



## Original Article

# Epidemiological survey of neurological diseases in a tribal population cluster in Gujarat

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### Abstract

**Background:** There are few community-based neuroepidemiological studies based in tribal communities. This cross-sectional community-based study explored the prevalence rates of neurological disorders in the tribal region of

Kaparada in Gujarat. **Methodology:** A two-stage methodology was used. Door-to-door surveys were conducted in the villages of Moti Vahiyal, Arnai, and Chavshala in Kaparada taluka in the Valsad district. Trained volunteers administered a questionnaire that assessed demographic details and common neurological symptoms in children and adults. Data were obtained from 8217 individuals from 1464 households using the questionnaire in stage 1. A number of 615 individuals reported at least one symptom. In stage 2, a team of neurologists conducted a medical camp to assess those “screened in” for neurological disorders. **Results:** The crude prevalence rate for neurological disorders in general was found to be 2592.19/100,000. The prevalence rates for lower motor neuron diseases were highest (1010.1), and the rates of epilepsy, movement disorders, stroke, vertigo, headaches, upper motor neuron diseases, and mental and behavioral disorders were found to be 255.6, 133.9, 109.53, 170.38, 511.4, 109.53, and 292.08/100,000, respectively. Age- and sex-specific rates and patterns varied for different disorders. **Conclusion:** The prevalence rates of most disorders were found to be lower than those reported elsewhere, but age and sex prevalence patterns were similar to existing research. Challenges in conducting such a study in a remote population are discussed.

**Keywords:** India, neuroepidemiology, neurological disorders, prevalence, tribal

## Introduction

The population of India of 1.247 billion accounts for a significant portion of the total population of the world, and around 68% of Indians live in rural areas.<sup>[1]</sup> A number of studies and reviews of studies<sup>[2],[3],[4],[5]</sup> report that the prevalence of neurological disorders is much higher in rural areas. At the same time, of the 1200 neurologists who are members of the Indian Academy of Neurology, most work in metropolitan cities, and rural parts of the country and interiors remain without specialists, leading to a wide gap between demand and supply of neurological health services in the country.<sup>[6]</sup> One of the first steps to start bridging this gap is to obtain relevant and representative neuroepidemiological data from different rural parts of the country which provides insights into the nature of concerns of our heterogeneous and vast population.

Furthermore, 8.61% of the population of India (around 104.28 million) comprise individuals belonging to various tribes according to the 2011 census.<sup>[1]</sup> These tribal communities face a number of diverse health concerns compounded by the difficult terrains that they live in and the ecological challenges that they face. Factors such as illiteracy, poverty, isolation, poor access to health care, and their

own particular traditions, customs, and habits may further exacerbate their concerns.<sup>[7]</sup> There is a need for more neuroepidemiological studies in India targeting specific tribal communities.

Systematic, community-based neuroepidemiological studies in India are limited. The prevalence rates of specific disorders have been described in studies and reviews of existing research.<sup>[3],[4],[8],[9],[10],[11],[12],[13]</sup> Relatively fewer studies have described the prevalence rates of a range of neurological conditions;<sup>[2],[14],[15],[16]</sup> however, most of the ones reviewed and published have been conducted in the north, east, and south parts of India,<sup>[2],[4],[5],[8],[11],[14],[15],[16]</sup> with the western and northwestern region relatively under represented (except for a study in Gadchiroli in the Western Ghats<sup>[13]</sup>). Barring some hospital studies and clinical profile-based studies in the state of Gujarat,<sup>[17],[18]</sup> to the best of the authors' knowledge, community-based studies of the prevalence of neurological disorders from this state are limited.

This cross-sectional epidemiological study was aimed at obtaining data about the prevalence of a wide range of neurological disorders, in a rural population cluster with a predominantly tribal population, in the state of Gujarat.

