***Title of the Paper***

**Trends in Mortality due to Acute Encephalitis Syndrome in Gorakhpur District of Uttar Pradesh: Who is Responsible?**

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**Trends in Mortality due to Acute Encephalitis Syndrome in Gorakhpur District of Uttar Pradesh: Who is Responsible?**

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**Introduction**

This paper seeks to analyse and offer an explanation for the mortality due to Japanese Encephalitis and Acute Encephalitis Syndrome for the period of 2005-2018. The paper argues that right through this period there have been an average of 300-400 deaths. This has peaked to over 1000 reported deaths. The paper explores the health services and health determinants that are responsible for this pattern of mortality and argues that irrespective of the political formation, the trend does not show any significant change. This wilful neglect of public health service in Uttar Pradesh in general and Gorakhpur in particular reflects the negligence and carelessness of the political class in Uttar Pradesh, which amounts to ‘Social Murder’(1) of the most marginalized communities. This paper is divided into four sections; the first section provides an overview of the trends in morbidity and mortality from 2005-2018. In this section the clinical features of JE/AES, incidents, trends and prevalence and mortality have been discussed. The second section deals with the health service determinants in Gorakhpur district. We examine the availability, accessibility, affordability and quality of public health services at the primary, secondary and tertiary levels. This section also will throw light on the interaction of National Vector Borne Disease Control Programme (NVBDCP) for JE/AES and public health services in Gorakhpur.

The third section examines the role of health system determinants that includes the physical, social and economic aspects. The availability of road and transport connection would have a bearing on the physical accessibility. Based on an earlier study (2) it has been observed that the mortality experience is disproportional borne by the working class and lower castes. The poor social and economic conditions of those who are most affected by the disease, act as a barrier in seeking treatment. The poor state of public health services coupled with a predatory and unregulated private sector causes treatment delays. This is an important reason for the large number of deaths at the Baba Raghav Das medical college, Gorakhpur. The last section analyses the complex interaction between health system and health service system determinants to locate the fault lines at various levels. It argues that the responsibility for these deaths has to be pinned on the political class, the medical bureaucracy, the administrators of Uttar Pradesh health services and lastly the medical and paramedical staff in at various levels of the health services.

**Methods**

This paper has accessed multiple sources of data to construct the core argument. It has accessed the National Vector Borne Disease Control Programme (NVBDCP) data base to analyse the trends in prevalence, incidence and mortality due to Japanese Encephalitis (JE)/Acute Encephalitis Syndrome (AES) from 2005-2019. For health services it has accessed the UP government and National Rural Health Mission data. Other relevant government reports were also accessed for issues of quality of health services. For a reconstruction of the most recent epidemic, we have compiled reports from national and regional newspapers. In order to understand the utilization behaviours and barriers to treatment access we have relied on a qualitative exploratory study conducted in a selected block of the district in 2015 (3). More recent published data has been analysed in order to substantiate our argument.

**Section 1**

***Trends in Mortality due to Acute Encephalitis Syndrome and Japanese Encephalitis: 2005-2019. Peaks in Mortality***

Acute Encephalitis Syndrome (AES) is characterised by an acute onset of fever which progresses and produces a change in mental status resulting in disorientation, confusion and coma in a person. Those patients having high grade fever for 5-15 days with any two of the following symptoms among headache, vomiting, delirium, stupor, abnormal movements, convulsions, neck rigidity, altered sensorium and unconsciousness are considered as Acute Encephalitis Syndrome (4). Acute Encephalitis Syndrome is a clinical condition that has different aetiological agents. One of the major agents is the Japanese Encephalitis Virus (JEV) along with other infectious or non-infectious causes. A confirmed aetiology is generally not required for the clinical management of AES. Thus surveillance for JEV infection in India has focused on identifying AES cases rather than JE cases (5).

