



ORIGINAL RESEARCH PAPER

Paediatrics

CLINICO-SOCIAL PROFILE AND PARENTAL PERCEPTION OF SOCIO-ECONOMIC CHALLENGES FOR CEREBRAL PALSY CHILD IN LOWER SOCIO-ECONOMIC STRATA

KEY WORDS: Cerebral Palsy, Social class, Economic Burden of Disease

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ABSTRACT

BACKGROUND: Physical independence ,schooling ,economic burden and social life affection are common issues among the children with cerebral palsy in lower socio-economic class in India. This study was planned with an objective of determining the clinico social profile and perception of parents about socio-economic challenges with regards to schooling, economic burden and physical independence for cerebral palsy child in lower socio-economic strata. Hence by knowing these factors, targeted issues can be managed with priority in lower socio-economic class.

Method : A prospective observational study was carried out from July 2015 to December 2015. Children diagnosed as cerebral palsy from 1 to 12 years were enrolled and interviewed at tertiary care hospital in predesigned pre validated questioner with specific emphasis on clinico social profile and socio economic challanges. Critically sick children were excluded .

Results: Total 50 children of were enrolled. Maximum number of cases were spastic (84%) variety .In spastic type commonest being diaplegic, followed by hemiplegic type. Most common prenatal factor associated with cerebral palsy was pregnancy induced hypertension (30%) followed by birth asphyxia. Parent perceived economic as well disease in a child affects social life.

INTRODUCTION:

Cerebral palsy is a static encephalopathy and may be defined as, "a non-progressive disorder of posture and movement often associated with epilepsy and abnormalities of speech, vision and intellect resulting from a defect or lesion of developing brain"⁽¹⁾. It involves a myriad of factors. Injury to the developing brain may be prenatal, natal or postnatal. Risk factors known to play a role in the development of cerebral palsy include multiple gestation, gender, infection, prematurity and low birth weight as well as genetic determinants⁽²⁾.

The overall prevalence is 2.5 per 1000 children in the world. About 2 to 3 out of every 1,000 children have CP, making it the most common neuro-developmental motor disability in children^(2,3).

Cerebral palsy is a clinical diagnosis. Most patients exhibit symptoms as infants or toddlers , diagnosis is often made before 2 yrs of age. Cerebral palsy can be classified on the basis of type and severity of the motor abnormality as spastic (may be diplegic, hemiplegic or quadriplegic), dyskinetic (choreoathetoid or dystonic), ataxic or mixed types of CP⁽²⁾. Delayed motor milestones are one of the common complaints⁽⁴⁾.

Especially in India with more patients from lower socio-economic class have many limiting factors for availability of multidisciplinary treatment which if given early can make a child at least self-dependent. Physical independence ,schooling, economic burden of disease and social life affection are common issues in lower social class.

This study was planned with an objective of determining the ,clinico social profile and perception of parents about socio-economic challenges with regards to schooling, economic burden and physical independence for cerebral palsy child in lower socio-economic strata. So by studying above factors ,social education and targeted issues can be managed with priority in cerebral palsy child in lower socio-economic class.

MATERIALS AND METHODS

A prospective observational study was carried out from July 2015 to December 2015. A total of 50 cerebral palsy children and their parents as a single unit were interviewed. The study included children already diagnosed with cerebral palsy at tertiary care hospital , department of pediatrics of Govt. Medical college Miraj and P.V.P. Government Hospital Sangli.

The inclusion criteria was a diagnosed case of cerebral palsy

between 1 year to 12 year of age, visiting OPD or admitted in the IPD belonging to low social class (Kuppuswamy) III, IV and V were included. Parents as single unit were enrolled & interviewed in predesigned pre validated questionnaire.

The exclusion criteria was, critically ill child admitted in pediatric intensive care unit and if the parents showing resistance in giving consent for history taking were excluded.

STUDY PROCEDURE

1. A detailed history was taken from parents and medical records were checked and entered into pre-structured proforma with specific emphasis on antenatal, birth history, neonatal history, chronic medical problems, and predisposing factors. Along with anthropometric measurements ,general, systemic and central nervous system examination were done . Socioeconomic status was classified according to modified KUPPUSWAMY classification⁽⁵⁾.

Cerebral palsy was classified according to the Edinbergh classification⁽⁶⁾.

Social interaction and dependency on parents or caretaker was enquired with specific emphasis on schooling and daily activities performed by the patient.

Physical dependence was defined as, any assistance required from caretaker to carry out day to day routine activities.

Schooling was enquired with emphasis on special schooling & mainstreaming.

Parental perception of disease affecting social life ,social stigma & stress on sibling were enquired. Parental perception about economic burden due to disease affecting their child were enquired.