## **Methodology**

### **Study area and population**

Kaparada is one of the six talukas in the district of Valsad in the state of Gujarat. The Valsad region is located in South Gujarat between north latitudes 20°10' and 20° 45' and east latitudes 72° 48' and 73° 43', at 12 m above sea level. It is surrounded by Navsari district in the north, Nashik and Thane districts of Maharashtra in the east, and the Arabian Sea to the south and west. The geographical terrain is hilly, and there are many forests, and it is among the regions receiving the heaviest rainfall. Due to this, it is difficult to access the region during the monsoon season, making access to health care and other amenities a challenge. Three villages in this Kaparada taluka were surveyed for this study, namely, Moti Vahiyal, Arnai, and Chavshala. According to the 2011 census, these villages cover an area of 573 hectares, 855.6 hectares, and 1381.1 hectares, respectively. These villages have 568, 468, and 508 households, respectively, and a population of 2918, 2716, and 3110. Sex ratios indicate almost equal male: female representation. Around 99% of the individuals in these villages hail from Scheduled Tribes. Literacy rates at the time of the census

were in the 50% for Moti Vahiyal and Arnai and around 30% for Chavshala.<sup>[1]</sup> The dominant language spoken is Gujarati and predominant religion followed is Hinduism.

## **Study design**

This study was part of a larger project to assess neurological health-care needs, provide services, and improve access to services, in some villages in Kaparada. A cross-sectional community-based prevalence study was conducted, and a version of Gourie-Devi's adaptation of Schoenberg's two-stage methodology was used to obtain data.<sup>[19]</sup>

## **The survey questionnaire**

The survey questionnaire was aimed at screening for a wide range of neurological disorders in both children and adults. It consisted of three sections. Section 1 noted demographic details such as age, sex, education, occupation, and religion, for all members of the household. Section 2 contained questions about symptoms of common neurological conditions in adults, specifically epilepsy, movement disorders, headaches, and stroke. Section 3 contained symptoms of neurological disorders in children, particularly cerebral palsy and developmental disorders. The questionnaire was developed by a team of neurologists and neurophysiotherapists, and it covered the most common neurological symptoms. The questionnaire was translated in Gujarati by language experts.

### **Stage 1**

A preliminary survey was conducted across the three villages to identify the number of households and participants.

Community health workers and teachers were identified to conduct the survey. A 2-day training on the survey was conducted for the health workers and refresher trainings followed at regular intervals.

These volunteers conducted the door-to-door survey, attempting to cover every identified household in the three villages. Information was obtained about every member of each household.

A team of neurophysiotherapists scrutinized the filled-in questionnaires for positive cases. Any individual who had reported yes to any single symptom was

considered to have been “screened in” and was eligible for stage 2.

## Stage 2

In stage 2, a team of six neurologists conducted a medical camp in these three villages, where they assessed the above individuals using history and clinical evaluation. The prevalence of neurological disorders was calculated based on the diagnoses provided by this team of doctors. Age- and sex-specific prevalence rates were calculated for eight broad categories of neurological disorders, namely epilepsy, stroke and stroke residue, movement disorders, upper motor neuron diseases, lower motor neuron diseases, headache, vertigo, and mental and behavioral disorders.

## Results

### Population characteristics

The trained volunteers identified 8537 individuals from 1464 households across the three villages. The nonresponse rate at stage 1 was 3.33%, and a total of 8253 individuals were screened. Nonavailability at the household and unwillingness were the two primary reasons for dropouts at this stage. Of 8353 individuals, data of 36 individuals were discarded as the forms were missing or incomplete (0.44% data loss), and a total population of 8217 was considered in this study (which is 96.25% of the total population identified). Of these 8217 individuals, 615 (7.48%) individuals reported at least 1 symptom and were consequently identified for further evaluation at stage 2.

Dropout rate at stage 2 was 56.91%. Of the 265 individuals who attended the medical camp and were examined by the team of neurologists, 207 (78%) individuals were diagnosed with a neurological disorder. Six (2.26%) of the ones examined were given more than one neurological diagnoses.

Age and sex distribution of the 8217 samples is presented in [\[Table - 1\]](#). The sample included 50.27% men and 49.73% women. Distribution of men and women across the different age groups was fairly comparable. Nearly 40.57% of the individuals were below 19 years of age and 7.96% were above 60 years of age.