The Acute Encephalitis Syndrome (AES) includes Japanese Encephalitis (JE) which shows similar neurological manifestations. There is seasonality attached to the occurrence of JE cases. It is usually found to occur during the monsoon and post-monsoon periods whereas the AES impacts round the year due to the complex nature of its aetiology. The case morbidity and fatality is really high in viral encephalitis which includes JE. Japanese Encephalitis is the most common cause of acute encephalitis across the world. It is a fever involving the central nervous system. It is a vector- borne viral disease transmitted through the mosquito that can cause inflammation of brain tissues leading to onset of fever, headache, confusion, and sometimes seizures.

JE is largely concentrated in South Asia, Southeast Asia, East Asia & Pacific which together is deemed as endemic regions. The occurrence of the disease highlights the inter relationship between man and birds, animal and the environment. The disease was first recognized as clinical entity in Japan in 1871. But the fatal human case was observed in 1934 in Japan itself (6). It was named then as Japanese B. Encephalitis (7). JE is a mosquito borne encephalitis which is caused by group B arbovirus. The disease transmission is caused by Culicinae mosquitoes. The Zoonotic nature of the disease explains the nature of virus which infects both humans and animals but humans in this cycle are accidental hosts. The infection of the virus ranges from non-specific febrile illness to severe neurological manifestations. The genotype of the virus is different as per the geographical distribution. In terms of virulence and host preference the serotype are similar. The disease occurs after the active carrier mosquito bites and then viral replication takes place. Children up to the age of 15 are at major risk of the disease. Only one tenth of the infected were more than 60 years of age (8).

The data available with the WHO shows that Japanese Encephalitis is a leading cause of viral infection for Acute Encephalitis Syndrome. The World Health Organization has defined under the JE surveillance the case definition as, “Clinically, a case of AES is defined as a person of any age, at any time of year with the acute onset of fever and a change in mental status (including symptoms such as confusion, disorientation, coma, or inability to talk) AND/OR new onset of seizures (excluding simple febrile seizures). Other early clinical findings may include an increase in irritability, somnolence or abnormal behaviour greater than that seen with usual febrile illness”. That means that the laboratory confirmed cased would be called JE cases rests are suspected JE cases (9).

The global disease burden is not known exactly because of the variation in the pattern of disease based on both ecology and season. The intensity and quality of JE surveillance varies around the world. Around 2 million people live in the high risk zone around the world where the humans and animals both are at risk. The countries like China and India are among them where an estimate of 700 million lives at risk (10). It has found that the South East Asian countries like Bangladesh, Indonesia, India, Sri Lanka and Thailand possess all the conducive factors for the natural transmission of JE. In Asia, JE is the main cause of viral encephalitis in many countries with nearly 68,000 clinical cases per year. The data shows 24 countries in the WHO South-East Asia and Western Pacific regions have endemic JE transmission which exposes more than 3 billion people at risk. The World Health Organization accepts the unavailability of cure for the disease which leads treatment to the relieving the patients from the signs and symptoms of the disease (11).

According to an estimate around 35000- 50000 cases reported annually in across the world within which 20-30% people dies and 30-50% survivors suffer neurological sequel (12). There are important global variations found in case of fatality proportion due to AES. The range of mortality ranges from 17 to 50% in South and South-East Asia but in developed countries AES mortality in limited to a mere 5%. The overall disability is as high as 40% (13).

The countries neighbouring India have shown a similar pattern of Japanese Encephalitis outbreaks. For instance in Nepal there was no difference between fatality rate of males and females over five years old in 1997. The noticeable factor was the gender difference of 65% more male patients in comparison to the females under five years but the case fatality rate was found higher in females by 2.1 times (14). An estimate says that around 50000 people get infected every year around the world. In this statistics around 10000 dies and 15000 get neurological disabilities for life (15). The first case of Japanese Encephalitis (JE) in India was found in Vellore District of Tamil Nadu in 1958 and first major outbreak in West Bengal in 1973. Prior to 1970s the disease had only affected the southern part of India but gradually it spread to the northern states of the country (16). World Health Organization has defined the South-East Asia and Western Pacific as the geographical locations at risk. The understanding of Japanese Encephalitis, as a major public health problem but in the absence of actual data the accurate disease burden is not known till date. The question that arises is whether it is possible to differentiate JE from other causes of AES clinically? JE infection is mostly represented by the acute encephalitis syndrome and clinically it is indistinguishable from the other causes of AES. Thus the WHO standard recommends the clinical syndrome surveillance for AES patients and then laboratory confirmation for JE virus infection (17).

