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# Childhood Neurological Illness in Nepal

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## ABSTRACT

The commonly encountered neurological disorders in Nepalese children are febrile encephalopathies, neurocysticercosis, and epilepsy, and neonatal encephalopathy, neuro-psychiatric and neuromuscular disease. Also, these children in Nepal remain one of the most vulnerable and marginalized groups in the community. Due to the lack of proper facilities some preventable and treatable neurological conditions continue to paralyze the children's physical and mental health. The alarmingly high prevalence of these neurological illnesses has high mortality and morbidity in children ultimately adding financial burden to the family, society and the country as a whole. The paucity of data and difficulties in proper collection of reliable facts further hampers to understand the actual magnitude of this problem.

**Key words:** epilepsy, neonatal encephalopathy, neurocysticercosis

## INTRODUCTION

Nepal has a population of 27.0 million among which 37% belongs to less than 15 years of age group and 30.9% of the population falls below the national poverty line with a considerable population living in the remote rural areas.<sup>1,2</sup>

In such condition the access to the health care and medical remedies of various diseases has been a matter of big concern especially for the poor and marginalized villagers. Though the government and other private agencies are vesting their efforts to provide health care facilities in the country, some complex health problems are remained unnoticed due to the lack of adequate research studies. Neurological illness in children is one of the examples of such cases. The neurological illness in children which is believed to have alarmingly high morbidity is being paid little attention. This chronic disease may keep the child in vegetative state for the rest of the life leaving the whole family crushed under the cruel quirk of fate.

Though Nepal is struggling hard in producing adequate manpower for combating such diseases, the majority of modern health care facilities across the country are devoid of specialist neurologist care. Notably, the 26 years of academic history of medical science in Nepal has mustered just 8 neurologists registered in Nepal Medical Council till the end of 2007.<sup>3</sup> Beside the human resources, the diagnosis of neurological illness is being hampered by the limited neuro-radiological, neuro-physiological diagnostic facilities and the specialized laboratory for confirming genetic and metabolic disorders.

In this background, this is an effort of reviewing available work done on neurological illness in children of Nepal with the objective to outline the common neurological illness in children. The literature search was done from the online medical libraries including Pub Med, HINARI, Google, and EMBASE. Also, various text books, national annual report from World Health Organization and Ministry of Health and Population, Nepal were consulted during the review process.

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**Table 1: Epidemiology of neurological illness in Nepalese children**

SN	Author	Design	Setting	Sample size	Outcome	Level of evidence
1	Singh et al.4 2009	Prospective observational study	Hospital based, Dharan	107	Pyogenic meningitis- 42% Non JE encephalitis= 25% JE encephalitis= 18% Cerebral malaria=7% TB Meningitis= 4%	Level II
2	Rayamajhi et al.6 2007	Prospective cross-sectional study	Hospital-based, Dharan	94	J.E was present in 62% Mortality in JE patient: 8.3% Neurological sequelae at discharge= 50% Neurological sequelae at 6 week follow up 18.8	Level II
3	Basu S et al.20 2007	Retrospective observational study	Hospital based, Pokhara	124	NCC Mean age of appearance of NCC =10.8 years Most common age group= 10 -12 years Incidence below two years= 8.9%	Level III
4	Shrestha BM.21 2008	Prospective Observational study	Hospital based, Lumbini	93	Incidence of NCC in < 6 years age group 10.3% Incidence of NCC in first onset seizure is 73%	Level III
5.	Nepal et al.24 2003	Cross sectional observational study	Community based survey, Morang	4,636	Prevalence of epilepsy = 7 per 1000	Level III
6	Finkenbine et al.25 1996	Cross sectional observational study	Community based survey	1,05,000	Incidence= 1.07 per 1000 Mean in delay in diagnosis= 6.5 years	Level III
7	Shakya et al.27 2003	Prospective observational	Hospital based, Kathmandu	50	Generalized tonic clonic seizure most common (36%) type of epilepsy Onset of First seizure in 40% is between 2 to 5 years.	Level III
8	Ellis et al.32 2000	Unmatched case control study	Hospital based, Kathmandu	21,609	Neonatal encephalopathy=6.1 per 1000 63% had moderate to severe encephalopathy	Level II
9	Lee et al.33 2008	Prospective cohort study	Community based, Sarlahi	23,662	Birth asphyxia death= 9.7/1000 live birth , 30 % of neonatal mortality	Level II
10	Shyangwa et al.36 2009	Cross Sectional	Hospital based, Dharan	151	Incidence of Psychiatric morbidity in physically ill children below 5 years= 2.6%	Level III
11	Tulachan et al.38 2010	Prospective Observational	Hospital based study, Kathmandu	188	Mental retardation 21.3%, somatoform disorder= 16.5% ADHD=10.1%	Level III