Table 1: Demographic details about the population sample

Age range (years)	Male (%)	Female (%)	Total (%)
0-9	21 (2.1)	20 (1.9)	41 (0.8)
10-19	848 (29.52)	859 (19.8)	1697 (20.37)
20-29	712 (27.24)	731 (18.43)	1463 (17.83)
30-39	582 (21.00)	589 (13.82)	1171 (13.52)
40-49	475 (17.15)	454 (11.11)	929 (11.31)
50-59	356 (13.42)	319 (7.41)	675 (8.21)
60-69	247 (9.07)	216 (5.05)	463 (5.35)
70+	80 (3.03)	94 (2.3)	174 (2.01)
Total	4119 (100)	4086 (100)	8205 (100)

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Nearly 99.63% of the individuals reported following Hinduism and 0.37% were found to follow Islam. 44.52% of the individuals were illiterate, 13.85% had completed some primary education, 22.36% had completed some secondary education, and 15.01% and 0.1% had completed their Secondary School Certificate or Higher Secondary Certificate, and/or some professional qualification, respectively. Data for 4.16% of the individuals were either not available or not applicable (very young children). For the adults (aged above 18 years), the chief occupation was farming with 89.19% engaged in this. 1.79% of the individuals were student. 4.21% of the individuals were unskilled laborers and 1.69% were either skilled laborers or engaged in professional work, while data for 3.12% were not available. The average size of the household was 5–6 members, with the smallest households having 1 member and the largest having 15 members. 47.61% of the households could be characterized as small (5 or less members), 46.65% were medium sized (6–9 members), and 5.74% were large (10 or more members).

## Prevalence

The crude prevalence rates of the major disorder categories are reported in [\[Table - 2\]](#). The crude prevalence of neurological disorders overall was found to be 2592.19/100,000. Lower motor neuron diseases were found to be the most frequent; this category included peripheral neuropathy and muscle diseases. Headache was the second most frequent. Some individual disorder crude prevalence rates were found to be 35.51/100,000 for Parkinson's disease, 73.04/100,000 for essential tremors, and 24.24/100,000 for Parkinson's plus syndromes. The prevalence was 24.34/100,000 for peripheral neuropathy and for intellectual disability and 60.86/100,000 for cerebral palsy. The neurologists also found a prevalence of 36.51/100,000 for leprosy sequelae – the cases identified had been previously treated for leprosy and showed associated deformities.

Neurological disorders	n	Crude prevalence rate out of 100,000
Encephalitis	21	21.00
Movement disorders	11	11.9
Stroke and stroke related	9	9.08
Visual	14	17.08
Headaches	42	511.14
Upper motor neuron diseases	8	8.08
Lower motor neuron diseases	83	1010.1
Mental and behavioral disorders	24	292.08
Total neurological disorders	213	2592.19

Table 2: Crude prevalence rates of neurological disorders

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Age-specific prevalence rates and sex-specific prevalence rates are reported in [\[Table - 3\]](#) and [\[Table - 4\]](#), respectively. For prevalence of neurological disorders

overall, a generally increasing trend with a plateau between the ages of 40 and 59 years was seen, with the highest prevalence for those aged above 70 years. The exception was the 10–19 years' age group that had the lowest prevalence rate. A female preponderance was seen in the diagnoses, with a more than two times higher rate of diagnoses among females as compared to males.

Table 3: Age-specific prevalence rates out of 100,000

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Table 4: Sex-specific prevalence rates out of 100,000

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Marked differences were seen in age- and sex-specific prevalence rates for different disorders. The highest prevalence rates for epilepsy were seen for the 0–9 years and 70 years and above age groups. 47.61% of those diagnosed with epilepsy were below the age of 10 years. 100% of those diagnosed with movement disorders were above 40 years of age and 80% were above 60 years, with the highest prevalence rates for the 60–69 years' age group. 100% of individuals diagnosed with stroke were above 50 years, and the prevalence rates were highest for those above 70 years, followed by those between 50 and 59 years of age. Increasing trends were seen for vertigo, upper motor neuron diseases, and lower motor neuron diseases, and for headache and mental and behavioral disorders, the pattern was varied. The most common childhood disorders were mental and behavioral disorders and epilepsy. The prevalence rates were higher for males than for females for epilepsy, stroke and upper motor neuron diseases, lower for males than females for movement disorders, vertigo, headache and lower motor neuron diseases, and roughly equal for both sexes for mental and behavioral disorders.