In India, Uttar Pradesh is accountable for more than 60% of all the cases reported under Japanese Encephalitis. Scientists attribute the causation of Acute Encephalitis Syndrome to a number of causes. Saxena (18) called AES the ‘*Undiagnosed illness*’. In this study it was found that there was large number of viral encephalitis in northern India during July 2005 to December 2005. The recorded Case Fatality Rate was 23.3% provided the true incidences were much higher, they note. The term undiagnosed illness was made on the basis of seeing the trend of AES from 1992 to 2008. The graphical presentation shows the increase in cases year by year (19).

The year 2009 has been a remarkable year in the study of Japanese Encephalitis; as it was separated from Acute Encephalitis Syndrome. This distinction has greatly helped in providing a clearer diagnosis and research analysis in the field of Acute Encephalitis Syndrome (AES). Before the distinction there were possibility of counting AES cases as Japanese Encephalitis cases and being treated accordingly. The major problem arises with this practice was the share of deaths due to AES would have counted as JE deaths apart from the treatment protocol of JE being followed in the broader symptoms of AES.

The above mentioned data signifies the quantum of the problem which has arises due to the poverty and social backwardness. The people who are affected from this disease condition are mostly the rural population who does not even have the basic needs of their human life. The high prevalence of morbidity and mortality in Uttar Pradesh highlights the association between poor socio-economic conditions and the disease.

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| **Trends in Acute Encephalitis Syndrome in India across political regimes in Uttar Pradesh** | | | |
| **Years** | **India (JE/AES combined)**  **Morbidity/Mortality** | **Uttar Pradesh (JE/AES combined)**  **Morbidity/Mortality** | **Government in UP** |
| **2005** | **6669/1682** | **6061/1500** | **SP** |
| **2006** | **2871/663** | **2320/528** | **SP** |
| **2007** | **4110/995** | **3024/645** | **BSP** |
| **2008** | **3889/684** | **3012/537** | **BSP** |
| **2009** | **4975/779** | **3073/556** | **BSP** |
| ***Source: NVBDCP, GoI*** | | | |

|  |  |  |  |
| --- | --- | --- | --- |
| **Trends in Acute Encephalitis Syndrome in India across political regimes in Uttar Pradesh** | | | |
| **Years** | **India (Acute Encephalitis Syndrome)**  **Morbidity/Mortality** | **Uttar Pradesh (Acute Encephalitis Syndrome)**  **Morbidity/Mortality** | **Government in UP** |
| **2010** | **5167/679** | **3540/495** | **BSP** |
| **2011** | **8249/1169** | **3492/579** | **BSP** |
| **2012** | **8344/1256** | **3484/557** | **BSP/SP** |
| **2013** | **7465/1270** | **3096/609** | **SP** |
| **2014** | **10853/1717** | **3329/627** | **SP** |
| **2015** | **9854/1210** | **2894/479** | **SP** |
| **2016** | **11651/1301** | **3919/621** | **SP** |
| **2017** | **13672/1097** | **4724/654** | **BJP** |
| **2018** | **11388/636** | **3080/230** | **BJP** |
| **2019 (Provisional)** | **14464/732** | **2185/126** | **BJP** |
| ***Source: NVBDCP, GoI*** | | | |

The data related to either Japanese Encephalitis or Acute Encephalitis Syndrome combined or separate shows the increase in the quantum of this disease. Before the separation in reporting of both these diseases in 2005, there was higher morbidity and mortality in the state. In 2005, more deaths were reported from Gorakhpur district of Uttar Pradesh. Majority of these deaths were reported at the Baba Raghav Das medical college hospital which is tertiary care center specialized for treatment of encephalitis in Eastern UP. Following the increase in reported cases in 2005, the next peak is in 2009 when more than 3000 cases were reported in Uttar Pradesh. This was the year when consecutive floods hit several districts. The etiology of disease shows that it gears-up in post-monsoon season and the flood affected areas contribute to the maximum exposure of the population to this disease.

