

A Snapshot of 1001 Children Presenting with Cerebral Palsy to a Children's Disability Hospital

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ABSTRACT

Background: Cerebral palsy (CP) has largely been an unaddressed problem in low and middle income countries (LMIC's). The purpose of this retrospective study is to provide a facility-based snapshot of CP in Nepal.

Methods: A retrospective chart review of 1001 patients diagnosed as having cerebral palsy, presenting to our institution from December 2008 to December 2011, was carried out.

Results: Majority of cases were found to be a result of birth complications and post-natal infections. Most children with CP were born at home, presented after walking age and came from socioeconomically unstable or borderline households. Less than 20% were attending school. Spastic diplegia was the most common presentation. Children with post-natal spasticity secondary to infection seemed to retain greater ambulatory potential.

Conclusions: In contrast to CP in developed countries, the etiology in LMIC's is largely related to birth-related complications and post-natal infections. There is an urgent need to address preventable causes of cerebral palsy in Nepal.

Keywords: Asphyxia; birth complications; cerebral palsy; infection; Nepal.

INTRODUCTION

Cerebral palsy and other developmental disabilities have largely been neglected in low and middle-income countries (LMICs), in part due to the challenges in providing even basic health services at the population level. As such, there is a paucity of information on the prevalence and functional consequences of a spectrum of impairment resulting from damage to the immature central nervous system. We have noted a significant increase in the numbers of patients with cerebral palsy presenting to our institution in recent years.¹ The goal of this retrospective study is to characterize the etiology and patterns of presentation in patients with cerebral palsy at our institution. The findings will help us establish

priorities and inform a comprehensive approach to service delivery aimed at improving function within a setting of limited resources.

METHODS

A retrospective chart review was performed on all patients diagnosed with cerebral palsy presenting to our center between December 2008 and December 2011. We collected data on age at presentation, birth history, medical history, predominant physiologic subtype, geographic subtype, associated conditions, home location, and socioeconomic status. All data was de-identified prior to analysis. Institutional review board approval was taken.

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RESULTS

Of 6876 patients seen in our clinic during the study period, 1001 were diagnosed with cerebral palsy (15%). The average age at presentation was 6 years (Table 1), and 63% were males. Only 22% patients presented for evaluation before 2 years of age. Ninety-four percent of patients were delivered vaginally (78% at home), 4.4% by Cesarean section, and 1.4% with the assistance of forceps. Most patients came from the central and eastern regions of the country (72.3%), while only 10% reside in the mid and far-western regions (Table 2). A majority of families were impoverished, and only 7.5% could bear all the expenses associated with raising their child (Table 3). Only 19% of patients were attending school.

Table 1. Age at Presentation.

Age (Years)	#/% Patients
< 1	110 (11%)
1 - 2	120 (12%)
2 - 5	313 (31.3%)
5 - 10	261 (26.1%)
10 - 15	183 (18.3%)
> 15	14 (1.3%)
TOTAL	1001

Table 2. Breakdown of patients from the five developmental regions of Nepal against the infant mortality rate, under-5-mortality rate, population in lowest wealth quintile and population without any education for those regions² * The remaining patients (3.8%) were from outside Nepal and are not included in this table. N=968, as data was unavailable for 38 patients.

Region	# patients	% of Patients*	Infant Mortality Rate (per 1000 live births)	Under-5-Mortality Rate (per 1000 live births)	Percentage Population in the Lowest Wealth Quintile	Percentage Population without any Education
Eastern	156	15.6%	47	55	16.2%	31%
Central	568	56.7%	52	60	13.7%	45%
Western	136	13.6%	53	57	14.8%	32.3%
Mid-western	82	8.2%	58	73	41.5%	47.8%
Far-western	21	2.1%	65	82	34.5%	50.3%

Table 3. Screening questionnaire used to measure the socioeconomic status, against the relative numbers and percentages of patients, from this study cohort.