12	Goiter and cretinism Project.42 1982	Prospective Observational	Community based		Goiter and cretinism prevalence= 0.7- 12.7%( depending on region of Nepal)	Level III
13	Pandit RP.48 2004	Cross Sectional observational	School based survey, central region	1154	104 has learning disability	Level III

Neurological illness in children in Nepal includes diseases with wide range of etiologies such as infection, birth asphyxia, trauma, genetic, metabolic and social factors. Very limited work has been done to find the actual burden of the different neurological disease in Nepalese children. Here, the status of neuroepidemiology of various common neurological illnesses in children in Nepal has been discussed briefly. Some of the important studies done in Nepal in this aspect have been summarized in Table 1.

#### A. FEBRILE ENCEPHALOPATHY

**Encephalopathy** denotes a diffuse and nonspecific brain insult resulting in altered sensorium with or without seizure and neurological deficit. It is an important cause of morbidity and mortality in young children. A hospital based study conducted in Eastern Nepal has revealed that pyogenic meningitis (42%) and viral encephalitis (18% case of Japanese Encephalitis and 25% other viral encephalitis) were the most common cause of acute febrile encephalopathy.<sup>4</sup> Cerebral malaria, tubercular meningitis and herpes encephalitis were seen in 7%, 4% and 1% cases respectively in the same study.

**Japanese Encephalitis (J.E.)**, which is caused by J.E. virus, is the most important arthropod borne viral encephalitis in Asia and the most common human epidemic encephalitis in world. It was first recognized in Japan in 1924 and in Nepal in Rupendehi district in 1978.<sup>5</sup> It mainly occurs in the autumn with alarming fatality rate. It also causes significant mortality and residual neurological sequelae in children. In a study conducted in Nepal, 62% of the total cases of viral encephalitis was reported due to J.E. virus and among them 8.3% succumbed to death where as 50% had neurological sequelae at the time of discharge.<sup>6</sup> In this study concomitant JE and cerebral malaria were seen in four (7%) and pyogenic meningitis in six patients. In non-JE patients the clinical features of measles such as erythematous rash or brownish desquamation were seen in 11.1%, enlarged parotids as in mumps in 8.3%, vesicular rash on erythematous base or dried up scabs of chickenpox in 5.6%, and few vesicles grouped at oral mucocutaneous junction as in Herpes simplex in 2.8%.

**Tubercular meningitis** is the most dangerous form of extra pulmonary tuberculosis occurring in 7 to 12% of tuberculosis patients in developing countries with a high rate of mortality due to the delay in diagnosis and proper treatment.<sup>7</sup> Recent data of Nepal shows that as many as 47,315 cases of tuberculosis are registered annually with 21,245 new smear positive cases. Similarly, tuberculosis in children represents 5 to 15% of all tuberculosis cases in Nepal.<sup>8</sup> It has been seen that tubercular meningitis occurs in approximately 7-12% of patients of tuberculosis.<sup>9</sup> Hence, the prevalence of the disease is supposed to be high in Nepal, however, there is no concrete authentic data in this regard.

The outbreak of cerebral malaria is not uncommon here and sometime reported in media as a mysterious killer in many remote part of Nepal.<sup>10</sup> About 15.6 million people (70% of the total population) are at risk to developing malaria in the country.<sup>11</sup> Falciparum malaria is found approximately in 15% of malaria smear positive cases. However, the reported malaria cases which used to range from 25,000 to 30,000 annually previously have now been dropped to 7,000 to 9,000 annually.<sup>12</sup>

**Typhoid encephalopathy** is another significant cause of febrile encephalopathy and these patients manifest with delirium, obtundation and stupor.<sup>13</sup> Kathmandu and Delhi, once labeled as typhoid capital of the world, still suffer from a high number of such cases every year.<sup>14</sup> In a hospital based Indian study typhoid is seen in the younger age group and its incidence in children below 5 years contributes around 44% cases and this scenario is expected to be similar in Nepal.<sup>15</sup>

#### B. NEUROCYSTICERCOSIS

**Neurocysticercosis (NCC)** is the most common parasitic disease of central nervous system in the world.<sup>16</sup> High prevalence of NCC has been reported from many tropical countries of Latin America, Africa and Asia.<sup>17,18</sup> The disease is one of the main cause of seizure and accounts for as high as 50% of patients presenting with partial seizure.<sup>18,19</sup> The scenario is not very different in Nepal.