## Discussion

This study is one of the very few epidemiological studies conducted in the western and northwestern part of India for a tribal population. It demonstrates that it is possible to systematically assess prevalence even in such remote locations using the standard two-stage methodology, and also illustrates the challenges in doing so.

## Overall prevalence of neurological disorders

In a systematic review of neuroepidemiological studies in India from 1982 to 1995 conducted by Gourie-Devi *et al.*,<sup>[19]</sup> rates of neurological disorders in the population were reported as ranging between 967 and 4070 with an average of 2394/100,000. In subsequent studies, rates of 3126/100,000 in the total population and 4070/100,000 in rural areas were reported from Bengaluru in 2004,<sup>[2]</sup> and the rate of 5168/100,000 was reported from Kashmir in 2016.<sup>[15]</sup> The current study found rates of 2592.19/100,000, which is close to the average mentioned,<sup>[19]</sup> but much lower than the rates in other areas. These differences could also be due to differences in the categorization of neurological disorders and the kinds of neurological disorders included across different studies, and it could also suggest geographical differences.

The age- and sex-specific prevalence trends in this study mirror those of previous studies, with rates increasing with age, and female preponderance. The rates of neurological disorders among children below 9 years in this study (1193.32/100,000) is much higher than in a previous study in Kashmir that reported 706/100,000.<sup>[20]</sup>

## **Epilepsy**

Reviews of epidemiological studies on epilepsy from different parts of the country have found very diverse rates, with reported ranges being 559–1000/100,000<sup>[11]</sup> and 300–1190/100,000,<sup>[3]</sup> and these trends are reported to be similar to trends seen in high-income countries where the range is from 270 to 1240/100,000.<sup>[3]</sup> The rate of epilepsy in this study was 255.6/100,000 falls below these ranges. The two peaks in prevalence rates in childhood and after 70 years of age found in this study are similar to the trends found previously in a number of Indian community-based epidemiological studies, for example, Mani *et al.* in 1998 and Banerjee *et al.* in 2010.<sup>[3]</sup> A male preponderance is noted in most community-based epidemiological studies<sup>[3],[11]</sup> and in a clinical-based study from the northwestern region of Chandigarh (geographically the closest to Gujarat compared to locations of other studies),<sup>[21]</sup> and similar trends are seen here.

## **Stroke**

The rates of stroke described in several reviews and studies are as varied as 44–898<sup>[9],[10],[12],[13],[14],[15],[16],[19],[22],[23],[24],[25]</sup> The rate reported in this study of

109.53 falls in this broad range. It is much lower than those in another tribal population of Gadchiroli in the Western Ghats (388.43).<sup>[13]</sup> Most but not all studies have reported a male preponderance<sup>[12],[13],[14]</sup> as was found in the current study, and the latter was also found in two clinical case studies from Gujarat itself.<sup>[17],[18]</sup> Highest prevalence of stroke in the above 70 years of age group is similar to other studies.<sup>[14]</sup> Previous studies have reported a fair percentage of cases of young-onset stroke,<sup>[10]</sup> but no such cases were found in this study. Types of strokes were not identified in this study. However, similar to the studies based out of the Gujarat Medical College,<sup>[17],[18]</sup> hemiplegia was the most common clinical presentation.

