

**A study on post effects of Acute Encephalitis Syndrome (AES)
among 1- 15-year old children in Muzaffarpur district,
Bihar**

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**Dissertation submitted in partial fulfilment of the requirements for the award
of the degree of
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DECLARATION

I hereby declare that this dissertation titled “A study on post effects of Acute Encephalitis Syndrome (AES) among 1- 15-year old children in Muzaffarpur district, Bihar” is the bonafide record of my original field research. It has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

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September 2022

CERTIFICATE

Certified that the dissertation titled “A study on post effects of Acute Encephalitis Syndrome (AES) among 1- 15-year old children in Muzaffarpur district, Bihar” is a record of the research work undertaken by Dr. Shruti Sarika in partial fulfillment of the requirements for the award of the degree of “Master of Public Health” under my guidance and supervision.

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LIST OF ABBREVIATION

AES	Acute Encephalitis Syndrome
JEV	Japanese Encephalitis Virus
CHPV	Chandipura Virus
NiV	Nipah Virus
WHO	World Health Organization
IEC	Information Education and Communication
SFGR	Spotted Fever Group Rickettsia
NICD	National Institute of Communicable Diseases
NIV	National Institute of Virology
RMRI	Rajendra Medical Research Institute
NCDC	National Centre for Disease Control
CDC	Center for Disease Control and Prevention
MCPG	Methylenecyclopropyl-Glycine
DEP	Diethyl Phosphate
OP	Organophosphate Pesticides
ANP	Atrial Natriuretic Peptide
BNP	B-type Natriuretic Peptide
LOS	Liverpool Outcome Score
TBM	Tubercular Meningitis
GMFCS	Gross Motor Function Classification System
PBS	Pediatric Balance Scale
NDT	Neuro Developmental Treatment
SI	Sensory Integration
SKMCH	Sri Krishna Medical College and Hospital

APL	Above Poverty Line
BPL	Below Poverty Line
PI	Principal Investigator
SD	Standard Deviation



ABSTRACT

Background: Acute encephalitis syndrome (AES) is a clinical condition related to high mortality outcomes. Many etiological factors are associated with this. In India, Japanese encephalitis (JE) virus is the leading cause of AES. But only few cases were JE positive in the outbreaks of AES in Bihar. The exact etiology of AES in Bihar is still unknown. Along with high mortality, literature indicates that this clinical condition is associated with high morbidity too. This research aims to examine the extent and nature of persistent morbidity following AES in Bihar.

Objectives: The specific objectives for this study are to document the health problems experienced by survivors of AES in Muzaffarpur district, Bihar and to describe the health seeking practices among the survivors of AES who continued to experience health problems.

Methods: This is a cross sectional observational study that used an interview schedule to obtain information from parents or caregivers of 103 surviving children who were diagnosed with AES and were treated and discharged from Sri Krishna Medical College & Hospital, Muzaffarpur, Bihar in the year 2019. For assessment of post effects after AES, the Liverpool outcome score scale has been used.

Results: Persistent AES, presenting with the initial symptoms or newer symptoms, was found among 18.4 percent of the children after discharge from the hospital. Persistent AES was more common among those who did not reach the tertiary care facility for the initial treatment. More than half of them did not continue with the prescribed treatments, partly due to costs involved. Of the 103 survivors, 28.1 percent presented with some form of dependency according to the Liverpool outcome score. A majority of these children were found dependent in getting dressed (23.3 percent) and almost one fifth of them (19.4 percent) could not be left alone after AES.

Conclusions: The prevalence of persistent AES is high among survivors of AES. This can be reduced by providing extra care addressing the need at the time of AES. Appropriate follow up care for persistent AES needs to be made accessible to all who need it regardless of the cost.

Chapter- 1

Introduction

1.1 Background

Defining AES: The World Health Organization (WHO) first used the term "acute encephalitis syndrome (AES)" in 2006 to describe a group of symptoms that included convulsions, altered consciousness, or both (Kumar, 2020). A number of neurological symptoms and an abrupt onset of fever are the hallmarks of acute encephalitis syndrome. There is coma, delirium, disorientation, or mental disorientation (Ghosh and Basu, 2016). The WHO defines a case of clinical AES 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) (Kakoti et al., 2013; Singh et al., 2020).

Prevalence in India and Bihar: Within India, 10485 instances of AES were recorded from 17 states, according to the National Vector Borne Disease Control Programme (NVBDCP). Among these, 632 fatalities with a case fatality rate of 6percent was reported in 2018([Acute encephalitis syndrome | National Health Portal Of India \(nhp.gov.in\)](https://nhp.gov.in)). In the state of Bihar, 2,876 instances of AES were reported between 2014 and 2021. There were 747 fatalities among them (GOI, 2021).

Long term effects of AES: A study in Assam found that 30 to 50 percent of AES have long-term mental consequences (Dutta et al., 2017). According to a study from Bihar, between 30 to 60 percent of patients would experience long-term neurological manifestations such as convulsions, tremors, paralysis, and other symptoms (Kakoti et al., 2013; Kumar et al., 2019). The child and the family are stressed out physically and

financially as a result of this enormous burden. Families that were already financially weak are made even more vulnerable by AES.

1.2 Causative agents for AES

Annual reports of clinical cases of Japanese encephalitis (JE) in Asia range from 30,000 to 50,000 (Kumar et al., 2019). The main factor causing AES in India is JE. JE is presumably the most prevalent type, but there are regional variants as well.

Infectious agents (viruses, bacteria, fungi, parasites, spirochetes, leptospira, toxoplasma, rickettsia, etc.) are the most common causes of AES in India (Datta and Karmakar, 2019). Some of the infectious agents that can cause AES include scrub typhus, the Nipah and Zika viruses, the toxins hypogycin and methylene cyclopropylglycine, the herpes simplex virus, dengue fever, and haemophilus influenza.

After the outbreak of JE in Gorakhpur and Basti division in East UP in 2005, all JE cases were reported under "Acute encephalitis syndrome" because the virus's source may vary and cause symptoms that are almost identical (Das, 2013).

1.3 Affected regions in India

The Indian states of Uttar Pradesh, Bihar, West Bengal, Assam, and Tamil Nadu are frequently impacted by AES. Patna, Jehanabad, Gaya, East Champaran and Muzaffarpur are the districts of Bihar that are affected. In 2011, North Bihar was the center of the AES outbreak (Sinha et al., 2020).

1.4 Seasonal variation and composition of AES affected persons

The monsoon and post-monsoon seasons are when AES most commonly occurs (Murhekar et al., 2021). AES prevalence peaks in the eastern state of Bihar from May to June, when litchi season begins. (Islam et al., 2017; Kumar and Karotia, 2019). In 2012, the male to female frequency of AES was 1.2:1 (Sahni, 2013) and children between the ages of 0 and 15 were the age group most affected.

1.5 Rationale

AES primarily affects children from lower socioeconomic classes and is more common in rural locations (Sahni, 2013). This exacerbates the burden on families that are already poor. When a child who is suffering from malnutrition also has AES, it causes further deterioration in their health status and makes them prone to other diseases. The family has to take care of the children if there are any residual complications and this increases their responsibility and decreases resources for income. If the children continue to experience any further complications and symptoms of AES, families have to seek care and this depletes the already limited resources. In spite of the various districts of Bihar being affected frequently during the past ten years, there are hardly any studies on the post effects of AES in Muzaffarpur, one of the districts of Bihar which was severely affected. The recurrent outbreak of AES in Muzaffarpur does not have any confirmed etiology. Research has been undertaken to identify the causes of this disease outbreak. Although associations have been observed, several hypotheses have been developed, no clear cause has yet been established. Numerous AES-prevalent states' research demonstrates that several neurological and cognitive abnormalities are evident in AES survivors (Murhekar et al., 2021). Proper rehabilitation can help the affected children to cope with their problems and reduce the financial and physical burdens of the children and their families. Therefore, this proposed study can fill the gap in the knowledge about AES after effects

and contribute to development of programmes to provide care and facilities to the AES survivors having long term complications after the initial AES episode.