It is only in 2009, that there is a separation of data between JE and Acute Encephalitis Syndrome. The data itself shows the structural fallacy in the previous model of data available. We have found more cases of AES than JE after post 2009 data. There were majority of cases being counted under Japanese Encephalitis rather than being counted as AES; a broader term and several other reasons for the disease conditions.

The picture gets grimmer for the AES cases in Uttar Pradesh after 2009. We see that the morbidity for the AES reached more than 3000 cases every year only in Uttar Pradesh. And mortality due to AES showed an increasing pattern. The year 2010, 2014 and 2016 were the peak years for Encephalitis cases at both the state and national levels. 2010 had approximately 5200 cases at the national level, of which 3540 cases were reported from Uttar Pradesh. A similar trend was observed in 2014 and 2016 when more than 10000 cases were reported at the national level and UP had the single largest share of these cases. Thus even during the peak years at the national level the state continued to report a major share of the cases reported under AES.

The incident of 60 children dying due to the lack of oxygen in Baba Raghav Das Medical College Gorakhpur (Uttar Pradesh) during 2017 was a case of sheer negligence on the part of state government. The reason of the deaths of these children is widely known. Through the media reports it has been highlighted that the Oxygen supply was stopped in the hundred bedded encephalitis ward in BRD medical college Gorakhpur. The reason given was the non-payment of dues related to the oxygen supplier of the medical college.

**Section 2**

***Health Services as a determinant of JE/AES in Gorakhpur District of Uttar Pradesh***

The health care system is designed three-tier in the district. It has sub-centres at the most peripheral level which covers a population of 3000-5000; Primary Healthcare Centres at intermediate level to cover a population of 20000-30000 and Community Health Centres at the population of 100,000. The government organizational setup appoints the District Magistrate as head who also acts as Chairperson of Integrated District health Society. There are 702 government healthcare facilities are available in the district.

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| **TABLE: HEALTH SERVICES DISTRIBUTION IN GORAKHPUR DISTRICT** | |
| ***Category*** | ***Numbers*** |
| *District Hospital* | *01* |
| *Community Health Centres* | *09* |
| *Primary Healthcare Centres* | *13* |
| *Additional Primary Healthcare Centres* | *61* |
| *Family Welfare/ Maternal and Child Health Centres* | *529* |
| *Female Hospitals* | *01* |
| *Urban Health Posts* | *15* |
| *Leprosy Hospitals* | *01* |
| *Homeopathic Hospitals* | *02* |
| *Mobile Dispensary* | *02* |
| *Medical Colleges* | *01* |
| *Source:* [*www.nlrindia.org*](http://www.nlrindia.org) | |

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| **TABLE: VARIOUS STAFF POSITIONS IN GORAKHPUR DISTRICT UNDER UP STATE GOVERNMENT** | | | |
| ***Category*** | ***Sanctioned*** | ***In Position*** | ***Leprosy Training Received*** |
| *Medical Officers* | *277* | *238* | *218* |
| *Pharmacist* | *100* | *98* | *73* |
| *Health Supervisors(F)* | *129* | *117* | *102* |
| *Health Supervisors(M)* | *137* | *117* | *105* |
| *Health Workers(M)* | *157* | *26* | *25* |
| *Health Workers(F)* | *545* | *514* | *405* |
| *Non Malaria Supervisors* | *12* | *11* | *11* |
| *Non Malaria Assistants* | *38* | *38* | *38* |
| *ASHA* | *2481* | *2481* | *NA* |
| *Source:* [*www.nlrindia.org*](http://www.nlrindia.org) | | | |

The Gorakhpur district of Uttar Pradesh has always grappled with serious health infrastructure problems. The district has 37% shortage of health sub-centers and only 45% of villages have access to sub-centers within five kilometers of its periphery. Also there is absence of sub-divisional hospitals in the district. It was also recorded that there have been 95.7 percent shortage of male health workers across the state. The condition of sub-centers across state is poor since around a third lack electricity and water. These data show why Uttar Pradesh has been ranked among the bottom three states in India for poor health infrastructure. The recent of deaths of JE/AES patients in BRD medical college was attributed to the failure of the health services due to poor infrastructural facilities. There are insufficient numbers of medical professionals at primary and secondary level care units across state (20).