In a study conducted in the western Nepal revealed that the mean age for appearance of NCC was 10.8 years

with range from 11 months to 15 years.<sup>20</sup> Most commonly affected group was 10 to 12 years of age and 8.9% patients were below 2 years of age. In this study the commonest type of clinical presentation was seizure (46%) followed by neuropsychiatric manifestation (25.8%), raised intracranial tension (20%) and focal neurological deficit (20%). In another study from Lumbini among the 93 consecutive patients presenting with new onset seizure 73% had NCC finding in radioimaging.<sup>31</sup> In this study the affected age group ranged from 2 to 14 years with preschool aged children (< 6 years) constituting 10.3% of the total patients.<sup>21</sup>

Thus, in Nepal, NCC has been a major public health hazard causing substantial neurological morbidity and economic hardship. It is supposed that there is wide variation in prevalence of this disease across the country and at some places, it is endemic. Poor sanitation facilities, ignorance of good hygienic practices and faulty food habits in low socio-economic strata are thought to be the factors contributing to the spread of such disease in the country. The disease is relatively more common in certain rural communities primarily due to poor sanitation, use of raw human faeces for fertilizing plants in garden or farms and lack of controlled pens for pigs.<sup>22</sup>

### C. EPILEPSY

Epilepsy is a common disabling neurological illness throughout the world with prevalence in the range of 0.5 to 0.9%, which is also an important pediatric problem in Nepal.<sup>23</sup> The incidence of epilepsy seems similar in Nepalese population. In a community based survey in Morang district, prevalence of epilepsy is found to be 7 per 1000 population.<sup>24</sup> Interestingly in this survey 9% of epileptic cases were being treated by traditional healers where as 29% of them had consulted faith healers in the past. As per the study, 40% of cases of the first seizure occurred in between age of 2 to 5 years. A survey from the Kaski district showed that there were 113 patients with epilepsy in a population of 105,000 with a mean duration of 6.5 years before diagnosis.<sup>25</sup> Prevalence is probably much higher as various surveys done in villages have shown that people believe in superstitions and are more likely to seek treatment from traditional healers (Dhamis, Jhankris, Tantriks- persons offering treatment through seeking the grace of divine power or favor of ghosts for the healing purpose).<sup>24,26</sup> This is also a reason for delayed diagnosis. A large uneducated rural population and dearth of doctors probably contribute to the frequent use of traditional healers. Various epileptic seizures in pediatric group have been analyzed in a hospital based study done in Kathmandu valley and it has been revealed that generalized tonic clonic seizure was the commonest (36%) followed by tonic (16%), complex partial (14%), atonic (12%) and absence (10%) and others (5%).<sup>27</sup>

### D. NEONATAL ENCEPHALOPATHY

Neonatal encephalopathy affects 2 to 8 per 1000 term infants world wide and is closely associated with early neonatal mortality and long term neuro-developmental sequelae in countries of both high and low income.<sup>28-</sup>

<sup>31</sup> A hospital based study by Ellis et al in Kathmandu showed prevalence of neonatal encephalopathy 6.1 per 1000 live birth of which 63% had moderate or severe encephalopathy.<sup>32</sup> This study also showed that both antepartum and intrapartum factors contributed significant role in causation of neonatal encephalopathy. According to another hospital based study with a total cohort of 21,609 live births, 131 term infant had neonatal Encephalopathy out of which 41% infants died, 18% developed severe neurological impairment and 2% had minor impairments.<sup>30</sup> Out of the children with major impairment, 78% had spastic tetraplegic cerebral palsy and 44% had multiple impairments. In a wide-ranged community based study in Sarlahi district, which included 23,662 infants, found death due to birth asphyxia 9.7 per 1000 live birth and accounted for 30% of neonatal mortality.<sup>33</sup> It was also found that maternal infections, prematurity and multiple birth were important contributing factors to mortality in infants with birth asphyxia.