1.6 Objectives

Given the burden AES causes to children and their families in Muzaffarpur district, Bihar, this study proposes to:

document the health problems experienced by the survivors of AES in Muzaffarpur district, Bihar and

describe the health seeking practices among the survivors of AES who continue to experience health problems

1.7. Chapterisation plan

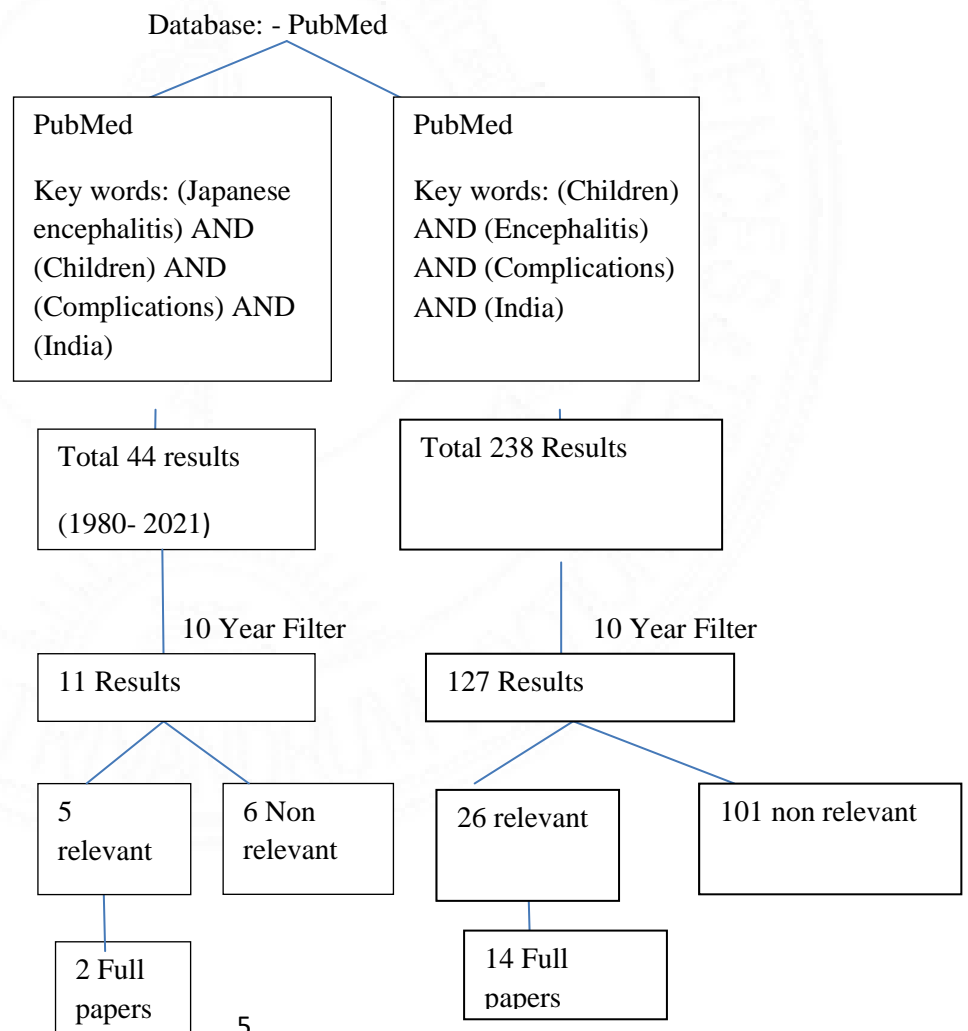
This thesis consists of 5 chapters, the first of which outlines the rationale for examining AES among children in Muzaffarpur district, the long term sequelae they experience and the care seeking they do for it. The second chapter provides the literature review justifying the study using available material. The third chapter describes the methodology used for identifying the children with post AES illnesses and the extent of their dependency. The fourth chapter describes all the results of the analysis undertaken and the last chapter (5th chapter) discusses the findings of the study and makes recommendations.

Chapter- 2

Review of Literature

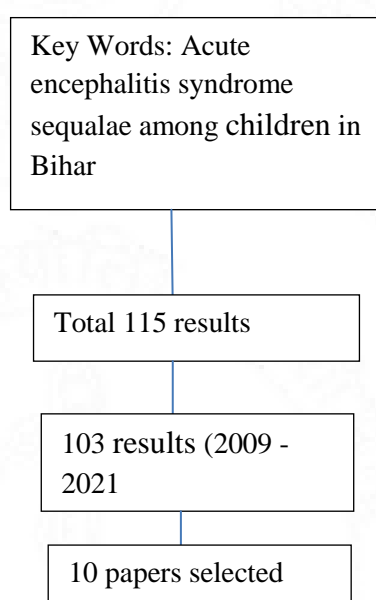
This review of literature included two specific data bases, PubMed and Google Scholar to identify relevant journal articles for consideration. Acute Encephalitis Syndrome is not always referred to as AES. It has been described as JE and AES alternatively. Therefore, for the PubMed search, the key words included JE. However, for the google scholar search, articles relating to key words that included sequaleae were used. These papers were grouped into the type of information they processed as definitions, etiology prevalence in Muzaffarpur, Bihar, and lastly the complications due to AES. These are depicted in figures 1 and 2 that describe the search strategy.

Figure 1. Literature Search Strategy: Database: PubMed



The studies were defined as not relevant to the present study after a careful reading of the content provided in the abstract. Efforts were made to obtain full text articles of all relevant papers and this literature review is based on the full text articles that could be accessed. In all, 16 papers that were identified as relevant and for which full texts were available were included.

Figure 2. Literature Search Strategy- Database - Google Scholar



Papers were selected on the basis of content as identified by the available abstract.

Among 103 papers identified, a majority were about the etiology of AES. So, on the basis of relevant content only 10 papers for which full texts were available, were selected.

Thus, in all, 24 papers for which full text articles could be accessed were reviewed for this literature review.

2.1. Defining AES

Clinical definition: 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) (Kakoti et al., 2013; Singh et al., 2020).

Clinical presentation: AES is said to present with high grade fever, altered sensorium, seizures, headache, vomiting and signs of meningeal irritation (Kakoti et al., 2013).

2.2 History of AES cases in India

Since the first report from Vellore, Tamil Nadu, in 1955, the history of AES in India has paralleled that of the Japanese encephalitis virus (JEV). In West Bengal's Bankura district, the first JEV outbreak was documented in 1973. Following that, outbreaks and isolated instances of AES have been the main factor contributing to the disease's early fatalities in India. The history of AES in India can be divided into three phases based on numerous surveillance data and outbreak investigations: (a) the time period prior to 1975, when a few cases with JE etiology were discovered; (b) the time period between 1975 and 1999, when more JEV cases were reported and frequent outbreaks led to the development of JE endemic regions close to the Gangetic plains and in parts of the Deccan and Tamil Nadu; (c) The AES picture underwent a significant change between 2000 and 2010, with an increase of non-JE outbreaks primarily brought on by viruses including Chandipura virus (CHPV), Nipah virus (NiV), and other enteroviruses (Bhattacharjee and Bhowmik, 2019).

After 2012, in India AES cases have shifted towards JE etiology. In India, reported endemic zone for JE was Uttar Pradesh (UP), Bihar, Assam, West Bengal and Tamil Nadu (Singh et al., 2020).

From 2014 to 2018 in last five years the epidemiology of AES and JE cases have changed with huge variation. The recent trend in India shows limited number of JE cases and more number of AES (Singh et al., 2020)

According to a study in the National Health Portal of India, cases of AES have primarily been recorded from April to June in Muzaffarpur, Bihar, notably in youngsters who are undernourished and have a history of visiting litchi orchards. In the Gorakhpur Division of Uttar Pradesh, outbreaks of the disease with significant case-fatality rates have been happening since 1978. (Bhattacharjee and Bhowmik, 2019).

2.3 Etiology of AES in India

Viruses are the primary cause of AES in India. Other causes, such as bacteria, fungi, parasites, spirochetes, chemicals, and poisons, are, however, also being mentioned. With over 50,000 cases and 10,000 reported deaths per year, Japanese encephalitis (JE) has long been thought to be the main cause of AES in Asia. (Kumar and Karotia, 2019)

An investigation in Gorakhpur, UP, and Assam revealed that the incidence of Japanese encephalitis-related AES has decreased following extensive JE vaccination and appropriate information, education, and communication (IEC) in AES-prevalent areas.

