willing to attend the physiotherapy department for at least 3 months for follow up. The children should not have undergone any surgical procedures to correct any limb defects and should have age appropriate behaviour.

Considering the time and resources available, a sample size of 100 CP children and their mothers were selected by convenience sampling. Potential participants were selected from the register of the Physiotherapy Department of the Lady Ridgeway Hospital and Navajeewana Centre. Children underwent screening to confirm the diagnosis and assess GMFCS level. An interviewer administered questionnaire was used to collect the socio- demographic data of the child and mother. The Thirty Second Walk Test (30Wts) in which children were asked to walk at their preferred speed was used to measure the walking speed of the children. Gross Motor Function Measure Sections D and E (GMFM66) were used to evaluate changes in gross motor function in children with CP, especially in walking, running, and jumping. Parental Stress Index (PSI) was used to measure maternal level of stress. The participants were divided into two groups (high stress & low stress) using the median stress score (51) as the cut off.

The Thirty Second Walk Test (30Wts) is an internationally recognized test to measure the walking speed of children, especially children with suspected limitations of mobility. Research done by Lorretta M Knutson and co-workers has proved that the thirty second walk test is a standard measurement for mobility⁶. Kristie F Borjinson and co-workers have validated the GMFM as a measure of change in motor function in children with spastic di-plegic cerebral palsy⁷.

Statistical analysis was performed using SPSS version 21.0 and the level of significance was considered to be at a $p < 0.05$. Pearson's correlation was used to analyse the relationship between maternal stress and motor performance of children with CP. Factors associated with maternal stress were analyzed using Pearson's correlation (age of mother and stress), one way ANOVA test (educational level of mother and stress, economic level of mother and stress) and independent sample t test (gender of child and stress).

Ethics clearance was obtained from the Ethics Review Committee of the Faculty of Medicine, University of Colombo prior to conducting the study.

Results

One hundred baby-mother pairs were recruited (62 males). Forty three percent of children were between the ages of 9-11 years. Only 8 children did not have siblings. Mothers' age ranged between 24 years to 52 years with a mean (SD) age of 33.38 (6.14) years. Most of the mothers were between the ages of 31-40 years and there were only 2 above 50 years of age. Most of the mothers had completed the General Certificate of Education (Advanced Level) (n=66) and all of them had completed the General Certificate of Education (Ordinary Level). Only 3 had tertiary level education. All mothers were housewives and the majority had a monthly family income between LKR 20,000-30,000 with 40% having a monthly income below LKR 20,000.

Level of stress of the mothers

Stress level scores ranged from 28 to 66 with a mean (SD) of 49.6 (10.2) Table 1 gives the distribution of the stress levels of the mothers. Most of the mothers (37%) had stress scores of 49-58. And 44% had high stress levels.

Table 1: Distribution of stress levels of the mothers

Stress level score	(%)
18-28	6
29-38	9
39-48	22
49-58	37
59-68	26
Total	100

N=100

Factors associated with the stress level of mothers

Factors associated with the stress level of mothers were assessed. Age of the mother did not show an association with stress ($r=0.05$, $p=0.633$). As shown in table 2, the highest mean stress scores (59.03 ± 3.309) were seen in mothers with a monthly income below LKR 20,000 while the lowest mean stress score (39.11 ± 7.688) was seen in mothers with a monthly income of over LKR 30,000. The association of mean stress scores and monthly family income was statistically significant ($F(2,97)=71.549$, $p=0.000$).

Table 2: Relationship between monthly income of family and level of stress

Monthly Family Income	N	Mean	SD	Significance
Below 20,000	40	59.03	3.309	*p= 0.000
20,000-30,000	51	44.00	8.080	
30,000-50,000	9	39.11	7.688	
Total	100	49.57	10.203	

*Significance is calculated using one way ANOVA test.

Table 3: Relationship between educational level of mother and level of stress

Educational level of mother	N	Mean	SD	Significance
Ordinary Level	31	49.68	10.374	*p= 0.501
Advanced Level	66	49.21	10.308	
Graduate	3	56.33	3.512	
Total	100	49.57	10.203	

Educational level was not significantly associated with stress levels of the mothers ($F(2,97)=0.697, p=0.501$) (Table 3). However, graduate mothers' mean stress scores were the highest compared to the other two groups.

The stress levels of the mothers with a female CP child were higher than those of the mothers with a male CP child. The mean stress score of mothers of female CP children was 53.47 (SD= ± 7.928) and the mean stress score of mothers of male CP children was 47.18 (SD= ± 10.748) and the difference was statistically significant ($t(94.54) = 3.357, p=0.001$).

