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Socio-demographic and clinical profile of pediatric patients with cerebral palsy in Gujarat, India

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Abstract

Purpose: Cerebral palsy is a common childhood neurodevelopmental disorder. The estimated prevalence of cerebral palsy in India ranges from 2.1 to 3 per 1000 live births as per published literature. The present study was aimed to study socio-demographic and clinical profiles of cerebral palsy children in the Gujarat state of India.

Materials and methods: A total of 481 cerebral palsy children were included from various physiotherapy, rehabilitation, and neurological setups across Gujarat between May 2018 and April 2019. Information regarding gender, age, city of residence, family details, types of cerebral palsy, and gross motor function classification system was collected using a simple survey form designed for the study.

Result: The study showed that 67.57% of children were male and 32.22% were in the age group of 48–96 months. When classified 77.34% had a spastic type of cerebral palsy, out of which diplegic cerebral palsy was reported to be the most common (42.83%). When assessed for functional levels, most of the children were classified in gross motor function classification system levels 3 and 4 (76.30%).

Conclusion: The findings of this study support the published data and emphasize the need for a robust and authentic official database of cerebral palsy in Gujarat and India to help in the estimation of the current disease burden and implementation policies for the prevention and management of cerebral palsy.

Keywords: Cerebral palsy, Disability, Family, Parents, Prevalence, India

Introduction

Cerebral palsy (CP) is the commonest neurodevelopmental disorder of childhood because of a non-progressive damage to the brain, which leads to various activity limitations caused by progressive postural and movement disturbances. Different prenatal, perinatal, and postnatal complications can lead to impairments such as motor dysfunctions, sensory disturbances, perception, intellectual problems, behavior issues, epilepsy, and secondary musculoskeletal problems [1].

Globally published literature has reported that the range of CP from 1.5 to 4 per 1000 live births but the prevalence range reported for India is higher ranging from 2.08 to 3.88 per 1000 live births [2]. Previously, Persons with Disability (PwD) act of India recognized disability in terms of visual, speech, hearing, locomotor, and mental disability. Recently, amendments in the act were done and The Rights of Persons with Disabilities (RPwD) Act, 2016 now covers CP in the sub-classification of physical disability as a locomotor disability [3]. It has been reported in the previous studies that awareness regarding the rights and legislations for the disabled is lower in India [4]. Socio-economic, physical, and psychological stress associated with raising a CP child has been studied by various researchers in India and in the state of Gujarat [5–7]. It has been reported in

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these studies that parents and families of CP children are experiencing higher levels of stress and depression and, on the whole, have a lower quality of life as compared to parents of healthy children [6–8].

Gujarat is one of India's fastest-growing states with 10th rank in per capita gross domestic product (GDP) with estimated GDP growth of 9.3% for the financial years 2019–2020 [9]. There is a lack of data describing the prevalence of CP in Gujarat and discussing it in the context of rehabilitative policies which are currently in practice. The paucity of studies presenting data regarding socio-demographic and clinical profiles can affect the current disease burden estimates and will further increase stress on the families' finances as well as on the national economy. The present study was aimed at studying socio-demographic and clinical profiles of children with CP and describes these characteristics.

Materials and methods

This cross-sectional study was conducted in pediatric patients with CP attending various physiotherapy, rehabilitation, and neurology clinics within Gujarat. Ethics approval was received from the institutional ethics committee with ref. no. GSIIEC/12/16.

Based upon the incidence rate of 3 per 1000 live births, the estimated number of children with CP in Gujarat is approximately 20, 000,000. Sample size calculation was performed using StatCalc statistical calculator (Ver. 7.2.2.2) from Epi Info software. At the alpha level = 0.05 and 5% margin of error, the minimum estimated sample size is 384 parents. A total of 481 children diagnosed with CP, within the age group of 0–12 years and who attended the study setting between May 2018 and April 2019, were included in the study. The parents of these children were approached by the researcher or the volunteers. Informed consent was received from the parents after a detailed explanation regarding the objectives and aims of the study. The parents of children were excluded if their children were diagnosed as having other neurological conditions such as autism, myopathy, and muscle dystrophy; the parents were diagnosed with a psychological and cognitive-behavioral illness; parents who were not able to understand and co-operate for the study; parents having a long history of diagnosed diabetes, hypertension, cardio-pulmonary, or renal illness; or parents who were unwilling for participation.