Nevertheless, AES manifestation persisted in some areas. Numerous research teams' investigations have revealed *O. tsutsugamushi* to be the primary etiology of AES

outbreaks in those areas, as the agent responsible for scrub typhus. (Khan et al., 2017;

Murhekar et al., 2021). Nearly 50 percent of the AES cases had molecular or serological

proof of *O. Tsutsugamushi* infection, whereas JEV and dengue virus were responsible for

10 percent and 7 percent of AES cases, respectively. Dengue fever (8percent), spotted

fever group rickettsia (SFGR) infection (6percent) and leptospirosis (3percent) were the

other major etiologies of AES. These results showed that *O. tsutsugamushi* infection was

the most prevalent cause of AES in kids during the monsoon and post-monsoon seasons.

(Murhekar et al., 2021). Scrub typhus can be suspected in a patients of AES along with

thrombocytopenia.

More than 35 percent of the patients in an outbreak in Assam tested positive for JE in 2008. Chandipura virus has been linked to outbreaks in Gujarat, and West Nile virus was linked to one in Kerala in 2011 (Ronan Kelly, 2014). According to a study conducted in Gaya, Bihar, JE is one of the most common types of viral encephalitis that affects youngsters in this area. (Shah and John, 2014)

2.4 Age Pattern of AES in India

AES primarily affects children between the ages of one and ten. Children in Gorakhpur under the age of 14 were primarily impacted. (Murhekar et al., 2021) The most affected age group in Assam was 0 to 15 years. (Dutta et al., 2017) AES patients in Bihar ranged in age from 1 to 15 years. With respect to JE, the age pattern ranged from 1 to 18 years. One to ten years old were particularly impacted, with 73 percent having JE, with 40 percent males and 33 percent females. (Kumar et al., 2019) Ages 2 to 10 (with a median age of 3.5 years) are the most vulnerable in Muzaffarpur, Bihar, to AES. (Sahni, 2013)

2.5 Seasonal variation in AES

According to a study conducted in Assam, the months of July through September saw the greatest number of cases of scrub typhus. The outbreaks in Bihar were limited to April to July, peaking in June. In contrast to the traditional September peak for JE, the AES outbreak concentrated in Muzaffarpur reaches its height in June. In the year 2011, Muzaffarpur experienced a bimodal peak. Between two summits, there have been observed rainy episodes. (Kumar and Karotia, 2019)

2.5. Presentation of AES in Muzaffarpur, Bihar

In Muzaffarpur, Bihar, during any outbreak investigation, they frequently classify it as "mystery sickness" because they are unable to provide a positive result using the available and known resources. Researchers from the National Institute of Communicable Diseases (NICD) in New Delhi, the National Institute of Virology (NIV) in Pune, the Rajendra

Medical Research Institute (RMRI) in Patna, the team from Madurai, Tamil Nadu, Safdarjung Hospital, and Lady Harding Medical College in New Delhi have conducted numerous camps in this area, but they have been unable to isolate any virus, bacteria, or other infectious organism in these outbreaks. (Sahni, 2013)

Therefore, In so far as the presentation of AES in Muzaffarpur, Bihar, no prodromal symptoms was noticed. The cases presented with acute onset fever and convulsions followed by loss of consciousness. Most of the cases showed hypoglycemia and the onset occurred early in the morning (Mukherjee et al., 2021; Sahni, 2013; Yewale, 2014). The disease is a form of 'hypoglycemic encephalopathy (Shah and John, 2014). The Muzaffarpur, Bihar enigma has been categorised as a noninfectious toxic encephalopathy by the National Centre for Disease Control (NCDC), New Delhi, and the Global Disease Detection, Regional Centre, India, Center for Disease Control and prevention (CDC), US (Jain et al., 2018).

Scrub typhus infection was also more likely to strike children who had recently been exposed to an outside environment when defecating in the open, playing in, or visiting agricultural fields (Murhekar et al., 2021). According to some research, AES may be caused by JE, a bat virus, mosquito or bed bug bites, heavy metals, unsanitary environments, viruses, pesticide residues, litchi fruit, high temperatures, and/or heat stroke (Nath et al., 2016). Most of the cases were identified from areas where litchi productivity is common (Kumar and Karotia, 2019). AES affected areas are mainly rural (Dutta et al., 2017; Sahni, 2013).

2.7 Hypothesis regarding AES in Muzaffarpur, Bihar

In Muzaffarpur, three potential unpleasant stimuli have been suggested. The first of these toxic stimuli was intense heat and humidity. (Sahni, 2013) Poisoning by pesticides used to protect litchi fruit was the second of these triggers to be listed (Islam et al., 2017).

Methylenecyclopropyl-glycine (MCPG), found in litchi, was the last of them (Shrivastava et al., 2017; Sinha et al., 2020).

According to a study, the AES outbreak was confined to the litchi growing regions and to the season. Four high-litchi productive blocks in Mushari, Bouchan, Minapur, and Kantiand Marwan reported the majority of the cases (Sinha et al., 2020). According to one study, eating litchi has to do with the recurrent outbreaks of AES in Muzaffarpur. The seed and aril of the litchi have been shown to contain MCPG and hypoglycin A. MCPG is known to inhibit gluconeogenesis and fatty acid -oxidation. Therefore, when a malnourished youngster eats litchi fruit, hypoglycemia happens quickly because MCPG also triggers the -oxidation of fatty acids for energy production and gluconeogenesis (which is prevalent owing to poor food consumption). However, Fatty acid metabolism is disrupted and glucose production is substantially reduced in the context of hypoglycin A/MCPG poisoning, which might result in the classic acute hypoglycemia and encephalopathy. (Shrivastava et al., 2017)

Diethyl phosphate DEP metabolites were found in the urine after analysis of the samples, indicating that the youngsters had been exposed to pesticides. Therefore, when evaluating the toxicity of litchi consumption, both the effects of MCPG and organophosphate pesticides (OP pesticides) should be taken into account. (Sinha et al., 2020)

It is observed that not many other litchi-growing regions around the world have reported AES. China, India, Vietnam, Thailand, Nepal, Bangladesh, Mauritius, the Philippines, Indonesia, Australia, Madagascar, Israel, Central & South America, New Zealand, Brazil, Taiwan, and South Africa are the principal litchi-producing nations in the world.

However, cases of AES have only been found in Vietnam, Bangladesh, and India. (Nath et al., 2016)

A review of 475 cases from Muzaffarpur in 2019 revealed that just 8 percent of AES-affected children have a history of eating litchis within five days of becoming ill, while 24 percent have a history of skipping dinner the night before.

The majority of outbreaks have occurred when temperatures are at their highest (38°C to 40°C) and humidity levels are at their highest (70percent to 80percent). As temperatures drop owing to rain, the number of cases abruptly drops to zero. As the children come from low socioeconomic households and some of them are used as child labour for picking and packing litchi, many children spend the most of their day outdoors playing, eating, and gathering litchi. The majority of the homes in this area are surrounded by farmland, litchi gardens, or other plantations that increase humidity by evaporating and transpiring moisture from the air. Additionally, the majority of the affected children was from communities with poor ventilation, unreliable electricity, and overcrowded housing. (Sahni, 2013).

Under nutrition, prolonged fasting, and litchi eating are three major variables linked to an AES outbreaks. Litchi is grown, harvested, and consumed throughout Bangladesh, yet only two districts have outbreaks related to it, according to a case control study done there. (Islam et al., 2017) The AES causing factor of a child under one who cannot eat litchi has been linked to and reported as being caused by high temperatures and/or sunstroke (Nath et al., 2016).

According to a research by Jacob John, inadequate nourishment, extreme heat, high humidity, and bad hygienic are the causes of AES. (Shah and John, 2014) Hypoglycemia is known to be induced by exposure to high ambient temperatures and has been found to be brought on by abnormal fat metabolism in rats and dogs (Prakash et al., 2019).

2.8 Complications following AES in India

According to a study conducted in Assam, 20 to 30 percent of JE cases are fatal and 30 to 50 percent of patients have long-term neuropsychiatric consequences (Dutta et al., 2017). The percentage of AES survivors who had long-term neurological manifestations in the form of convulsions, paralysis, tremor, and other symptoms was estimated by another study to be between 30 and 60 percent in Bihar (Kumar et al., 2019).