SOCIOECONOMIC STATUS			Number of Patients	Percentage
Socioeconomically Stable	Can bear all expenses for the child	Have in excess of daily needs; Some savings	75	7.5%
Socioeconomically Borderline	Difficult to bear all expenses for the child	Have just enough for daily living; No savings	517	51.6%
Socioeconomically Unstable	Cannot bear expenses for the child	Do not have enough even for daily living; No savings	409	40.9%

Table 4. Distribution as per the functional classification and subdivisions into anatomical types.

Functional Classification	Post-natal CP (n=516)		Peri-natal CP (n=274)	
	# Patients	Percentage	# patients	Percentage
Community Ambulator	173	33.5%	66	24.1%
Hemiplegic	110	63.6%	36	54.5%
Diplegic	63	36.4%	30	45.5%
Household Ambulator	81	15.7%	50	18.2%
Diplegic	69	85.2%	41	82%
Hemiplegic	8	9.9%	8	16%
Total Body Involvement	4	4.9%	2	4%
Exercise Ambulator	33	6.4%	20	7.3%
Diplegic	29	87.9%	17	85%
Hemiplegic	3	9.1%	2	10%
Total Body Involvement	1	3.0%	1	5%
Non-Ambulators	110	21.3%	72	26.3%
Total Body Involvement	103	93.6%	64	88.9%
Diplegic	7	6.4%	8	11.1%
Not Classified*	119	23.1%	66	23.7%

Table 6. Selected data from the Human Development Report, United Nations Development Project, 2010.²⁷

Author	Location	Etiology or Contributing Factors (%)									Physiologic Abnormalities (%)				Geographic Classification (%)		
		Prenatal		Perinatal			Postnatal				Spast	Dyskin Extrapyr Athetosis Mixed	Hypo	Atax	Hemi	Di or Tri	Quad
		Prem/ LBW	Misc	Asph	Jaun	Tra	Inf	Seiz	Tra	CVA							
Singhi ¹⁰	India	13	-	45	22	-	15	25	-	-	70	22	8	17	22	61	
Belonwu ¹¹	Nigeria	3	-	46	13	1	10	12	1	-	42	7	22	-	-	-	
Nottage ¹²	Nigeria	-	2	20	41	2	22	-	-	-	91	28	7	1	20	8	71
Karumuna ¹³	Tanzania	13	9	20	8	9	18	19	-	-	76	14	10	-	36	20	20
Lagunju ¹⁴	Nigeria	7	8	39	24	-	6.1	-	-	-	79	15.8	-	4.9	-	-	-
Lagunju and Okafor ¹⁵	Nigeria	-	-	45	26	-	11	-	-	-	-	-	-	-	-	-	-
Ogunlesi ¹⁶	Nigeria	1	-	58	37	-	22	2	47	-	80.4	7.6	12	0	20	14	66
Arens ¹⁷	South Africa	-	-	-	-	-	56	-	20	10	79	6	2	5	-	-	-
Junega ¹⁸	India	-	-	-	-	-	-	-	-	-	-	-	-	-	23	27	39

Table 5. Comparison of patients with prenatal (n=274) and postnatal CP (n=516) based on anatomic subtype and functional classification. * Children who were less than two years were not classified as their walking potential could not be determined.

Socioeconomic Parameter	Nepal	Niger	Norway
Human Development Index (169 countries surveyed)	138	167	1
Per capita	\$ 1,201	\$675	\$58,810
Per capita Health Expenditure	\$53	\$35	\$4,763
% GDP spending on health	2.0	2.8	7.5
% GDP spending on education	3.8	3.7	6.7
Physicians per 10,000 Population	2	<0.5	39
Hospital beds per 10,000 Population	50	3	39
Infant Mortality Rate per 1000 Live Births	41	79	3
Under-5-Mortality Rate per 1000 Live Births	51	167	4
Maternal Mortality Rate per 100,000 live births	830	1800	7
Expected Years of Schooling (years)	8.8	4.3	17.3
Population with Severe Deprivation in Education	38%	87%	0%
Population with Severe Deprivation in Health	58%	64%	0%
Population with Severe Deprivation in Living Standards	77%	93%	0%

The cerebral palsy was felt to be associated with pre-natal events in 22 (2.2%), peri-natal events in 274 (27.4%), and postnatal events in 516 (51.6%). An association could not be identified in 22.8% of patients. A variety of possible causes were identified in those with a prenatal etiology (Figure 1). The most common perinatal cause was birth asphyxia (Figure 2), and infections such as meningitis, encephalitis, pneumonia, and neonatal sepsis accounted for 76% of post-natal cases (Figure 3). Three percent of patients had a sibling

affected, suggesting the possibility of a heritable metabolic or neurologic disease such as hereditary spastic paraparesis.