A self-designed questionnaire was used after establishing initial psychometric properties including content validity, face validity, and reliability (Appendix 1). The detailed process of the development and validation of the survey questionnaire is described in previous publication by the author [10]. The parents were requested to provide information about the socio-demographic characteristics; antenatal, perinatal, and post-natal history; type of

CP; and GMFCS score; along with pertinent details, it was verified with available documents.

The data were stored using Microsoft Excel 2007, and descriptive statistical analysis was performed using IBM SPSS Statistics 20. Continuous measurements were presented as mean \pm SD (Min-Max), and results on categorical measurements were presented in number (%).

Results

The study included 481 children with CP from a total of 26 study settings spread across 7 cities and towns of Gujarat state. Most of the children were recruited from Surat and Bhavnagar, i.e., 20.79%, followed by Vadodara (18.71%), Ahmedabad (18.30%), Rajkot (14.97%), Morbi (5.82%), and Vapi (0.62%). Out of these, the majority of participants (56.13%) of this study were recruited from clinical setups of various types. The participants from hospital-based rehabilitation setups (25.16%) and other setups such as special school and residences (18.71%) were also included (Table 1).

As shown in Table 2, out of total 481 respondents, 88.15% were female participants and only 11.85% were male. Majority of respondents among parents of the CP children were mothers (80.87%). The mean age of the parents of CP children was 32.61 ± 5.9 years, and majority of the parents, i.e., 71.73%, belonged to the age group of 28-37 years. 52.18% of the parents had a graduate level of education qualifications, 64.24% were house makers, and 91.27% of the respondents were married.

The mean age of the children which were included in this study was 5.32 ± 3.13 years. 61.12% of the children were from the age group of 24–96 months. Out of 481 children, 67.57% were male, and 42.83% were diagnosed as having spastic diplegic CP (Table 3).

Table 4 shows socio-demographic characteristics of the family of children with CP. Most of the families

Table 1 Distribution of participants

		No. of participants	Percentage
City/town	Ahmedabad	88	18.30
	Vadodara	90	18.71
	Surat	100	20.79
	Rajkot	72	14.97
	Bhavnagar	100	20.79
	Morbi	28	5.82
	Vapi	3	0.62
Study setting	Hospital	121	25.16
	Clinic	270	56.13
	Others (special school, residence etc.)	90	18.71

Table 2 Demographic characteristics of caregivers of CP children

No.	Demographic characteri	stic	No. of participants	Percentage
1	Gender	Female	424	88.15
		Male	57	11.85
2	Primary caregiver	Mother	389	80.87
		Others	92	19.13
3	Age group (years)	18–22	9	1.87
		23–27	61	12.68
		28–32	182	37.84
		33–37	163	33.89
		38–42	33	6.86
		43–47	24	4.99
		48 & above	9	1.87
4	Education	Postgraduate & more	34	7.07
		Graduate	251	52.18
		Secondary/higher secondary	110	22.87
		Primary	63	13.10
		Uneducated	23	4.78
5	Occupation	Housemaker	309	64.24
		Business/executive/manager	38	7.90
		Farming/medium business/clerk	73	15.18
		Skilled labor/small job	56	11.64
		Others	5	1.04
6	Marital status	Married	439	91.27
		Separated	20	4.16
		Divorced	5	1.04
		Widowed	17	3.53