A study conducted in Assam considered impairment of consciousness, weakness (monoparesis, hemiparesis, and quadripare sis), focal or generalised abnormal limb tone (hypertoniaandhypotonia), focal or generalised abnormal limb reflexes (hyperreflexia and hyporeflexia), and a diagnosis of new-onset or recurrent seizures as neurological sequelae. (Kakoti et al., 2013)

In the Gorakhpur epidemic, children had a (38.4percent) mild, (13percent) moderate to severe degree of disability with impairment in cognition and behaviour, and (10percent) impairment in mobility and activity limitation in self-care. More than half of OT-AES survivors reported some level of impairment(51.4percent).(Murhekar et al., 2021)

Studies among JE survivors in eastern UP found that between 27 percent and 50 percent had moderate to severe impairment. Seizures, urinary incontinence, abnormal behaviour, needing assistance with dressing, or being unable to be left alone without injury were common sequaleae. Additionally, performance at school or at work sometimes declined (Prakash Gangwar et al., 2020).

Poor perfusion, a Glasgow coma scale of 8 or higher, and more than two witnessed seizures were found to be indicators of a poor result at hospital release in research on the long-term effects of the Japanese encephalitis (JE) virus in central Sarawak, Malaysia

(Singh et al., 2015). In another case study, a patient with post-encephalitis sequelae did take longer to regain their ability to walk and this process was facilitated with consistent physiotherapy (Goyal et al., 2020).

More than a quarter (27percent) of the AES patients experienced hypernatremia while they were hospitalised. The levels of Atrial natriuretic peptide (ANP) and B-type natriuretic peptide (BNP) were elevated during hypernatremia and persisted as high even after the hypernatremia in TBM and AES had been corrected (Misra et al., 2018). Two independent predictors of a poor outcome were inadequate nutrition and the need for ventilator support within 48 hours of arrival (Singh et al., 2015).

As noted by GMFCS and PBS, respectively, interventions including physical therapy based on NDT and SI principles assisted in the improvement of the child's gross motor skills and balance. Additionally, an improvement in vision that is related to the connection between the vestibular and visual systems was noted (Goyal et al., 2020).

2.9. Summary

AES in India has three phases – the first period before 1975 when it could be ascribed to JE, the period between 1975-99 when JE become endemic in parts of India and the period between 2000-2010 with most outbreaks being non-JE and related to viruses.

Most frequent causes for AES have been O Tsutsugamushi infection, or due to JEV or dengue.

Children between the ages 1-10 are most frequently affected.

AES seems to be seasonal with most cases occurring between June to September.

In Muzaffarpur, Bihar, AES is common among children from lower socio-economic households in the lichi cultivating blocks.

A significant proportion of the children affected by AES experience long term sequelae following the initial episode.



Chapter- 3 Methodology

This chapter outlines the study methodology, including the study design, setting, sampling strategies and analytical methods used.

3.1 Study design

The study proposed to identify the extent of persistence of symptoms among children with AES in Muzaffarpur district. Given the available time in which the study needed to be completed (two months for field work), only a cross-sectional study could be envisaged. Therefore, the study design was cross-sectional, attempting to capture the persistence of AES among children who were afflicted and survived in 2019.

3.2 Study setting

The study was located in Muzaffarpur district, Bihar. Muzaffarpur was selected because of the high prevalence of acute encephalitis syndrome (AES) in the recent years. The study population consisted of children who survived AES and fulfill the inclusion criteria given below:

1. children who had got treatment in any Govt. hospital after a diagnosis of AES,
2. children who recovered from AES at least one year before this study,
3. children who did not have any neurological disorder from birth or after birth before AES,
4. children who did not have any mental disorder before AES and
5. parents of AES affected child who were willing to participate

The exclusion criteria are listed below:

1. death after recovery from AES,
2. children who have not been hospitalized due to AES,
3. children having some neurological or mental disorder before AES manifestation

3.3 Sample size: estimation and justification

Sampling frame – To estimate the sample size, the population needs to be defined.

For this study, the study population consists of the total children aged 1-15 in

Muzaffarpur as on May 1 2022 who were afflicted by AES in 2019 and survived it.

However, such a list is not easy to obtain. The sampling frame, consisted of all

survivors of AES cases from Muzaffarpur district for the year 2019. However, an

exact list of such children is not available. The only information available in the

public domain regarding the reported number of cases of AES in Bihar for the period

2019 is 292 according to official records. (Directorate of National Vector Borne

Disease Control Programme- Delhi).

Operationalising the sampling frame: Since an exact frame of all cases for

Muzaffarpur was not available, it was operationalized to the list of surviving children

listed as patients in the only government tertiary care institution (which would have

been the referral centre for all such cases) in Muzaffarpur district. This consisted of

the 217 children listed as survivors who were discharged from the SKMCH,

Muzaffarpur for the year 2019.

Sample size – Using the reported prevalence of 35 percent (Kumar et al, 2017) for

post effects of AES and 5percent precision the sample size was estimated to be 135.

This sample was to be achieved through substitution for non-response.

3.4. Sample selection strategy

Defining the cases: Identification of children with AES and their accurate diagnosis

is difficult. Therefore, participants were to be selected from the list provided by a

tertiary care hospital which serves as the referral center for AES cases in the District.

This would ensure uniformity of diagnosis and treatment (to the extent possible

within the system).

Sampling strategy: Random sampling without replacement from the list of recovered children provided by hospital was done until 135 children with parents/guardians were selected using the Random Numbers option of open epi (Version 3.01). If the parents or guardians decline to participate, the next number to the random number was selected until a parent/guardian who was willing was located. The dropout cases were to be replaced and the reason for declining was to be documented.

3.5 Deviations in the sample size and strategy due to field level conditions

During field work for data collection, I found that many addresses were not correct, and many children were not traceable. As some of the households belonged to migrant workers, they were not available in their reported addresses. Due to these reasons, the achieved sample size was only 103. Random sampling was done by generating random numbers from the Random number generation software by TPAL. Using this, this number participants were selected from different villages. Within each village, some participants could not be located for various reasons were replaced by other AES afflicted children from the same locality. However, several additional children who were survivors of AES were identified in the community and these were included as part of an attempt to achieve the required sample size. The number of such cases was 23. Three such cases were treated from a Private Hospital (Kejriwal hospital) and one case was treated from private clinic. The participants who were not in the list provided by SKMCH were from Ahiyapur (6), Motipur (1), Kanti (7), Shivaipatti (1), Jaitpur(1), Mustafapur (2), Bochahn (2), Mushari (2), Karja (2), Shahebganj (1), Kalayanpur (1), Minapur (5), Bhagwanpur (1), Madhopur (1), Kataru (1), Gayghat (1), Basara (1) and Panapur (1). These included cases of AES affected children, who were afflicted with AES in the year 2018 and 2020. The number of

such cases was 14. Of these 14, 6 cases were from 2018 and 8 cases were from 2020. In spite of all these efforts made to achieve the required sample size without compromising on the scientific sampling strategy, the achieved sample size was only 103.

3.6 Data collection techniques

A semi structured interview schedule was used for data collection. For assessing simple cognitive and behavioral functions, basic motor and self-care skills the “Liverpool Outcome Score (LOS)” was used. This tool has been developed for assessing disability in children after encephalitis caused by JEV and has been validated in India. There are 15 functions/activities in this tool, of which 10 questions are to be posed to care givers and 5 are observations about child performing simple activities. The scores for each question ranged from 5 indicating full recovery and 4 indicating minor sequel with no effect on physical functions, personality change or receiving medicine. Score 3 indicates moderate sequel mildly affecting functions, probably compatible with independent living. Score 2 indicates severe sequel impairing function making patient dependent. Score 1 is for death (a possible sequelae, but not included in this study).

3.7 Plan for data collection and analysis

Data collection was done from 13 March 2022 to 12 May 2022 by the Principal Investigator. A home visit for the survey according to the address provided by hospital had been taken up. A total of 103 interviews were completed. Interviews were undertaken only after obtaining informed consent. Analysis used SPSS version 26 statistical software. It included computation of simple percentages and examining associations using chi-square tests for association. Given the restricted sample size, additional multivariate analysis was not considered.

3.8. Expected outcomes

This study proposed to identify the number and nature of possible after effects of AES and the health seeking practices for those health problems among children affected by AES in Muzaffarpur.

3.9 Ethical considerations

Although there were no identifiable risks for participating in the study, some participants were uncomfortable to discuss their child's health problems. After identification of the health problems due to AES there was no treatment option for the affected children due to resource constraints or lack of knowledge. Data was collected only after getting informed consent from the care giver. All the data collected was kept confidential. The study was undertaken only after getting the approval of Institutional Ethics committee of (SCT/IEC/1826/JANUARY-2022). Suggestions were given to the care taker to visit the govt. health facility and continue the prescribed medication as appropriate.