Uttar Pradesh is among the highest populous states with about 200 million people with a sum of 75 districts, 814 blocks and 97,609 villages. In terms of health and nutritional outcomes, infrastructure and coverage indicators, it is considered to be among the poorly developed states marked by wide intra state disparities. The health services in UP face a serious deficit in the availability of human resources. Uttar Pradesh also has the lowest share of female health workers with only 19.9 percent in comparison to the national aggregate of 38 percent.

For example, most of the 30 Indian districts ranked lowest in terms of density of nurses were [located in UP](http://www.who.int/hrh/resources/16058health_workforce_India.pdf), with some also located in Bihar and Jharkhand. UP, which had 16.16% of the country’s population, had only 10.81% of overall health workers. The recent data which Uttar Pradesh Government highlight major gaps in the public health sector in the state. There is a shortfall of 84 percent in specialists at CHCs in 2016 (21). One-third of the PHCs do not even have a lab technician. Given the weak public health services, the effectiveness of all National Programmes is severely hampered. The performance of the national programme is dependent on the robustness of the public health services.

The operational guidelines of National Programme for Prevention and Control of Japanese Encephalitis/ Acute Encephalitis Syndrome, Government of India (GOI) 2014 has focused on three broad categories for the management of the situation including Preventive measures which includes sanitation, safe drinking water, improvement of nutrition level, secondly Case Management which includes capacity building of human resource and finally Rehabilitation which talks about the physical and social rehabilitation of the disabled children. The goals of programme are to reduce mortality, morbidity and disability.  The objectives of this programme is to focus on the worst affected districts, strengthen surveillance systems including referrals, supply pure and safe drinking water to the larger population, improve nutritional status of children and finally intensify the Information, Education and Communication (IEC) related to the epidemic. For the implementation strategy these guidelines has assigned specific roles and responsibility to the various ministries such as Ministry of Health and Family Welfare, Ministry of Social Justice and Empowerment, Ministry of Drinking Water and Sanitation, Ministry of Housing and Urban Poverty Alleviation, Ministry of Human Resource Development and Ministry of Women and Child (22). While the National Programme innovated and improvised their strategies through inter departmental co-ordination, its implementation faced challenges due to the weakness of the public health service infrastructure. This explains why the there was such high mortality rates despite the best efforts of the NVBDCP and these trends were apparent from the early 2000s across different political regimes in the State. Both the National and Regional Parties did not give priority to the recurrent epidemics resulting in large number of deaths.

***Political Regimes (BSP/SP/BJP) in Uttar Pradesh and priorities for health***

Regardless of political regimes whether Bahujan Samaj Party (BSP), Samajwadi Party (SP) or current Bhartiya Janta Party (BJP) was in power, the morbidity and mortality rates have been uncontrolled in the state. In 2005, the Samajwadi Party was in power and it was among the worst epidemic of Japanese Encephalitis and Acute Encephalitis Syndrome. After this epidemic, the State government adopted some measures that led to the next year data shows that the positive measures that led to halving the morbidity and mortality in relation to the previous year. However, from 2007 to 2012, there was once again a peak in morbidity and mortality due to JE/AES. During this period, it was the Bahujan Samaj Party that was in power. The question that arises is whether the change in political regime resulted in a lack of continuity in the measures initiated by the SP to respond to the epidemics. It is well known that health is not a priority for most political parties and frequent administrative changes hamper the functioning of the public health services. Subsequently, the return of Samajwadi Party and most recently the Bhartiya Janta Party has not made much difference to the handling the annual epidemics..