### E. NEURO-PSYCHIATRIC AND DEVELOPMENTAL DISORDERS

Behavioral and developmental disorders are the two broad groups of mental health problems in children.<sup>34</sup> These developmental disorders are quite common worldwide and are a result of genetic aberrations, obstetric problems, postnatal insults and many others.<sup>35</sup>

In a developing country, child mental health receives little attention. There is paucity of Nepalese study on psychiatric morbidity in children.

In a hospital based study done in eastern Nepal to evaluate psychiatric morbidity among physically ill patients, the majority of them were found to have concentrated among age group of 15 to 24 years and the incidence in the age group below 5 years age was 2.6%.<sup>36</sup> In another study done in same region in a tertiary level hospital, among the children and adolescent attending psychiatric OPD 15% were diagnosed to have depression, 13% with deliberate self harm, 12% conversion disorder, 11% migraine and 10% seizure disorder.<sup>37</sup> Similarly, in another hospital based study done over one year in Kathmandu valley, among the 188 new cases who attended a child and adolescent guidance clinic, majority were between 10-12 years of age.<sup>38</sup> Among them 21.3% had mental retardation, 16.5% had somatoform disorder (conversion disorder 50.8% and pain disorder 32.3%) and 10.1% had attention deficit hyperactivity disorder.

**Mental Retardation** has also been identified as a significant problem among Nepalese population. Its prevalence in the world is 2.5% to 3% among which 0.4% of general population are severely handicapped with an I.Q. below 50.<sup>39,40</sup> The prevalence may be higher in Nepal. A Nepalese survey in 1989 found 4.1% of the general population suffered from mental retardation out of which 40% were less than 14 years of age.<sup>41</sup>

**Cretinism** which is a preventable cause of mental retardation is more prevalent in iodine deficient areas of Nepal. A random survey conducted in various districts of the country by the Goiter and Cretinism Eradication project of the Ministry of Health revealed prevalence ranging from 0.7% to 12.7%. The prevalence was higher in hilly areas.<sup>42</sup> Similarly, the neurological cretinism which manifests as mental retardation associated with deafness and spastic paraplegia but without clinical hypothyroidism was also more common in the hills.<sup>43</sup> This is again attributed to iodine deficiency in the hills. For the eradication of this disease, The Goitre and Cretinism Eradication project was established in 1979 as an autonomous unit and was linked with the Expanded Programme of immunisation.<sup>44</sup>

**Cerebral palsy** is also a common problem in Nepal and it is the consequence of poor obstetric care, poor medical facility, wide spread illiteracy, genetic predisposition, improper diagnosis and treatment of various neurological illness, etc. On the basis of data from other developing countries with similar demographic and socio-economic profiles to Nepal, it has been estimated that there are over 60,000 children in Nepal with cerebral palsy.<sup>45</sup> It is also estimated that less than 1000 of these children receive any type of biomedical therapeutic assistance, such as physiotherapy, speech or occupational therapy. The same study has also shown various misbeliefs about the cerebral palsy prevalent in Nepalese community such as this disability is being taken as parental or child sins in previous life or the result of contamination through the mother coming in contact with disabled child during her pregnancy or astrological mischance and so on. Cerebral palsy cases in Nepal are a genuine case of "hidden catastrophe" as little is done at the national level for its prevention and for the rehabilitation of children suffering from such disease.

**Autism** is another problem among Nepalese children but it remains under reported. There is no reliable estimate of this disease in Nepal as there is lack of awareness amongst people and diagnosis is weak. However, the disease in the neighboring country India and China is estimated roughly around two million and 1.1 million respectively. Autism Care Nepal estimates autistic population lies from 10,000 to 50,000 in Nepal and the incidence may be increasing as in other developed countries.<sup>46</sup>

**Learning disability** has affected approximately 5% of children in the west are identified as having some type of it.<sup>47</sup> The situation in Nepal seems not very different from that and seems worse. In a study of 1154 fifth grade children in central region of Nepal there were 104 cases with learning disability in mathematics. The same study found that self study habit, parental behavior, and socioeconomic status had affect on their learning disabilities. Most of the learning-disabled children in the study belonged to either low or high income socioeconomic status.<sup>48</sup> Learning disability is taken as a social stigma in a society which puts a large premium on academic excellence so even well educated families are reluctant to seek help. Matters are worsened by lack of specialized learning centers catering to the learning disabled. Hence, actual incidence may be higher in Nepal.