## **Movement disorders**

The prevalence of movement disorders was found to be 133.9/100,000. The crude prevalence rate of Parkinson's disease was found to be 35.5/100,000, which is in keeping with rates of 6–53 reported in review<sup>[19]</sup> and in other rural studies.<sup>[2],[14],[15]</sup> The rates of essential tremors are markedly different in different studies, and in some, they have been reported to vary from 8 to 395.<sup>[19]</sup> Following global trends,<sup>[26],[27],[28]</sup> most of the cases were reported in individuals above 60 years of age. Global trends suggest a slight male preponderance in most countries, except for Asia, where the rates are more equal across sexes; in the current study, a slight female preponderance was seen for seen for Parkinson's disease, but a high one was seen for movement disorders in general. There was a 24.24/100,000 prevalence of Parkinson's plus syndromes. The rates of Parkinson's plus syndromes have not previously been reported in the Indian epidemiological surveys reviewed by the authors.

## **Other disorders**

The rates of headache were lower than other studies in Bengaluru, Kashmir, and West Bengal.<sup>[2],[15],[16]</sup> The rates of vertigo were markedly different from those reported in another study conducted in West Bengal.<sup>[16]</sup> The rate of cerebral palsy were lower than those seen in Kashmir.<sup>[15]</sup> The high rates of lower motor neuron diseases could be related to the heterogeneous nature of the classification.

In sum, it appears that the prevalence rates found in this tribal population are either on the lower end or much lower than available figures, especially for

figures previously found in rural populations. However, apart from Parkinson's disease, the age and sex distribution of diagnoses show patterns similar to those in other studies in India.

## **Limitations**

This study was done in a small population with limited resources. All the diagnoses were based purely on the clinical history and examination. This may have limited diagnostic accuracy pending further imaging and test results. 78% of the individuals who were screened and who attended the medical camp in stage 2 actually received a diagnosis of a neurological disorder. Around 21% of the patients identified with neurological conditions were referred for further imaging to clarify the diagnoses.

The high coverage of the population (96.25%) in stage 1 is noteworthy. However, the dropout rate of 56.91% at stage 2 is a major concern. Possible reasons for the high dropout rates could have been that the individuals forgot the dates of the camp, were at work, or could not leave the house, on the specific dates that the team of the neurologists conducted the medical camps, or because their reported concerns were perceived by them to be very vague and diffuse, and the individuals felt that these were not worth the visit to a doctor. The team took several steps to attempt to reduce dropout rates. The health volunteers visited every single household the day before the camp to remind individuals of the camp date; they also visited each household on the day of the camp to remind the individuals again and on occasion, personally accompanied individuals to the camp venue. The camp was held at a prominent place that was well known and easily accessible in the community. The neurologists themselves conducted home visits to the houses of those individuals with mobility restrictions. The camp was conducted in batches held at different times including evening hours, to make it easier to accommodate individuals' work hours. A follow-up visit by the neurologists was organized in 3 months for those who missed the first camp. Notwithstanding these efforts, the dropout rate persisted. The remoteness of the area and the near-impossibility in accessing it during the monsoons because of its geographic location made further follow-up visits by the doctors a significant challenge. This highlights the difficulties in finding prevalence estimates in such locations.

The questionnaire used for identifying patients had been vetted by a team of senior neurologists. It was previously piloted in an informal settlement in

Mumbai, where the volunteers were observed by neurologists and physiotherapists while they conducted the assessment to check for accuracy in administration. On its subsequent use in Kaparada, the high diagnoses rate (78%) among those who were screened as positive (out of those who attended the camp) testifies to the utility of the questionnaire as a screen for common symptoms of neurological disorders. However, difficulties faced by the team with respect to camp attendance and remoteness of the location making regular doctor visits difficult made it difficult to gather the necessary requisite data to ascertain the sensitivity and specificity of the instrument.

Notwithstanding the challenges, the highlight of the study was the snapshot captured of the rates of neurological conditions in a region that is not otherwise studied, among a population that is often ignored in research studies. Kalkonde *et al.*<sup>[13]</sup> highlighted that there were few epidemiological studies in rural areas and that no epidemiological study in rural areas had been conducted in 20 years (before theirs in 2016). They outlined the need for more current epidemiological data, given the transitioning nature of the Indian rural units. More robust studies in ethnically diverse groups in varied parts of the country are highly recommended. Another highlight of the study was that it combined research with service. All patients were provided medications and other treatments free of cost, and they were directed to other relevant intervention professionals.