Chapter 4

Results

This chapter describes the results of the analysis carried out using the information collected from the 103 care givers of children affected by AES in Muzaffarpur district, Bihar. The specific objectives of this study were to document the health problems experienced by the survivors of AES in Muzaffarpur and to describe the health seeking practices among those who continued to experience problems.

This study had an estimated sample size of 135. However, due to various reasons attributable to field level problems in identifying the listed survivors of AES, only 103 survivors could be identified. As a consequence, the validity of the findings needs to be situated in keeping with the required sample size. The specific reasons for the limited sample size and the validation of the sample population vis-à-vis the one planned form the first part of the results section. This is followed by the description of the analysis carried out with the available sample size.

To document the health problems experienced by the survivors of AES, the prevalence of persistent AES among the survivors was calculated. In addition, the characteristics of the children with persistent AES symptoms are also detailed. The AES symptoms and the functional efficacy achieved by the survivors following the episode were measured using the Liverpool Outcome Score and this was also computed and the survivors were classified on the basis of their functional ability. The score was used to classify the children by the extent of their dependency and this is has also described in this chapter.

4.1 Validation and limitation of sampling strategy

In the year 2019, total number of AES cases reported in Sri Krishna Medical College and Hospital was 437. Out of the 437, 28.1 percent (123) children with AES died. Out of total

437, 70.9 percent (310) were from Muzaffarpur district. Out of 310, 26.5 percent (82) children died and 3.2 percent (9) children were documented as having left the hospital against medical advice and 1 child was referred.

For the cross-sectional study, I had estimated a sample size of 135, using the reported prevalence of 35 percent for post effects of AES with 5 percent precision. The list provided by Sri Krishna Medical College and Hospital (SKMCH) had listed 217 AES afflicted children who had been treated and discharged from the hospital in the year 2019. From this list, participants were selected using random numbers. During field visit for data collection, I found that many addresses were not correct, children not traceable and some families who were migrant labours elsewhere were not available at their stated addresses. Due to these reasons, I could interview only 103 caregivers of children affected by AES.

Validating the sample selected:

Due to the limitations mentioned earlier, the achieved sample was just 76.3 percent of the planned sample size. This is definitely inadequate to make any estimates of prevalence. However, what is being attempted is merely a description of the children with persistent problems following an episode of acute encephalic syndrome admission to the SKMCH, Muzaffarpur in 2019.

To examine whether the achieved sample was similar to that which was listed in the sampling frame, we compare the age-sex distribution of the children listed in the sampling frame (217 children) and the achieved sample (103 children). This has been described in table 1.

Table 1: Comparing age and sex distribution of children with AES discharged from Sri Krishna Medical College and Hospital and the achieved sample

Age group	Sex		Total
	Male	Female	
1-5	21.8	17.4	19.4
5-10	61.5	64.5	58.5
10-18	16.7	18.1	17.5
Total	100.0 (96)	100.0 (121)	100.0 (217)

Age group	Sex		Total
	Male	Female	
1-5	11.3	16.0	13.6
5-10	69.8	70.0	69.9
10-15	18.9	14.0	16.5
Total	51.5 (53)	48.5 (50)	100 (103)

The achieved sample does not vary drastically in terms of age -sex distribution from the age sex distribution of the children listed in the sampling frame obtained from the SKMCH for the year 2019. For this reason, it can be said to be representative of the AES survivors, though the sample size would not be adequate for any estimations.

4.2 Prevalence of persistent AES and the symptoms at the time of initial AES

Out of 103 AES survivors 18.4 percent were having either their old symptoms of AES or newer symptoms due to AES after discharge from the hospital (persistent AES).

Symptoms experienced during initial AES were mostly fever, convulsion and unconsciousness. Almost all children 100 percent (103) experienced convulsions at the time of initial AES.

Table 2: Pattern of symptoms experienced during initial hospitalization among AES survivors in Muzaffarpur, Bihar

Symptoms	Percentage of children with symptoms
Persistence of health problems among AES survivors	18.4
Fever	99.0

Unconsciousness	88.3
Vomiting	35.9
Convulsions	100.0
Drowsiness	45.6
Drooling	19.4
Diarrhea	11.7
Total	100.0 (103)*

*multiple symptoms were experienced by the same child. Percentages do not add to 100.

4.3 Number and pattern of new and continuing symptoms among survivors of AES with persisting symptoms

Of the 103 survivors, a majority had no persistent symptoms (81.6 percent). Thus, the percentage of children with persistent AES was 18.4 percent. The continuing symptoms are described in table 3. Among the 19 (18.4 percent) children with persistent symptoms of AES, 47.3 percent were having continuing episodes of convulsions and 26.3 percent were having episodes of unconsciousness. In addition to the initial symptoms, some caretakers reported newly occurring symptoms for their wards. These new symptoms following the first episode of AES have been listed in table 4. Weakness in hand and leg and speech difficulties were experienced by 21.1 percent of the survivors of AES.

Table 3: Number and pattern of continuing symptoms among survivors of AES with persisting symptoms in Muzaffarpur, Bihar

No: of symptoms	Percentage of children
No symptoms	89.3
Only one symptom	3.9
Two symptoms	3.9
Three symptoms	2.9
Symptoms	Percentage of children with persistent symptoms
Fever	10.5
Unconsciousness	26.3
Convulsions	47.3
Drowsiness	5.3
Drooling	15.7
Diarrhea	5.3
Total	100.0 (19)

Table 4: Number and pattern of new symptoms among survivors of AES in Muzaffarpur, Bihar

Symptoms	Percentage of children
Second time AES	5.3
Speech difficulties	21.1
Convulsion	15.8
Mental problem	10.5
One side face weakness	5.3
Weakness in hand and leg	5.3
Weakness in both hands and legs	21.1
Weakness in both legs	5.3
Unconsciousness	5.3
Anger	10.5
Neck pain	5.3
Problem relating to ability to study	5.3
Total	100.0 (19)

4.4 Care seeking for persistent AES

At the time of initial episode, among 103 survivors of AES, 35 percent had directly gone to the Sri Krishna Medical College and Hospital (Govt. hospital), 27.2 percent went to private sector clinics and 26.2 percent went to the PHC first. Among 63 who first went to the health facility other than Govt. hospital 98.4 percent went subsequently to the Govt. hospital for the treatment of initial AES. Due to the replacement of children in the SKMCH list by those in the villages, 4 children treated elsewhere are included.

Table 5: Distribution of survivors of AES by health care facilities used at the time of initial AES in Muzaffarpur, Bihar

Health facility visited	Initial facility visited %	At least one alternative facility visited after initial facility %
Govt. sub centre	1.9	0.0
PHC	26.2	0.0
Govt. hospital (Sri Krishna Medical College and Hospital)	35.0	98.4
Private sector hospital	2.9	1.6
Private sector clinic	27.2	0.0
Pharmacist	2.9	0.0
Others	3.9	0.0

Total	100.0 (103)	100.0 (63) [#]
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#-Among those who used more than 1 facility

Among 103, only 38.8 percent children, who directly went to the Govt. hospital got effective treatment at the time of initial AES. More than half of the children had been taken to another health facility (56.3percent) before reaching the Government health care facility.

Table 6: Distribution of survivors of AES by effectiveness of health facility used at the time of initial AES and number of health facilities used, Muzaffarpur, Bihar

Perceived effectiveness of treatment	Perception of treatment	%
	Effective	38.8
	Not-effective	61.2
Number of health facilities used	Health facility	
	None, Straight to Sri Krishna Medical College & Hospital (SKMCH)	38.8
	One other health facility/ provider	56.3
	Two other health facilities/ provider	4.9
	Total	100.0 (103)

Among survivors of AES with persistent AES, 52.6 percent were not seeking care anywhere for persistent AES (see table 7). So in effect, they are not continuing any medication for persistent AES. Among these, 21.1 percent were seeking care in Sri Krishna Medical College and Hospital. Five of the 19 children (26.3 percent) were not taking medications because no improvement was noticed by the care takers after consuming the provided medications. Three of the 19 children were not taking medications because of the expenses involved in buying them.