The government of Nepal spends less than 1% of total health budget on mental health care. The country is still devoid of mental health act. Not only this, the national mental health policy formulated in 1997 is yet to be fully operational and child mental health has hardly received any attention from the government. The traditional / religious healing methods are still practiced actively in this respect in various parts of the country.

## F. NEUROMUSCULAR DISEASE

A wide range of neuromuscular diseases are encountered in Nepal. According to the estimate of Muscular Dystrophy Foundation Nepal, the number of muscular dystrophy patients in Nepal is around 25,000 with **Duchenne Muscular Dystrophy (DMD)** accounting for approximately 24%.<sup>49</sup>

The status of the DMD patients is very serious in the country, as about 85 per cent are from very low-income group. The situation of patients with muscular dystrophy seems to be pathetic as revealed by a study done to see the physical and psychosocial aspect by Bhattarai et al in which 63.63 % were anxious, 54.54 were fearful and 81.8% had acting out trait. The situation is grave because among them 54.54% had low socioeconomic status and only 18.18% could study above class ten.<sup>50</sup>

Acute flaccid paralysis is commonly reported in Nepal as it is one of the notifiable disease. The Acute Flaccid Paralysis (AFP) surveillance effort in Nepal started through the network of the Early Warning and Reporting System (EWARS) in 1995.<sup>51</sup> The total AFP case in 2009 was 446 without any new polio cases. However in the year 2007 and 2008, there were 5 and 6 polio cases detected respectively. Genetic sequencing has confirmed that cases of poliomyelitis reported in Nepal in last few years has resulted from repeated import of the virus from



neighboring countries where it is endemic, rather than from internal spread.<sup>52</sup> The long and open border with the Indian states of Uttar Pradesh and Bihar, which together have one of the highest wild poliovirus transmission rates in the world, have always been of concern for those who have been involved with the polio eradication program in Nepal.

**Tetanus** remains an important cause of death particularly in the developing world. In Nepal there were 6700 estimated death due to neonatal tetanus with mortality rate of 8.8 per 1000 live birth in the year 1990.<sup>53</sup> In the year 1997, estimated death due to this declined to 5800 with mortality of 7 per thousand live births. During the fiscal year 2006/ 2007, 42 cases of neonatal tetanus and 155 cases of non neonatal tetanus were reported. As per a hospital based study conducted at Dharan from 2004 to 2006, there were 19 cases of pediatric tetanus (1-14 years age) and 5 case of neonatal tetanus.<sup>54</sup> In order to control tetanus, government of Nepal has launched different programs since 1989 like expanded program on immunization (EPI), maternal and neonatal tetanus elimination program, safe motherhood program, training of birth attendance etc. This has significantly contributed to reduce the burden of this disease. Neonatal tetanus has been eliminated (less than 1 case per 1000 live birth) in Nepal since 2005.<sup>55</sup>

## G. STROKE

Stroke in children is relatively rare and is more often seen secondary to various factors such as heart disease, intracranial infection, vascular malformation, metabolic and hematological disorders and the vasospastic condition like migraine disorders.<sup>56,57</sup> The actual incidence of stroke in children is not known in Nepal. A hospital based study in eastern Nepal done in 2006 yielded 150 CT confirmed stroke cases over a period of one year (104 males and 46 females) in the age group of as young as 7 years with 42% of them having hemorrhagic (intracerebral and subarachnoid) strokes however the study doesn't give incidence only in pediatric age group.<sup>58</sup>

From the foregoing delineations what we gather is that neurological illness is widespread among the children of Nepal but very limited study has been done so far in this perspective. The extreme geographical conditions, inaccessible places and rudimentary data-collecting systems have prevented health officials from obtaining an accurate picture of the neurological disorder. Lack of awareness and superstition prevalent in Nepalese society is another complexity that keeps on incapacitating such children from several curable neuropsychiatric disorders. In spite of the progress achieved significantly

in decreasing the burden of some diseases like, neonatal tetanus and poliomyelitis in the country, majority of children are still suffering from other serious neurological disorder due to inadequate facilities. As it is obvious that these cases can be dealt effectively and efficiently by advancing medical care physiotherapy and intensive rehabilitation, an integrated effort from national and international institutions and professional experts of this field is required in order to establish a well-facilitated unit for neurological treatment in Nepal and fight back the overwhelming condition.

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