## **Conclusions**

The team further intends to conduct a detailed analysis of the cost of treatments, access to delivery systems, treatment compliance and other healthcare variables, in this region, and combine this data with the prevalence data, to design and execute effective health-care models for this region, in an attempt to bridge some of the glaring treatment gap for neurological conditions in India.

## **Financial support and sponsorship**

The study was supported by Bombay Hospital.

## **Conflicts of interest**

There are no conflicts of interest.

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**Table: 1**

Age range (years)	Male (%)	Female (%)	Total (%)
0-9	831 (20.12)	845 (20.68)	1676 (20.4)
10-19	848 (20.53)	809 (19.8)	1657 (20.17)
20-29	712 (17.24)	753 (18.43)	1465 (17.83)
30-39	582 (14.09)	578 (14.15)	1160 (14.12)
40-49	475 (11.5)	454 (11.11)	929 (11.31)
50-59	356 (8.62)	319 (7.81)	675 (8.21)
60-69	247 (5.97)	234 (5.72)	481 (5.85)
70+	80 (1.93)	94 (2.3)	174 (2.11)
Total	4131 (100)	4086 (100)	8217 (100)

Table 1: Demographic details about the population sample

**Table: 2**

Neurological disorders	<i>n</i>	Crude prevalence rate out of 100,000
Epilepsy	21	255.6
Movement disorders	11	133.9
Stroke and stroke residue	9	109.53
Vertigo	14	170.38
Headaches	42	511.14
Upper motor neuron diseases	9	109.53
Lower motor neuron diseases	83	1010.1
Mental and behavioral disorders	24	292.08
Total neurological disorders	213	2592.19

Table 2: Crude prevalence rates of neurological disorders

**Table: 3**

Age	Total population	Epilepsy	MDs	Stroke	Vertigo	Headache	UMN	LMN	M and B	Total neurological disorders
0-9	1676	536.99	0.00	0.00	0.00	0.00	119.33	0.00	536.99	1193.32
10-19	1657	60.35	0.00	0.00	0.00	0.00	60.35	120.7	241.4	482.8
20-29	1465	273.04	0.00	0.00	136.52	341.3	68.26	341.3	136.52	1296.93
30-39	1160	258.62	0.00	0.00	0.00	948.28	86.21	948.28	86.21	2327.59
40-49	926	107.99	107.99	0.00	215.98	1403.89	0.00	2807.78	323.97	4967.6
50-59	675	0.00	148.15	888.89	296.3	740.74	148.15	1777.78	444.44	4444.44
60-69	481	415.80	1455.3	207.9	1039.5	1455.3	207.9	3742.2	415.80	8939.71
70+	174	574.71	1149.43	1149.43	1724.14	574.71	1149.43	5172.41	0.00	11494.26
Total	8217	255.6	133.9	109.53	170.38	511.14	109.53	1010.1	292.08	2592.19

MDs=Movement disorders, UMN=Upper motor neuron diseases, LMN=Lower motor neuron diseases, M and B=Mental and behavioral disorders

Table 3: Age-specific prevalence rates out of 100,000

**Table: 4**

Sex	Total population	Epilepsy	MDs	Stroke	Vertigo	Headache	UMN	LMN	M and B	Total neurological disorders
Male	4131	338.9	72.62	145.24	48.41	48.41	193.66	387.32	290.49	1525.05
Female	4086	171.32	195.79	73.42	293.69	978.95	24.47	1639.75	293.69	3671.07
Total	8217	255.6	133.9	109.53	170.38	511.14	109.53	1010.1	292.08	2592.19

MDs=Movement disorders, UMN=Upper motor neuron diseases, LMN=Lower motor neuron diseases, M and B=Mental and behavioral disorders

Table 4: Sex-specific prevalence rates out of 100,000

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