**Section 3**

***Who is responsible and accountable for the failure to control epidemics?***

There are several actors and agencies which are responsible for the failure to control the recurrent epidemics due to JE/AES since the early 2000s. At the local level there are major gaps in implementation of National programmes and the priority given to each of these by the State government. For example it was observed that JE/AES was given a lower priority compared to other programmes like Janani Suraksha Yojana (JSY). It is well known that the JSY is well funded by the Central government and has political backing. The scheme uses cash incentives to motivate health workers to perform for the programme. Therefore at the grassroots level, health workers give priority to those programmes that have political weight and are better incentivised. This results in the lack of a dedicated workforce for JE/AES and the programme relies on human resources from other national programmes on a shared basis. This is one major reason for poor outcomes of the programme. The national programme for the Prevention and Control for the Japanese Encephalitis and Acute Encephalitis Syndrome has tried to correct this anomaly by employing inspection in-charge at the district level. This only partly addresses the problem because of the weakness at the grass root levels continue. The problem is one of how the respective state government decides to work in close co-operation and co-ordination with a centrally sponsored and directed programme. It is often observed that the failings of the health service system are not adequately acknowledged and addressed. The easy option is to shift the blame on the patients by labelling them as ignorant and therefore do not access treatment in time. This amounts to victim blaming rather that addressing the structural reasons in the health system and health service system that are responsible for delayed treatment resulting in mortality. The case in point is the death of sixty children in the BRD medical college in 2017 and what are the reasons for this inhuman tragedy? These deaths expose the long years of underfinancing, lack of adequate human resources, dysfunctional services at the primary and secondary levels of care in the public health services. In the specific case, the BRD medical college did not have the required supply of oxygen cylinders due to non-payment to suppliers. UP has faced many serious lapses and scams in relation to tendering and purchase of supplies. The deep corruption has compromised the functioning of health services at all levels. Within the medical college hospital one can observe the role of middle men who facilitate patients for a payment as they help them negotiate their way through the maze of the hospital for treatment.

**Section 4**

***The complex interaction of Health System and Health Service System Determinants***

Such cases highlight the ubiquitous, subtle and the invisible form of structural violence. As defined by Johan Galtung, it refers to the social, political and economic arrangements in the social world that cause harm to individuals and groups. Therefore structural violence is informed by ideas of inequalities, exploitation and social justice (23).

Vulnerable sections in any society are the primarily affected by structural inequalities of poverty, inadequate health care, homelessness, unemployment and physical violence. Seen in this light, structural violence can be used to describe the social forces that create and sustain conditions of harm that would otherwise be avoided.  It occurs when a structure in the system itself produces policies that discriminate and prevent individuals to realize their full potential, whereby perpetuating violence, which is manifested in terms of unequal access to resources and unequal life chances.

Structural violence was reflected in the callousness of the State machinery in responding to the providing medical attention to children who were in a serious condition. As discussed there were serious anomalies found in Baba Raghav Das Medical College in Gorakhpur (UP). The oxygen supply was not available due to the government not paying the suppliers on time. The process of tendering, supply and payment was due entirely to the callousness and carelessness of the government. This highlights the fact that people relying upon government or state run public health facilities are vulnerable to such serious setbacks. Their economic and social status does not allow them to avail costly private health services. In other words we can say that the structural inequality in the system neglects the needs of vulnerable and marginalized people.The case of AES exemplifies the willful neglect and denial of care to children belonging to the most marginalized social groups who bear the highest burden of morbidity and mortality.

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**Abstract**

This paper produces an analysis on failure of the system and state in dealing with the severe disease condition commonly known as Encephalitis. The Acute Encephalitis Syndrome has impacted the eastern Uttar Pradesh before several decades. With every passing year the disease has linear progression and it turned into an endemic in this area. During the different regimes in the state, the state measures to tackle the situation could not contribute much, resulting into the continuous morbidity and mortality in the locale. The paper analyses the encephalitis data from 2005 to 2019 for understanding the role of state machinery and fixing the responsibility towards the failure of health system towards the disease condition, Acute Encephalitis Syndrome.

**Keywords**

Acute Encephalitis Syndrome, Japanese Encephalitis, Gorakhpur, BRD Medical College, Mortality, Morbidity.