Table 3 Demographic characteristics of CP children

No.	Demographic ch	aracteristic	No. of participants	Percentage
1	Gender	Male	325	67.57
		Female	156	32.43
2	Age group	< 12 months	11	2.29
	(months)	12-24 months	82	17.05
		24-48 months	139	28.90
		48-96 month	155	32.22
		96-144 months	94	19.54
3	Type of cerebral palsy	Spastic hemi- plegia	107	22.25
		Spastic diplegia	206	42.83
		Spastic quadri- plegia	59	12.27
		Dystonic/athetoid	104	21.62
		Ataxic	5	1.04

were joint families (70.48%) with 62.79% having > 4 family members and 77.75% families having ≤ 2 children. Out of 481 families, 46.99% had only 1 earning family member, whereas 0.62% did not have any

earning member in the family and depended upon aid from the government or non-governmental aid agencies. 57% of families had a monthly total income of > 20,000 INR and 67.57% of families lived in owned homes with 70.89% residing in houses with \leq 3 rooms. Almost all families lived in a household with the availability of clean drinking water (94.18%) and household electricity (98.54%).

As it is shown in Table 5, 83.37% of the children were born at the hospital or clinic by qualified medical doctor, 93.76% were single births, and 38.05% were full-term normal deliveries. A total of 47.82% of children had suffered some kind of antenatal complications followed by pre-natal complications (23.91%) and postnatal complications (15.59%). Most of the children had birth weight >2.50 kg (45.74%) followed by 1.50–2.49 kg (38.05%), 1–1.49 kg (14.35%), and <1 kg (1.87%) in descending manner. For the 44.07% of children, neonatal intensive care unit (NICU) admission was not required, whereas 39.92% of children were advised NICU admission but only 35.6% were advised for neurodevelopmental follow-up by the consulting physician after discharge from hospital or clinic.

Table 4 Socio-demographic characteristics of families of CP children

Demographic characteristic		No. of participants	Percentage
Type of family	Joint (3 or more generations and their spouses living together)	339	70.48
	Nuclear (a couple and their dependent children)	141	29.31
	Others	1	0.21
Family members	<u>≤</u> 4	179	36.38
	> 4	302	62.79
Earning family members	0	3	.62
	1	226	46.99
	2	136	28.27
	>2	116	24.12
Monthly income	>20,000 Rs.	274	57.0
	10,001–20,000 Rs.	146	30.4
	5000–10,000 Rs.	50	10.4
	<5000 Rs.	11	2.3
Type of residence	Owned	325	67.57
	Rented/other's ownership	156	32.43
Number of rooms	≤3	341	70.89
	> 3	140	29.11
Availability of clean drinking water	Yes	453	94.18
,	No	28	5.82
Availability of household electricity	Yes	474	98.54
,	No	3	0.62
	Others	4	0.83

The parents or caregivers described their complaints about children with CP through categories such as movement difficulty, speech and communication issues, hearing problems, vision problems, epilepsy/convulsion, learning difficulty, difficult behavior, or other specific complaints. Most of the time, the complaints were found to be associated with movement difficulties (n=178, 37.01%). It was reported that the complaints in singularity were less common and parents had multiple complaints related to their child's problems. It is shown in Table 6.

The levels of disability for child with CP are classified here by grading them with GMFCS levels. The GMFCS scoring is to be done by skilled person, and so, the physiotherapist treating that child or the volunteer taking the parents' interview was assigned responsible about it. The distribution of levels of disability is shown in the Table 7. It shows that a total of 76.30% of children were classified as having levels 3 and 4 in GMFCS.

Discussion

CP is reported to have various prevalence rates and clinical patterns between geographical areas. This may be because of different causes including etiological

factors, use of different classification systems, quality of the study, and sample size included in the study. With increase in numbers and quality of healthcare facilities, actual survival rates of pre-mature and low birth weight babies have increased. A recent systematic review by Chauhan et al. (2019) has described paucity of high-quality population-based prevalence studies on CP in India and reported overall pooled prevalence of CP per 1000 live births to be 2.95. They also emphasized the need for a large-scale good quality community-based studies for evaluating risk factors and clinical profiles of CP children from different age groups [2].