Table 7: Pattern of treatment seeking for persistent AES among survivors of AES in Muzaffarpur, Bihar

Health facility being visited	Percentage of children with persistent AES
No where	52.6
Govt. hospital (SKMCH)	21.1
Private homeo clinic	10.5
Private sector clinic	10.5
Private sector hospital	5.3
Total	100.0 (19)

The means of paying for the initial treatment is described in table 8. Almost half of the parents (43.7 percent) pay for treatment and medications using household savings/incomes. However, more than a third (34.0 percent) had to borrow money to treat their children.

Table 8: Payment method used for treatment & purchase of medications by the parents of AES survivors in Muzaffarpur, Bihar

Mode of payment	Percentage of households
Household income/ savings	43.7
Borrowing	34.0
Sale of physical assets	4.9
Contribution from friends and relatives	17.5
Other sources	0.0
Total	100.0 (103)

In table 9 and 10, the treatment status of children with persistent AES symptoms is described. More than half of the children were not taking any medications for various reasons.

Table 9: Distribution of survivors of AES with persistent AES by continuing medication status, Muzaffarpur, Bihar

Medicine taking status	Percentage of children with persistent AES
Continuing medication	47.4
Not continuing medication	52.6
Total	100.0 (19)

Only approximately one third (36.6 percent) children with persistent AES were taking all the medicine that was prescribed by the doctor. A majority of them were not taking medications because caregivers stated that they noticed no improvement in the health condition.

Table 10: Reasons for not taking medications for persistent AES, Muzaffarpur, Bihar

Reasons for not taking medications	Percentage of children
Medications are expensive	15.8
Care taker decided that it is not needed	10.5
Child refused to take the medications	5.3
Others decided to not given medications to the child	5.3
Other reasons (no improvement)	26.3
Taking all prescribed medicine	36.8
Total	100.0 (19)

4.5 Profile of survivors of AES with persistent AES

Table 11: Age-Sex distribution of survivors of AES in Muzaffarpur, Bihar

Age group	With persistent AES	Without persistent AES	Total
1-5	35.7	64.3	100.0 (14)
5-10	16.6	83.4	100.0 (72)
10-15	11.7	89.3	100.0 (17)
Total	18.4	81.6	100.0 (103)
Average age			
N	19	84	103
Minimum	3	3	103
Maximum	12	13	103
Mean	6.58	7.3	103
SD	2.52	2.46	103
Sex			
Male	18.9	81.1	100.0 (53)
Female	18.0	82.0	100.0 (50)
Total	18.4	81.6	100.0 (103)

Out of 103 children, 51.5 percent were male and 48.5 percent were female. Among male children, 18.9 percent reported with Persistent AES. Among female children 18.0 percent reported the same. Younger children aged 1-5 were more prone to manifest with persistent AES when compared to those aged 5-10 or 10-15. However, the highest

proportion of children with persistent AES was in the age group 5-10 (12/19). There were no noticeable difference in the mean age of children with persistent AES and those without it. It was 6.58 for those with persistent AES (sd =2.52) and 7.3 for those without persistent AES (sd =2.46).

Table12 Provides the socio-economic profile of the households of the survivors by the status of the persistence of the symptoms of AES. A majority of the survivors of AES were from the OBC group and merely 5 of the 103 children were from the general or upper caste category. But of these 5 children, 2 had persistent symptoms of AES. On the other hand, gap in the percentage of children with persistent AES between OBCs and Scheduled Caste children was narrow.

A majority of the survivors of AES were from households with BPL cards. The lone child from a household with APL card however had persistent AES. The average monthly household income for the households of children with persistent AES was Rs.6947.37, which is higher than that of households of children without persistent AES (Rs6500). It should be noted that the variation in the household income for children with persistent AES was considerably higher when compared to households without persistent AES indicating the greater economic heterogeneity among these households.

Table 12: Socio-economic profile of survivors of AES with persistent symptoms in Muzaffarpur, Bihar

Socio-economic factors	With persistent symptoms [19]	Without persistent symptoms [84]	Total [N=103]
Religion			
Hindu	20.2	79.8	91.3 (94)
Muslim	0	100.0	8.7 (9)
Caste			
General	40.0	60.0	100.0 (5)
Other backward castes	19.0	81.0	100.0 (58)
Schedule caste	15.0	85.0	100.0 (40)
Schedule tribe	0	0	0
Educational status of care taker who is mother			
With formal education	16.7	83.3	100.0 (6)
Without formal education	16.3	83.7	100.0 (43)
Educational status of care taker who is father			
With formal education	40.0	60.0	100.0 (10)
Without formal education	8.3	91.7	100.0 (24)
Educational status of care taker who is other than father or mother			
With formal education	0.0	100	100.0 (4)
Without formal education	31.3	68.8	100 (16)
Economic status of the households of the survivors of AES (as determined by type of ration card)			
APL		100.0	0
BPL		18.0	82.0
No Card		0	100.0
Average monthly income of household			
N		19	84
Minimum		2000	2000
Maximum		20000	20000
Mean		6947.37	6500.00
SD		4904.38	2930.93

Table 13 gives the distribution of the occupational status of the head of the household and the care taker of the survivors of AES. A majority of the heads of households were working as casual labour in the agricultural or non-agricultural sector as were the care takers.

Table 13: Distribution of survivors of AES according to occupational category of the head of the house and care taker of AES survivor in Muzaffarpur, Bihar

Type of work	Type of work of head of the house percentage	Type of work of care taker of AES survivor percentage
Self- employed in agriculture	3.9	1.9
Self- employed in non-agriculture	29.1	21.4
Regular wage/ Salary	1.0	1.9
Casual labour in agriculture	34.0	39.8
Casual labour in non-agriculture	31.1	17.5
Unable to work due to child care requirement	0	4.9
Others	1.0	12.6
Total	100.0 (103)	100.0 (103)

4.6 Describing survivors of AES by dependency status using Liverpool outcome score (LOS)

For the assessment of any dependency after AES, I computed the Liverpool outcome score. In this scale, a score of 5,4,3 indicates no dependency and a score 2 indicates dependency in any item. Out of the 103 AES survivors, 28.1 percent (29) children showed dependency in at least one of the items of the Liverpool outcome score. More than one fifth (23.3 percent) of the children were dependent for dressing. Close to another fifth (19.4 percent) cannot be left alone unattended following AES.

Table 14: Distribution of children affected by AES by their dependency status across different domains of functioning using the Liverpool Outcome Score (LOS), Muzaffarpur, Bihar

Items	Dependency (Coded 2 in LOS) %	Independence (Coded 3,4,5 in LOS) %
Speech & communication	4.9	95.1
Feeding	6.8	93.2
Leaving alone	19.4	80.6
Behaviour	1.0	99.0
Recognition	2.9	97.1
School & working	0	100
Epilepsy/ seizures	1.9	98.1

Dressing	23.3	76.7
Bladder & bowel control	3.9	96.1
Hearing	0.0	100
Sitting	4.9	95.1
Standing up	8.7	91.3
Walking	9.7	90.3
Hands on head [#]	1.0	99.0
Picking up [@]	4.9	95.1
Total percentage of children	28.1	71.9

One girl with AES has been immobilized post AES and that's why her parent could not responded meaningfully, therefore this has been coded as dependent.

@Five children were not present at the time of Interview, so evaluation has been done as per parents' response. Two children were coded as dependent and 3 were coded as independent.

4.7 Socio-economic and cultural correlates of dependency status of survivors of AES

Among Muslims exactly one third of the children were dependent (33.3 percent) and among Hindus, nearly a third were dependent. However, it should be noted that more number of children in dependent category (26/29) were Hindus. Forty percent of General category children in terms of caste (indicative of upper caste) were dependent. However, a majority of the dependent children were from other backward category (20/29) (see table 15).