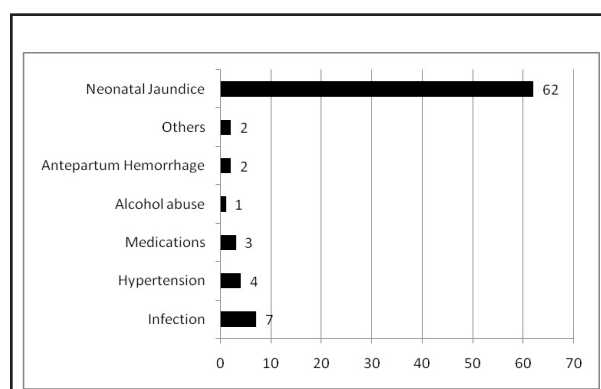


Figure 1. Cerebral palsy attributed to pre-natal events.

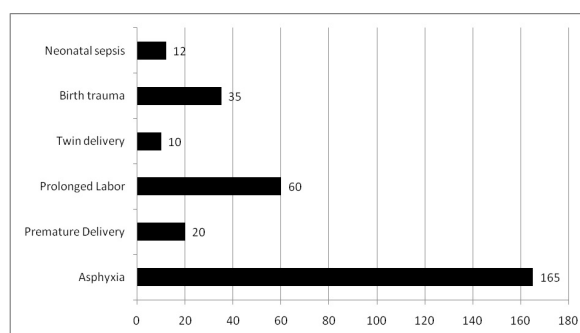


Figure 2. Cerebral palsy attributed to peri-natal events.

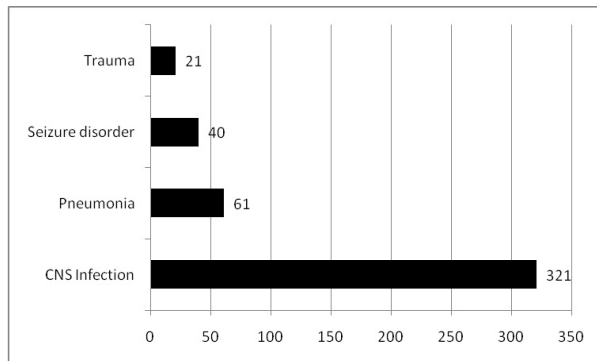


Figure 3. Cerebral palsy attributed to post-natal events. More than 50% of cases were attributed to post-natal events.

The predominant physiologic subtype was spastic (90%), followed by hypotonic (8%), athetoid (1%) and ataxic (1%). Geographic subtypes included hemiplegia (29.2%), diplegia/triplegia (40.6%), and quadriplegia (30.3%). The most common associated conditions included mental retardation (10.3%) and seizure disorder (5.9%). Mental retardation (10.3% of total patients) was associated with acquired post-infective cerebral palsy in 8.4 % (33 cases).

Thirty-four percent were community ambulators (96% hemiplegia or diplegia/triplegia), while 22% were household or therapeutic ambulators, and 22% were nonambulatory (89% quadriplegic). Table 4 compares ambulatory status in patients with perinatal versus post-natal etiologies, and suggests that a great number of patients with a post-natal cause achieved or maintained community ambulation.