Motor Performance of children with Cerebral Palsy

The 30 seconds walk test

Scores of the 30s walk test ranged from 8 to 30m with a mean of 18.49m (SD= ± 5.89512). Most of the children (47%) were able to score between 17-24m. Only 17 children were able to walk more than 25m.

Gross Motor Function Measure

Scores in the GMFM section D ranged from 9 to 37 with a mean of 23.33 (SD= ± 5.946) Most of the children (54%, n=54) scored between 21-30 and 15 children scored above 31. Scores of the GMFM section E ranged from 16 to 72 with a mean of 54.86 (SD= ± 13.094). 48% scored between 41-60 and only 14 children scored below 41. Scores of the GMFM section D & E ranged from 27 to 109 with the mean of 78.19 (17.5) Most of the children (n=58) scored between 61-90 and only 2 children scored below 30.

Relationship between maternal stress level and motor performance of children

The correlation between maternal level of stress and motor performance was evaluated and according to Pearson's correlation there was no significant association between mothers' stress level and any of the measures used to assess motor performance of the CP children (Table 4).

Table 4: Correlation between maternal level of stress and motor performance

Motor performance measure	R	p
The 30s walk test	0.106	0.296
GMFM section D	-0.068	0.503
GMFM section E	0.022	0.83
GMFM section D & E	-0.007	0.947

Discussion

Although almost 35% of Sri Lankan women are in the work force, all the mothers in our study were house wives⁸. In this study sample, 66% of mothers had completed the G.C.E. A/L examination but were not employed. This indicates that having a child with CP in the family has affected their economic situation, as many mothers although they had the capacity to be employed would have stayed back at home to take care of their disabled child.

In this study, 44% of mothers had high levels of stress. A cross-sectional study done in Europe by Parkes et al. to assess stress in parents (n= 818) of children with CP (using PSI short form) showed that 26% of mothers had high levels of stress⁹. This difference could be due to the difference in social support provided by European governments when compared to Sri Lankan social services. In Western societies the social services departments provide not only financial support but also trained carers to look after the baby and transportation facilities to take the child to hospital for regular follow up. In the local setting, all these have to be organized by the family itself and, naturally, this would increase stress in Sri Lankan mothers. Furthermore, Sri Lanka, like many other Asian countries has societal pressures that are different from European countries. Mothers would have more fears regarding the future of their child as well as have to cope with the social stigma surrounding having a disabled child.

Unlike previous studies in Bangladesh¹⁰ and India¹¹ our study did not show an association between the age of the mother and the level of stress. A possible explanation could be that the participant mothers in our study were above 25 years of age and life experience and maturity could have provided them with some coping skills.

The economic status of the family was inversely correlated with the level of stress. This is not surprising in a setting where there is minimum support from the state or other organizations to ease the economic burden of caring for these children. Similar data had been shown before in a Sri Lankan study¹² as well as in a study from Bangladesh¹⁰.

The culture of Sri Lanka is such that parents sacrifice most of their time and resources for the betterment of the family and the situation only becomes worse when there is a child with special needs. Mothers in this study were unemployed, although many had completed their secondary education. Therefore, the fathers become the sole breadwinners, which directly affect the economy of the family. In Asian countries children are kept under the protection of their parents for a long period of time, sometimes until the late twenties. In Sri Lankan society, the girl gets special protection and parents take utmost care to ensure a secure future for her. However, if there is a girl child with special needs in the family, the parents would have even more stress regarding her future.

Similar to this study that did not show any correlation between the stress level of the mother and the motor performance of child, Parkes et al. in their study, did not show

any association between the level of maternal stress and motor impairment⁹. A study done by Park and co-authors to determine parenting stress in parents of children with cerebral palsy and its association with physical function reported that the global function scores of the pediatric outcomes data collection instrument and ambulatory states (gross motor function classification system) were significant factors contributing to the total PSI score, where parents of children with a more favorable function showed a higher PSI score¹³. A Taiwanese study to determine parental stress and related factors in parents of children with cerebral palsy reported that the PSI total scale score was significantly associated with the child's severity of motor disability and age of commencing rehabilitation¹⁴.

When it comes to motor performance of a child and its contribution to maternal stress, it is not easy to understand the relationship. Motor performance of children can be affected when parents having high stress and lack of coping strategies become less interested in the child's rehabilitation process and do not provide effective physical training. In contrast, lack of motor abilities or severe motor impairment of a child makes parents more disappointed and stressed. When there is no improvement in motor function, it causes stress to parents too. This stress may lead to lack of interest in the child's rehabilitation programme and further reduce motor performance of child. This enters into a vicious cycle. Therefore, finding no relationship between motor performance of the child and maternal stress was an unexpected finding-

One of the main factors that increased the level of stress in this population of mothers is low family income. Compared to many countries, the social welfare for a family burdened with a child with special needs is very limited in Sri Lanka. Although our study did not show that it affects the functional outcome of the affected children, it could have a bearing on the psychological aspects of the CP child and the happiness and quality of life of the other members of the family. Therefore, providing adequate social support to families of children with CP is of paramount importance.