Table 15: Socio-cultural profile of survivors of AES and dependency status, Muzaffarpur, Bihar

Variable	Categories	Dependent	Independent	Total
Religion	Hindu	27.7 (26)	72.3 (68)	100 (94)
	Muslim	33.3 (3)	66.7 (6)	100 (9)
<hr/>				
X ² with 1 df = 0.131, p-value = 0.718 ^a				
Caste	General	40 (2)	60 (3)	100 (5)
	OBC	34.5 (20)	65.5 (38)	100 (58)
	SC	17.5 (7)	82.5 (33)	100 (40)

X^2 with 2 df = 3.740, p-value= 0.154

Almost all the children who were survivors of AES were from households with BPL cards. There was only one child who came from a household with an APL card and that child was not dependent following AES. Among those with BPL card, 28.9 percent of the children were reported to be dependent using the Liverpool outcome score. The percentage of dependent children by educational status of either the caretaker or the spouse of the caretaker did not vary drastically. It ranged between 25.0 percent for those with formal education and was slightly higher for children whose caretakers did not have any formal education (28.9percent). There was hardly any variation in the percentage of dependent children by educational status of the spouse of the caretaker 27.3 percent for those with formal education and 28.3 percent for those without formal education.

As almost all survivors of AES were from BPL households, it was not possible to check for association by type of ration card. Dependency due to AES is not significantly associated with religion or caste or formal education of care taker and the spouse of care taker.

Table 16: Socioeconomic profile of survivors of AES and dependency status, Muzaffarpur, Bihar

Variable	Categories	Dependent	Independent	Total
Ration card*	APL	0	100 (1)	100 (1)
	BPL	28.9 (28)	71.1 (69)	100 (97)
Whether the caretaker had ever received any formal education	Yes	25 0(5)	75 0(15)	100 0(20)
	No	28.9 (24)	71.1 (59)	100 0(83)

X^2 with 1 df= 0.122, p-value= 0.727

Whether the spouse of the caretaker had received any formal education	Yes	27.3 (3)	72.7 (8)	100 0(11)
	No	28.3 (26)	71.7 (66)	100 0(92)

X^2 with 1 df = 0.005, p-value= 1.00^a

a= Fisher's exact test value

4.8 Patterns of health care seeking among survivors of AES using dependency status

Dependency was higher (42.9 percent) among those who used private facilities of other facilities (Pharmacists, local indigenous providers) (see table 17). However, more number of the children who were dependent had used the Government allopathic health facility (18/29). The mean distance of health facility used at the time of initial AES was 14.5 kilometers. Thirty eight percent children travelled distance more than the mean distance for the treatment of initial AES (see table 18). More than half (56.3 percent) children went to one more health facilities before they got effective treatment for initial AES.

Dependency is higher among children who went to two more other health facilities for the effective treatment of initial AES (see table 20). Dependency after AES is not significantly associated with health facility used during initial AES or distance of the health facility used during initial AES or number of health facilities used and their effectiveness during initial AES.

Table 17: Distribution of AES survivors according to health facilities used by AES survivors during initial AES and their dependency status

Variable	Categories	Dependent	Independent	Total (N= 103)
Health Facility used	Govt. allopathic	27.7 (18)	72.3 (47)	100 (65)
	Private allopathic	25.8 (8)	74.2 (23)	100 (31)
	Private others	42.9 (3)	57.1 (4)	100 (7)
	Total	28.2 (29)	71.8 (74)	100 (103)

X^2 with 2 df= 0.839, p-value= 0.657

Table 18: Distribution of AES survivors according to distance of the health facility used by the survivors of AES during initial AES and their dependency status

Variable	Categories	Dependent	Independent	Total
Distance according to Mean distance	Distance <= Mean distance [@]	28.6 (18)	71.4 (45)	100 (63)
	Distance > Mean distance [@]	27.5 (11)	72.5 (29)	100 (40)
	Total	28.2 (29)	71.8 (74)	100 (103)

X^2 with 1 df= 0.014, p-value= 0.906

@ Mean distance= 14.45 km

Table 19: Distribution of AES survivors according to effectiveness of treatment received during initial AES and their dependency status

Variable	Categories	Dependent	Independent	Total
Whether treatment received at the time of initial AES was effective	Yes	30.0 (12)	70.0 (28)	100.0 (40)
	No	27.0 (17)	73.0 (46)	100.0 (63)
	Total	28.2 (29)	71.8 (74)	100.0 (103)

X^2 with 1 df= 0.110, p-value= 0.740

Table 20: Distribution of AES survivors according to number of health facilities visited at the time of initial AES and their dependency status

Variable	Categories	Dependent	Independent	Total
Number of health facilities visited during Initial AES	None, Straight to Sri Krishna Medical College & Hospital	30 (12)	70 (28)	100 (40)
	One other health facility	25.9 (15)	74.1 (43)	100 (58)
	Two other health facilities	40 (2)	60 (3)	100(5)
	Total	28.2 (29)	71.8 (74)	100 (103)

X^2 with 2 df= 0.565, p-value= 0.754

Summary

1. The sample size collected was just 76.3 percent of the planned one. However, the age-sex distribution of the 103 children more or less matched the population indicated in the list provided by SKMCH, Muzaffarpur.
2. Out of 103 AES survivors 18.4 percent were having either their old symptoms of AES or newer symptoms due to AES after discharge from the hospital (persistent AES). Symptoms experienced during initial AES were mostly fever, convulsion and unconsciousness.
3. Among the 19 (18.4 percent) children with persistent symptoms of AES, 47.3 percent were having continuing episodes of convulsions and 26.3 percent were having episodes of unconsciousness.
4. Among new symptoms weakness in hand and leg and speech difficulties were experienced by 21.1 percent survivors of AES.
5. At the time of initial AES among 103, 35 percent directly went to the Sri Krishna Medical College and Hospital (Govt. hospital).
6. Among survivors of AES with persistent AES, 52.6 percent (10) were not seeking care anywhere for persistent AES. So in effect, they are not continuing any medication for persistent AES. Among those continuing care, 21.1 percent (4) were seeking care at the tertiary care govt facility, Sri Krishna Medical College & Hospital.
7. Out of 103 children, 51.5 percent were male and 48.5 percent were female. Younger children aged 1-5 were more prone to manifest with persistent AES when compared to those aged 5-10 or 10-15. There were no noticeable differences in the mean age of children with persistent AES and those without it. A majority of the survivors of AES were from households with BPL cards. The average

monthly household income for the households of children with persistent AES was Rs.6947.37, which is higher than that of households of children without persistent AES (Rs6500).

8. Out of the 103 AES survivors, 28.1 percent (29) children showed dependency in at least one of the items of the Liverpool outcome score. More than one fifth (23.3 percent) of the children were dependent with respect to getting dressed. Close to another fifth (19.4 percent) cannot be left alone unattended following AES.
9. Most of the children who were dependent belonged to Hindu religion (26/29). The percentage of children who were dependent was lower for caretakers with formal education but this association was not significant.
10. Dependency was more (42.9 percent) among those who used private facilities or others (Pharmacists or local indigenous providers). However a majority of the households among those who were dependent (18/29) had used the Government allopathic health facility. Dependency is more in children who went to two more other health facilities for the effective treatment of initial AES.

Chapter- 5

Discussion

This is a cross sectional study to estimate the prevalence of persistent acute encephalitis syndrome and the health problems experienced by the survivors of AES in Muzaffarpur, Bihar and to describe the health seeking practices among those who continued to experience problems.

In the year 2019, a total 310 AES cases reported to Sri Krishna Medical College and Hospital from Muzaffarpur district. This represents 70.9 percent of the total reported cases from all over Bihar. Out of 310, 26.5 percent (82) children died in the hospital due to AES. Of the 82 children who died, 68.3 percent (56) were female and 31.7 percent (26) were male. Majority of the children (65.9 percent) were under five years of age. The mean age of children who died due to AES was 5.02 years with a standard deviation of 2.31 years. The average duration of stay in the hospital for the children who died was 1.55 days with a wider standard deviation of 3.53 days. The average duration of stay in the hospital for children who were discharged from the hospital was 4.36 days with a standard deviation of 7.19 days.

5.1 Methodology

The cross sectional survey used for data collection had an estimated sample size of 135 on the basis of a reported prevalence of 35 percent for experience of post effects of AES with 5 percent precision. These 135 cases were to be selected randomly from the list of 217 cases from Muzaffarpur provided by SKMCH for the year 2019. Due to misreporting of addresses and migration of survivors and other unknown reasons, only 103 survivors could be identified to be included in the survey.