2. Data analysis was done by using Microsoft Excel 2010 .
3. Written informed consent were taken from parents.
4. Ethical Committee approval was taken from Institutional Ethical Committee .

RESULTS

Total 50 children of cerebral palsy in the range of 1 to 12 yrs, were enrolled from July 2015 to December 2015. The study included more boys (64%) than girls (36%). Around 78% among them were Hindu in religion 22% of them Muslims. As per modified Kuppuswamy classification, maximum cases belonged to class IV 28(56%) followed by class III 12(24%). Consanguinity is found in only 16% of cases.

Table 1: Demographic Factors

General Factors	No. of cases(Percentage)
i) Gender	
Male	32(64%)
Female	18(36%)
ii) Socio-economic status	
III	12(24%)
IV	28(56%)
V	10(20%)
iii) Religion	
Hindu	39(78%)
Muslim	11(22%)
iv) Consanguinity	
Yes	8(16%)
No	42(84%)

Table 2: Clinical Types Of Cerebral Palsy As Per Edinbergh Classification

Type of cerebral palsy	Number	Percentage
i) Spastic	42	84
a) Diplegic	25	59.52
b) Hemiplegic	11	26.19
c) Quadriplegic	5	11.9
ii) Dyskinesia	1	2
a) Choreoathetoid	1	2
b) Dystonic	-	-
iii) Ataxia	4	8
iv) Mixed	3	3

Maximum number of cases were spastic (84%) variety .In spastic type commonest being diplegic, followed by hemiplegic type.

Table 3: Predisposing Factors Of Cerebral Palsy

Prenatal factors	No.(%)
PIH	15 (30)
Maternal age (<20)	10 (20)
Trauma	3(6)
Anemia	2(4)
Infection	1(2)
Natal Factors	
Birth asphyxia	24 (48)
Prematurity	11 (22)
Postmaturity	10 (20)
Low birth weight	12 (24)
Postnatal factors	
Neonatal jaundice	6(12)
Hydrocephalus	1(2)
Unknown (Can not be specified)	4 (8)

Most common prenatal factor associated with cerebral palsy was pregnancy induced hypertension (30%). Birth asphyxia was the single most common perinatal factor . Total 54% of babies had been admitted to NICU. In 8% of cases no any predisposing factor were found .

Table 4: Socio-economic Burden

Various heads under socio-economic burden	Yes (%)	No(%)
Physical dependence	50(100)	0
Schooling (Between age group of 3 to 12 years)	12(25)	38(64)
Special school	9(75)	-
Mainstreaming school	3(25)	-
Subjective feeling of economic burden by parents	50(100)	-
Social Life		
Affects parents social life	48(96)	-
Social stress on siblings	21(42)	-
Social stigma	4(8)	-

The dimensions of physical independence, economic burden, social integration and parents social life were more severely

affected. One positive aspect of this study was that in spite of the illiteracy and the lower socio-economic status of the family, social stigma was not a part of this society. Only 25% of children were even sent to schools of which 75% were enrolled in special school for the disabled where all the special needs of the children were taken care of and they were also provided physiotherapy. Majority of parents perceives as their social life is affected (96%) and 21(42%) feels social stress on sibling.

Common worries were about the future of the child, need for more support services for health problem

DISCUSSION:

Results of our study shows that in lower socioeconomic strata physical independence, economic burden, social integration and parents social life were severely affected in a child having cerebral palsy .Spastic diplegic cerebral palsy was commonest type of palsy and pregnancy induced hypertension and birth asphyxia were commonest risk factors among lower socioeconomic class.

It was observed that males (64%) were more affected with a sex ratio of 1.7:1. Similar results were noted in various other studies(1,2). Around 78% of them affected were Hindus. With the best of our knowledge and extensive search we were not able to find out exact religion wise studies in India. The higher incidence of the disease in Hindus could probably be the result of population distribution around the area where the study was conducted. There was no role of consanguinity seen in this study. However, in a study by Areeb Sohail Bangash et al consanguinity was found to be the main risk factor(2).

Eighty four percent of the cases constitute of spastic cerebral palsy of which 59.52% were of diplegic variety followed by hemiplegic. Consistent results were obtained in various studies^{1,2,7}. However in the study by Ashutosh Gangil et al(8), spastic quadriplegia was more common with the incidence of 75%.

In our study diplegic cerebral palsy is the most common variety, this is because in our study we have more number of low birth weight babies as mothers are from lower socio-economic class and diplegic palsy is more in low birth weight babies. Hence results are in contrast to other studies.