Limitations

The study was carried out in only two settings so that subject recruitment was limited. There was a lack of variation in the study sample in terms of socioeconomic status and ethnicity as most of the mothers were Sinhalese and from the lower income group. All of them were educated up to a certain extent. The homogeneity of the characteristics of the mothers limits the generalizability of these findings. This research is also limited by the lack of a comparison group.

Other limitations seen in this study are that children were anxious in the presence of a stranger and were reluctant to perform to the best of their ability on commands. Because of the nature of children it was difficult to gain maximum performance in some tests. Every child who participated in this study had locomotor ability up to some extent. So lack of variability in functional abilities also limited the study.

Conclusion

According to the results of the study, nearly half of the mothers were suffering from high levels of stress, directly influenced by the economic status of the family.

Economic burden and female gender of child were major associates for stress. Therefore, apart from providing the free health services required for the management of such children, it is important to provide adequate social support to affected families which would, in return, improve the quality of care given by the mother for rehabilitation of the child with CP and uplift the quality of life of the entire family.

References

1. Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy. *Dev Med and Child Neuro.* 2005; 47; 571–576. <http://dx.doi.org/10.1017/S001216220500112X> PMID:16108461
2. MyChild at Cerebral Palsy.org [Internet]. Michigan: Help Resources for Children with CP. [cited 2014 Nov 24]. Available from <http://www.cerebralpalsy.org/about-cerebral-palsy/sign-and-symptoms>
3. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. *SeminPediatrNeurol* 2004(11):78-86. <http://dx.doi.org/10.1016/j.spen.2004.01.009> PMID:15132256
4. Peter Rosenbaum. Cerebral palsy: what parents and doctors want to know. *BMJ* [Internet] 2003 May [cited 2014 Nov 14] 326(7396): 970-974. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1125882/>
5. Aloysius C. Cerebral Palsy Least understood physical disability. *The Nation.* Jun24 2012.
6. Knutson LM, Schimmel PA, Ruff A. Standard Task Measurement for Mobility: Thirty-Second Walk Test. *Journal of paediatric physical therapy.* 1998. Available from http://www.researchgate.net/publication/232206611_Standard_Task_Measurement_for_Mobility_Thirty-Second_Walk_Test
7. Bjornson KF, Graubert CS, Buford VL, McLaughlin J. Validity of the Gross Motor Function Measure. *Journal of paediatric physical therapy;* 1997. Available from http://www.researchgate.net/publication/232172406_Validity_of_the_Gross_Motor_Function_Measure
8. Department of Census & Statistics. *Bulletin of Labour Force Statistics of Sri Lanka, Sri Lanka Labour Force Survey, Department of Census & Statistics, Sri Lanka.* 2011.
9. Parkes J, Caravale B, Marcelli M, Franco F, Colver A. Parenting stress and child with cerebral palsy: a European cross sectional survey. *Dev Med and Child Neuro.* 2011; 53(9): 815-821. <http://dx.doi.org/10.1111/j.1469-8749.2011.04014.x> PMID:21707599
10. Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Paediatric Psychology.* 2000; 25(6):427-430. <http://dx.doi.org/10.1093/jpepsy/25.6.427>
11. Vijesh PV, Sukumaran PS. Stress among mothers of children with cerebral palsy attending special schools. *Asia Pacific Disability Rehabilitation Journal.* 2007; 18(1): 76-92.
12. Wijesinghe CJ, Cunningham N, Fonseka P, Hewage CG, Ostbye T. Factors associated with care giver burden among caregivers of children with cerebral

- palsy in Sri Lanka. *Asia-Pacific Journal of public Health*. 2015; 27: 185-195.
<http://dx.doi.org/10.1177/1010539514548756PMid:25204802>
13. Park MS, Chung CY, Lee KM, Sung KH, Choi IH, Kim TW. Parenting stress in parents of children with cerebral palsy and its association with physical function. *Journal of PeadiatricOrthopaedics B*. 2012; 21(5): 452-456.
<http://dx.doi.org/10.1097/bpb.0b013e32835470c0>
14. Wang HY, Jong YJ. Parental stress and related factors in parents of children with cerebral palsy. *Kaohsiung Journal of Medical Sciences*. 2004; 20(7): 334 – 340.
[http://dx.doi.org/10.1016/S1607-551X\(09\)70167-6](http://dx.doi.org/10.1016/S1607-551X(09)70167-6)