Present study included 481 children with CP from 7 cities and towns of Gujarat. As 4 of these regions were large metro cities of more than 20 lakh population, the proportionate data gathered from these cities can be considered as representative. Most of the data was received from clinical setups providing the CP children with physiotherapy and rehabilitation services, which shows the extent of reach of rehabilitative efforts in Gujarat.

Four hundred twenty-four caregivers of the CP children included in this study were females out of which 389 were mothers of the children. These findings concur with the findings of many studies across globe depicting similar findings that mothers bear the primary responsibility

Table 5 Details of birth history of the child

		No. of participants	Percentage
Place of birth	Hospital/clinic—by a doctor	401	83.37
	Home—by midwife	76	15.80
	Home—without an experienced person	4	0.83
Type of birth	Single	451	93.76
	Twins	29	6.03
	Triplets or more	1	0.21
Type of delivery	Full term—normal	183	38.05
	Full term—abnormal	175	36.38
	Preterm—normal	46	9.56
	Preterm—abnormal	77	16.01
Type of complications	Prenatal maternal illness	115	23.91
	Perinatal complication	230	47.82
	Postnatal complication	75	15.59
	No significant history	61	12.68
Birth weight of child	> 2.50 kg	220	45.74
	1.50-2.49 kg	183	38.05
	1-1.49 kg	69	14.35
	< 1 kg	9	1.87
Duration of NICU admission	Not Required	212	44.07
	1–14 days	192	39.92
	15–21 days	50	10.40
	> 21 days	27	5.61
Advice about neurodevelopmental follow-	Not required	310	64.4
up	Weekly	51	10.6
	Fortnightly	59	12.3
	Monthly	61	12.7

Table 6 Parents' chief complaints about their children

Parents' chief complaint	No. of participants	Percentage
Primary movement difficulty	178	37.01
Primary speech & communication issues	2	0.42
Epilepsy/convulsions	14	2.91
Primary movement difficulty with other minor issues	246	51.14
Primary other issues with minor movement difficulty	41	8.52

Table 7 Distribution of levels of disability in children with CP

	•	
GMFCS level	No. of participants	Percentage
Level 1	14	2.91
Level 2	87	18.09
Level 3	184	38.25
Level 4	183	38.05
Level 5	13	2.70
Total	481	100.00

of caregiving and are usually the first victims of parenting stress [11–13]. Out of all the respondents, majority were in the age group of 28-37 years (n=345, 71.73%) suggestive probable role of age associated expectations and responsibilities affecting the process of parenting. Parkes et al. (2011) conducted a study to assess impact of the caring for CP child across Europe and observed that the young parents with higher educational qualifications have a specific perception regarding their expectations

and ambitions and consider caring for a child with disability more stressful [14]. Similarly, Qayyum et al. (2013) described the role of parental education and pressure of social acceptance to be more in the young and educated parents of CP children [15].

More than 50% participants (n=285, 59.25%) had at least graduate level education. Conclusions of study by Barbosa et al. (2016) and Parkes et al. (2011) suggested that low education levels increase hindrances for effective social integration of caregivers, children, and their families, thereby affecting the quality of life of parents [14, 16]. Parental occupation has shown to be one of the causative factors associated with stress in parents of CP children in a previous study [17]. In a study by Lowes, Clark, and Noritz (2016), parents having full-time and part time professional or trade-related occupation were found to be having comparatively less total stress. In the cases where both the parents were unemployed, the levels of stress were found significantly high [18]. Contradicting results were found in a previous study where the parents who worked as professionals, managers, and small businessmen were found prone to stress and the probable reasons for that as described by authors were impaired sense of competence, restrictions on other life roles, marital conflicts, lack of social support, and depression [19].

Marital status of the caregiver is reported as one of the important factors affecting caregiver wellbeing and quality of life of child with CP. While western studies have shown significant correlation and effect of marital status on parenting and vice versa, the studies in India and Bangladesh have shown that marital status may impact the caregiving process but it is not affected due to the child's disability or burden of caregiving associated with it [20, 21].