DISCUSSION

Disability has largely been neglected as a public health issue in low and middle income countries (LMICs). Statistics from UNICEF suggest that as many as 150 million people who are less than 18 years of age are disabled, and the Global Burden of Disease study (2004 update) suggested that there were 93 million disabled children worldwide, 13 million of whom had severe disability.^{2,3} Quantifying the prevalence of a childhood disability is difficult given the lack of uniformity in methodology between studies, and the challenges of designing measurement tools that are culture and language specific.⁴ In a systematic review of the literature, Maulik et al found that the prevalence varies from 0.4 to 12.7 percent (0.1-0.4% motor disability).⁵

Sauvey performed a household survey in 24 rural development communities in Nepal, and estimated the prevalence of disability to be a 1 percent, most commonly locomotor dysfunction (0.89%).⁶ The prevalence varied between villages (0.4-6.4%), and it was suggested that disabled persons have a lower chance of receiving an education, have a lower likelihood of receiving formal medical care, and may be less likely to lead a dignified life. Karki et al reported on self reported disability in a cross sectional household survey in eastern Nepal, and found that 3.5% of those less than 15 years of age considered themselves disabled.⁷ Fifty percent had physical disability, 12% of which was due to trauma.

Cerebral palsy is one cause of childhood disability, and may be described as a disorder of movement and posture arising from damage to the immature brain. A wide spectrum of impairments may be observed depending on the pattern of injury, and the disability associated with these impairments depends on contextual variables. While the central nervous system abnormalities may remain static, musculoskeletal abnormalities progress with growth, and the needs of the patient evolve as they move through childhood into adolescence and adulthood. The incidence of cerebral palsy is between 1 and 2.5 per thousand live births in both economically developed and underdeveloped regions.^{8,9}

The Hospital and Rehabilitation Centre for Disabled Children is a tertiary hospital caring for children and adolescents with musculoskeletal conditions. We found that 15% of outpatients seen during the study period had a diagnosis of cerebral palsy. In many respects, our findings are consistent with other studies from countries with similar economic indicators Table 6.¹⁰⁻¹⁸ In contrast to economically developed countries where there is access to neonatal intensive care, only 2% of our patients had cerebral palsy associated with prematurity, which is consistent with the available literature (1-13%) (Table 6). The most common association involves events during delivery, presumably leading to asphyxia with or without intracerebral trauma, reported in 20-58% of cases in the studies reviewed and 44% in the present series.

The findings of the present study coupled with those in the literature have implications for both the prevention and treatment of disability due to cerebral palsy. Many cases can be prevented with improvements in antenatal health care and the availability of services to address complications of pregnancy. Although significant improvements have been made in maternal and child-health in Nepal in recent years, only one in three deliveries is attended by a skilled birth attendant, only 50% of women have four or more ante-natal visits during pregnancy, and only 45% receive post-natal care in the days following delivery (MOH).¹⁹ Only 22% of our patients were born at a hospital. In another study of 21,000 births from in different regions of Nepal, only 7% of deliveries were attended by a traditional birth attendant, and 48 percent of deliveries were attended by relatives, usually the mother-in-law.²⁰ When mothers who gave birth at home were asked their reasons for not going to the hospital for delivery, 62% felt it was unnecessary and only 5% cited cost as a factor. In fact Nepal has introduced several incentive programs encouraging birth in a health facility to promote safe motherhood.¹⁹ This information highlights the need for maternal education, as well as the provision of maternal health care services.

Rural origin, low levels of education, and low socioeconomic status are all barriers to accessing or utilization of care. More than half of the patients in the present study were from the central region of Nepal, which affords easier access to our facility. The limited number of patients coming from the mid and far western regions may be due to impaired access care due to poor socioeconomic status, low levels of education, logistics of transport and/or other variables Table 2. The mid-western and far -western regions have the highest infant and under-5-mortality rates.¹⁹