Various predisposing factors causing damage to the developing brain may lead to clinical picture of cerebral palsy and may act prenatally, natively or postnatally. Most common prenatal factor associated with cerebral palsy seen in our study was pregnancy induced hypertension (30%). Gowda VK et al⁽⁸⁾ has observed similar results. Birth asphyxia is the most important perinatal factor. This finding is consistent with study by Punit Sharma et al⁽⁹⁾. In the present study low birth weight of the baby emerged to be the most common postnatal factors. As our study included people from lower socio-economic strata, lack of antenatal care puts the mother and her unborn child at an increased risk of prenatal, natal and postnatal complications during pregnancy thereby increasing the risk of cerebral palsy in the unborn child.

There was 100% dependence of child on his parents to carry out his daily activities which completely disrupted parents social life. A wide range of problems are faced by the parents and other family members. They are constantly in a state of stress. Worries ranging from child's future, health problems to the economic burden experienced while meeting the needs of the child are all what they think for an entire day. Similar study conducted by Nimbalkar et al⁽⁹⁾ shows , that parent faced a wide range of psychosocial problems⁽¹⁰⁾. In our study we have also noted that sibling of a cerebral palsy child is also affected with psychosocial neglect.If cerebral palsy affected child is younger, elder sibling has to take his responsibility when parents are busy. This scenario is more commonly seen in lower socio-economic strata in India.

Social stigma was not a major problem of this strata of society. Parents even enrolled their children to school (25%). Some in special schools while others in the mainstream. However, all of this tremendously increased the economic burden on the parents.

There is a need to provide them with long-term care, taking into account medical and social aspects as well as rehabilitation, education, and assistance⁽¹¹⁾. This long-term care must be suited according to children's developmental stage and their physical, psychological, and social development within their life contexts. Disease also affects family as a whole, due to the resulting distress, adjustment efforts, and changes in quality of life. This impacts heavily on the national health systems which must set up a strong network of services under one roof for children with cerebral palsy.

CONCLUSION:

Spastic diplegic cerebral palsy was the commonest palsy and pregnancy induced hypertension, birth asphyxia were common risk factor associated in children with cerebral palsy in low socioeconomic.

Parent perceived economic as well disease in a child affects social life.

REFERENCES:

1. Puneet Sharma, Usha Sharma, Ashok Kabra. Cerebral palsy – Clinical profile and predisposing factors, *Indian Pediatrics* 1999;36: p1038 -1042.
2. Areeb Sohail Bangash, Muhammad Zaid Hanafi, Rabialdrees, Nohsheen Zehra. To determine the risk factors and associated types of CP in squatter settlement of Karachi, 2010-2011, pages 32-36.
3. Neil McIntosh, Peter Helms, Rosalind Smyth. Forfar and Arneil Textbook of Paediatrics, 6th ed. Spain, Churchill Livingstone, Euope Publication, 203. page nos. 647 – 660.
4. Siġan SN, Uzunhan TA, Aydinli N, Eraslan E, Ekici B, Caliskan M Effects of oral motor therapy in children with CP, *Ann Indian Acad Neurol*. 2013 Jul – Sep; 16(3): 342-346.
5. Zakirhusain Shaikh, Rambha Pathak. Revised Kuppuswamy and B G Prasad socio-economic scales. *Int J Community Med Public Health*. 2017 Apr;4(4):997-999
6. Luzia Lara Pfeifer, Rodrigues Silva, Carolina Funayama, Jair Santos. Classification of Cerebral Palsy. *Arq Neuropsiquiatr* 2009;67(4):1057-1061
7. Anwar S, Chowdhury J, Khatun M, Mollah AH, Begum HA, Rahman Z, et. al. Clinical profile and predisposing factors of CP, *Mymensingh Med J*. 2006 Jul; 15(2): 142-5.
8. Gowda VK, Kumar A, Shivappa SK, Srikanteshwara PK, Shivananda, Mahadeviah MS, et al. Clinical profile, predisposing factors and associated co-morbidities of children with cerebral palsy in South India. *J Pediatr Neurosci*. 2015 Apr-Jun;10(2):108-13.
9. Nimbalkar S, Raithatha S, Shah R, Panchal DA. A qualitative study of psychosocial problems among parents of children with CP attending two tertiary care hospitals in Western India, *ISRN Family Med*. 2014 Feb 20; 2014: 769619.
10. Rentinck IC 1, Ketelaar M, Jongmans MJ, Gorter JW. Parents of children with CP: a review of factors related to the process of adaptation, *Child Care Health Dev*. 2007 Mar; 33(2): 161-9.
11. Trabacca A1, Vespino T1, Di Liddo A1, Russo L1 Multidisciplinary rehabilitation for patients with cerebral palsy: improving long-term care. *J Multidiscip Healthc*. 2016 Sep 22;9:455-462. eCollection 2016.