In the present study, majority of the children were boys (n=325, 67.57%). This suggests the commonly reported fact that the prevalence of CP is higher in male as compared to the female [1, 22]. Most of the children were from the 2–8 years age group (n=294, 61.12%) indicating one of the probable factors affecting the experiences of parenting. As the age of children increase, the height and weight also increase in proportion to it. The active phase of physical growth can lead to various musculoskeletal problems, in parents, due to lifting and carrying children. The requirement of change of assistive device, individual transportation vehicle, child's emotional, and behavioral changes, etc., can lead to further increase in burden of parenting the child. A higher number of cases of spastic diplegic CP (42.83%), followed by spastic hemiplegia, dyskinetic, spastic quadriplegic, and ataxic types of CP, are similar to other studies from India as well as from other countries [23, 24]. Previous studies from more developed countries have reported hemiplegia as the most common form of spastic CP [25], and athetoid CP, particularly secondary to neonatal hyperbilirubinemia, has reported to be disappeared from many parts of the developed world, although, studies suggest a significant proportion of CP cases in India [26].

The families of children with CP were mostly joint families (n=339, 70.48%) having more than 4 members (n=302, 62.79%) and less than 2 children in family (n=374, 77.75%). Joint families were reported to be the source of pressure and time-crunch in a previous study on Indian parents done by Upadhyaya and Havalappanavar in 2008 [27]. In most families, the earning member of family was reported to be one only (n=226, 46.99%) and monthly family income of more than 20,000 INR (n=274, 57%). Majority families were residing in house of ownership (n=325, 67.57%) with less than 3 rooms (n=341, 70.89%) and availed toilet facility within home (n=280, 58.21%), clean drinking water (n=453, 94.18%), and household electricity (n=474, 98.54%). These findings are suggestive of a higher-middle class lifestyle for the parents included in the sample for present study. Delialoglu et al. (2009) found out difference between depression levels between mothers of children with CP and mothers with normal children and concluded additional factors such as family income are associated with higher depression levels in mothers of children with CP [28]. Many studies in India have also reported that economical stress is one of the most common reasons for parenting difficulties especially for parents of disabled children and has been correlated with higher levels of parental stress, distress, anxiety, depression, and caregiver burden, etc. [6, 29, 30].

Most of the children were born at hospital or clinic by a qualified doctor (n=401, 83.37%) suggesting the reach of medical services to most of the population and general awareness of people regarding the same. The results of 2 different studies in Indian population concur with the results of present study [23, 31]. Out of 481 children, 93.76% were having single birth whereas 38.05% were delivered at full term through normal delivery. Respondents reported total 36.38% cases of full-term delivery with significant perinatal event which is almost as much as the normal full-term delivery. Preterm deliveries with or without any significant events are considered a risk factor for CP. It was observed that approximately 25.57% of total children had history of preterm birth which can be considered significant. Many recent studies show a gradual rise in the prevalence of CP due to increase in number of children with low and very low birth weight because of the change in the survival of low and very low birth weight infants [23]. Birth asphyxia was previously proposed to be an important perinatal factor, but recently, the role of birth asphyxia in the causation of CP

has been questioned. Along with asphyxia, multiple pregnancies, instrumental delivery, and cesarean section have been reported as important risk factors by Nafi (2011) in Jordanian children with CP [32].

Another significant risk factor for CP is birth weight of the child. In present study, approximately 54.27% children were born in low birth weight to extremely low birth weight categories. More than 55% of the children had a history of admission in NICU for more than 1 day due to any reason. This suggests that NICU admission is one of the most important factors which can be useful in the prediction of a probable developmental delay [33, 34]. It was reported that 64.4% of the children were not advised for neurodevelopmental follow-up by the consulting physician, suggesting a lack of such practice pattern in an Indian scenario. As there is a scarcity of a reliable source of literature suggesting effects of low birth weight, history and duration of NICU admission, and practices in neurodevelopmental follow-up practices for the population under study, it is not possible to compare these observations and comment on the generalization of these data.