Socio-cultural factors influence the family's and the communities' perception towards the disease and its treatment. As such, improving the lives of children with a disability involves first understanding their perceptions of the condition and the associated functional limitations, and then designing a contextually relevant strategy to address their needs. Some attribute the disease to supernatural causes and almost all seek traditional

healers at some point during the course of treatment.^{21,22,23} Conflicts with traditional beliefs are best avoided as they may be an important support mechanism for the patient and the family to cope with the protracted and often permanent nature of this problem. A study looking at perceptions of disability among mothers of children with disability found that both traditional beliefs and family members exerted considerable influence on the perceived cause of disability, the type of treatment sought and the expectations from treatment.²¹ This study also found that when healthcare providers educate the mothers on their child's problems and make them participate in ongoing treatment in a controlled setting, such as a rehabilitation facility, realistic goals can be set and the mother in turn, can be empowered to influence her family's perceptions. The authors concluded that a community-based family-centered approach to treatment and rehabilitation can be effective in building realistic goals and the health care provider can play a crucial role to this effect. Parents with positive perception of their child's disability were able to help other parents develop positive perceptions and set realistic goals for their children with disability.^{21,22}

Morgan et al. studied parental perceptions of family-centered practices in rural Cambodia by structured interviews and found that a family-centered approach to rehabilitation was valued, the needs and preferences were similar to those of parents in Western context, and included collaborative partnerships, information exchange and respectful care. This three-pronged approach led to a process of realistic goal setting for the child in context to his particular needs and environment. The authors also observed that collaborative partnerships were most likely to succeed in children with milder forms of CP whereas those caring for children with more severe forms of CP felt ill-equipped to deal with their children's complex needs and preferred that the health care provider make decisions and implement treatment for their child.²⁴

Our study revealed that 65% of patients were ambulatory, including a greater percentage of diplegia (38%) and hemiplegia (27%). This difference may be due to the fact that most quadriplegic patients living in austere environments, especially

the mid and far-western mountain regions, are less likely to survive and/or reach a treatment facility. One Study reported that 23% of cases in that study were secondary to infections and bilirubin encephalopathy compared to 39% (infections) and 6% (bilirubin encephalopathy) in this study.¹⁰ 75% children had associated problems compared to 22% in the present study. This noticeable lower incidence of associated problems in our cohort reflects a limitation of our approach, which is mainly targeted to identifying locomotor problems. In either case, the importance of measures to reduce the burden of preventable causes of cerebral palsy in the developing world is obvious.

One study of 100 children with cerebral palsy found that 82% of the children had disabilities related to other systems which had been overlooked or were not recognized by the parents or the primary care physicians.²⁵ A study found higher mortality rates, up to 9%, in rural children with cerebral palsy compared to their urban counterparts; those with least contact with disability services were more likely to succumb.²⁶

There are several important limitations that must be mentioned, including those inherent to any retrospective review. Both the histories and patient evaluations were performed by a host of physicians and physiotherapists, and there were no standardized criteria for determining physiologic subtype. While the most predominant subtype was spastic, it is likely that many patients had mixed involvement, and the subtle manifestations of athetosis or ataxia for example might have been missed. Associated disabilities are most likely under-represented due to a lack of a standardized form for data collection.

A comprehensive strategy to address the diverse needs of patients with such a spectrum of pathology and their families must incorporate preventive, curative, and rehabilitative elements, and must be community based. Prospective research studies are suggested to define the magnitude of the problem, and to accurately classify the spectrum of disability through both community and facilities based assessments. The impact of these impairments on patient function and on the activities of daily living must be evaluated with a contextually relevant

tool. Realistic goals can only be established if we understand the perception of patients, families, and communities, what they hope to achieve with treatment, and what resources are available for treatment. Understanding health care-seeking behavior of patients and their families can help us to gain a better understanding of the perception of the individual and the community regarding patients with cerebral palsy. It would be interesting and informative to explore the perception of traditional healers and their approach to counseling and treatment, as their opinion is often sought prior to any consideration of visiting a doctor. We must also consider what resources are available for treatment and rehabilitation. With this knowledge a comprehensive, community based strategy for enhancing the lives of children and adults with this developmental disability can be achieved.

CONCLUSIONS

In summary, the present study, inspite of its many limitations, brings to the fore the importance of recognizing the burden of cerebral palsy in Nepal. It paves way for more research on the etiology and pathophysiology of cerebral palsy in Nepal. Such information and data may then be utilized to effectively strategize our approaches to this important public health problem in Nepal.

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