When asked to report their complaints about their child's problems, most of the time, responses were found to be associated with movement difficulties (n=178, 37.01%). This shows that generally parents' primary concern is the motor disability or movement disorders, which can be due to ease of recognizing and comparing motor milestones with children in the same age group. The findings are supported by observations of Qayyum et al. (2013) in a study of Pakistani primary caregivers of children with disabilities, where they reported that most of the responses were related to deformities that were visibly noticed and recognized, including deformity of any of the functional body parts or anywhere in the body [15]. As reported by Nafi (2011), speech delay was the most common associated problem followed by mental retardation, seizures, hearing problems, and autism [32].

As reported by caregivers, GMFCS levels for most of the children were between level 3 and level 4 (i.e., 76.30% of total children). This is suggestive that the children had limited mobility with or without assistance from a device or physical assistance and were able to access community with help. It was expected that the parents or caregivers in India and especially Gujarat will be less familiar with the concept and classification, which was proven to be true in most of the cases except an exclusion of the clinical rehabilitation setup at Rajkot. Here, all the parents (n=48) were explained about the system and were taught to identify the current level as well as any change in level of motor functioning of their child. It was done as a part of their regular parent awareness sessions where the center provided parents with basic education about the

condition, handling and treatment techniques, observation strategies, assistive aids, etc. These kinds of practices can lead to major changes in perceptions and practices of parenting a CP child and are expected to be followed in widespread manner in the field.

Limitations of the study

As for any study, the current study also has its limitations. The study population majorly covered parents from urban areas of Gujarat making representation from semi-urban and rural areas less. As the survey questionnaire was in Gujarati language only, the parents who could not read Gujarati were not able to understand and reply the questions without help or researchers or volunteers. Future study may focus more on rural population and shall use language other than Gujarati leading to wider coverage and representation.

Clinical implications

- The data will serve to create basis for nationwide register of cerebral palsy patients including socio-demographic, clinical, and other important details.
- The information can help to establish associations and correlations between various socio-demographic factors, child birth-related factors, and clinical profile of cerebral palsy children.
- The data will be helpful in estimation of current burden of disease on the regional and national economy and can guide in implementation of existing policies for preventive and rehabilitative measures for cerebral palsy children.

Conclusion

This study was aimed at studying socio-demographic and clinical profiles of CP children in Gujarat. Mothers of CP children from families living in higher-middle socio-economic lifestyle, residing in own homes and having monthly income of more than 20,000 INR participated in this study. Spastic diplegic cerebral palsy was the commonest clinical type and the children with CP had limited functional mobility with GMFCS levels 3 and 4 and needed assistance to access community. The study confirms role of prenatal and perinatal complications; low birth weight and history of NICU admission in development of CP. Medical facilities are reaching most of the areas in Gujarat and essential services like NICU are available to majority of children, but the practice of advising neurodevelopmental follow-up after discharge from hospital is not yet so much prevalent among consultants.

Abbreviations

CP: Cerebral palsy; GDP: Gross domestic product; GMFCS: Gross Motor Function Classification System; NICU: Neonatal intensive care unit; PwD: Persons with disability; RPwD: Rights of persons with disabilities.

Supplementary Information

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Additional file 1. Appendix.

Additional file 2. Implications for rehabilitation.

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Authors' contributions

VR conceptualized and designed the study methodologically as well as collected, analyzed, and interpreted the data and was the main contributor in writing and revising the manuscript. YS conceptualized the study and helped in writing, revising, and finalizing the manuscript. The authors read and approved the final manuscript.

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Availability of data and materials

Data will be shared on specific request to the author depending upon the nature and purpose of the requirement.

Declarations

Ethics approval and consent to participate

Ethics approval was received from IEC of B. J. Medical College & Civil Hospital, Ahmedabad, Gujarat (India).

Informed participation consent was taken for each subject after providing written information about the study at the start of survey.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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