5.2 Prevalence of persistent AES and the initial symptoms at the time of AES

Among survivors of AES the prevalence of persistent AES (either old symptoms of AES or newer symptoms due to AES after discharge from the hospital) was 18.4 percent. This is less than reported prevalence of 21.13 percent in a study conducted in Assam for neurological sequelae after JE (Kakoti et al., 2013) and 30 percent reported prevalence in another study from Assam earlier (Baruah et al., 2003). The reason for the low prevalence in this study may be due to governmental efforts and preparedness which resulted in quick medical attention for patients, and this resulting in better recovery. During peak season for this illness, whoever reported with hypoglycemia with fever and lack of consciousness, the hospital treat that case as AES. So, the classical AES among the children reported as AES from the hospital is fewer in number. The effect of this could explain the reduced prevalence of persistent AES in this study. Symptoms experienced during initial AES were fever, convulsions, unconsciousness, drowsiness, drooling, vomiting and diarrhea. Almost all children 100 percent (103) experienced convulsions at the time of initial AES.

Number and pattern of new and continuing symptoms among survivors of AES with persisting symptoms

Majority of survivors of AES had no persistent symptoms (81.6 percent). Among the 18.4 percent children with persistent symptoms of AES, 47.3 percent were having continuing episodes of convulsions and 26.3 percent were having episodes of unconsciousness. Other old symptoms include recurrent episodes of fever, diarrhea, drowsiness and drooling. In addition to the initial symptoms, some caretakers reported newly occurring symptoms for their wards. These new symptoms following the first episode of AES were weakness in

hand and leg, speech difficulties, unconsciousness, convulsions, one side face weakness, mental problems, increased anger, neck pain, problem related to ability to study.

Care seeking for persistent AES

At the time of initial AES among 103, 27.2 percent went to the private sector clinics and 26.2 percent went to the PHC first. Among those who first went to the health facility other than Govt. hospital 98.4 percent subsequently went to the Govt. hospital for the treatment of initial AES. Among survivors of AES with persistent AES, 52.6 percent were not seeking care anywhere for persistent AES. So in effect, they are not continuing any medication for persistent AES. Among these, 21.1 percent were seeking care in Sri Krishna Medical College and Hospital. Five of the 19 children (26.3 percent) were not taking medications because no improvement was noticed by the care takers after consuming the provided medications. Three of the 19 children were not taking medications because of the expenses involved in buying them. Almost half of the parents (43.7 percent) pay for treatment and medications using household savings/ incomes. However, more than a third (34.0 percent) had to borrow money to treat their children. Only approximately one third (36.6 percent) children with persistent AES were taking all the medicine that was prescribed by the doctor.

Profile of survivors of AES with persistent AES

Prevalence of AES did not vary by sex. Younger children aged 1-5 were more prone to manifest with persistent AES when compared to those aged 5-10 or 10-15. The mean age of children with persistent AES and those without it is also not noticeably different.

A majority of the survivors of AES were from the OBC group and merely 5 of the 103 children were from the general or upper caste category. But of these 5 children, 2 had

persistent symptoms of AES. On the other hand, gap in the percentage of children with persistent AES between OBCs and Scheduled Caste children was narrow.

A majority of the survivors of AES were from households with BPL cards. The lone child from a household with APL card however had persistent AES. The reason behind this may be all the children in this study were from Govt. medical college, which is mostly used by persons from the lower socioeconomic background. The average monthly household income for the households of children with persistent AES was Rs.6947.37, which is higher than that of households of children without persistent AES (Rs6500). The variation in the households with persistent AES was considerably higher when compared to households without persistent AES indicating the greater economic heterogeneity among these households. Only 1.9 percent survivors of AES were having health card under Rastriya bal swasthya karyakram (RBSK). In spite of functional RBSK programme in Muzaffarpur, the gap between programme and service in the field are visible in this study. In 24.3 percent of the households ASHAs were not visiting to monitor the child survivors of AES.

Describing survivors of AES by dependency status using Liverpool outcome score (LOS)

Using Liverpool outcome score, 28.1 percent (29) children of age group 1 to 15 were classified as dependent in Muzaffarpur, Bihar in at least one of the items. This is less than prevalence reported in a cohort study in east India among children of age group 0 to 12 years using LOS (Dutta et al., 2021). More than one fifth (23.3 percent) of the children were dependent for dressing. Reduced speech and communication was noticed among 6.8 percent and 4.9 percent have not demonstrated any speech after AES. For feeding, 6.8 percent always need more help and 8.7 percent occasionally needed more help. Following

AES, 7.8 percent children cannot be left alone and 2.9 percent children can be left alone briefly, but only in familiar environments. Among those with dependency as classified by the LOS, 22.3 percent children get angry easily following AES. A very small percent of the children (1percent) cannot recognize anyone and one percent are able to recognize only some of the family members. About seven percent (6.8percent) of the children who were working or studying before the illness, are unable to do their work or study after AES. For about 4 percent of the children (3.9percent) even though they were not working or studying before their illness, their caregivers think that they will not be able to do so following AES. About 7 percent of the children were having seizures on almost all days after illness and nearly 8 percent (7.8percent) need more help in dressing than before. Close to four percent (3.9percent) had incontinence on bowel and bladder issues. Only one percent reported reduced hearing in one or both ear. Nearly six percent (5.8percent) children need help even for sitting, 2.9 percent children need help for standing and 3.9 percent were not able to walk. About 3 percent of the children (2.9percent) were unable to pick up anything.

Socio-economic and cultural correlates of dependency status of survivors of AES

All Muslims of this sample belonged to BPL category. The educational status of the care taker or spouse of the care taker was also very low. Only 11.1 percent (1) had institutional education up to primary and no one in the category of spouse of the care taker had ever been to school. Average monthly income of Muslims in this sample was also lesser than that of Hindus in this study. Minimum monthly income of Muslims was Rs2000 and maximum monthly income was Rs 6000 with an average monthly income of Rs.4777.78 (sd- Rs1301.71), which is less than average monthly income of Hindus (Rs.6755.32 with a sd- Rs3444.45). The average number of children was 4.67 with sd 1.8. It shows comparative bigger family size among Muslim households. These may be the reason for

dependency is nearly one third of the children among Muslims. More number of children in dependent category belonged to Hindu households because of the nature of the distribution of people by religion in Muzaffarpur. Only 5 of the 103 children were from the general or upper caste category. But of these 5 children, 2 had persistent symptoms of AES. Dependency constituted 40 percent of General category children. Nearly 30 percent of the children were dependent for care takers, who were not received any formal education are dependent.

Patterns of health care seeking among survivors of AES using dependency status

Dependency is more (42.9 percent) among those who used private facilities or others (Pharmacists, local indigenous providers). Mean distance of health facility used at the time of initial AES was 14.5 kilometers. Thirty eight percent children travelled a distance more than 14.5 kilometers for the treatment of initial AES. More than half of the children (56.3 percent) went to one more health facility before they got effective treatment for initial AES. Dependency is more in children, who went to two more other health facilities for the effective treatment of initial AES. This clearly indicates that presenting at the designated tertiary care facility for the initial episode and not delaying is very important for appropriate recovery.

5.3 Strengths and limitations of the study

Strength: This is the first community based study to determine the extent of persistent AES in Muzaffarpur district and the extent to which such children seek health care for these persistent health problems associated with AES in Muzaffarpur, Bihar. Much of the research has focused on the outcome of AES of different origin for example JE positive AES, Scrub typhus originate AES etc. but AES which is prevalent in Bihar is of different

origin. The exact cause is not known yet. So, the outcome of this kind of AES is also unknown.

Limitation: The achieved sample size for this study was only 76.3 percent of the estimated sample size, which is insufficient to generalize the result. Among 103 sample, 4 cases were not treated in any govt. health facility. So the diagnosis of AES is not confirmed.

This study considered only those children who survived after getting treatment and were discharged after AES. The survivors of AES with most severe persistent AES may have died.

The sample for this study was selected from only one govt. medical college and so, the variation in terms of socioeconomic background is not much.

5.4 Conclusions

Mortality among children affected by AES in Muzaffarpur district, Bihar is a serious problem. AES seems to be a problem among poorer households and those with limited resources (BPL card holding householders). Further, nearly one fifth of the survivors of AES are left with persistent problems that disable them from functioning independently. More than a quarter of the children were classified as dependent using the LOS measure. Some of these children could not be left alone at all, and this would be seriously restrictive for the families looking after these children. Care seeking for these problems are limited due to lack of improvement for several but lack of resources for a few. This could be a result of limited understanding of the requirements of care and inability to manage care due to limited resources within the households. Some households even had to borrow to provide a modicum of care for their children/wards. ASHAs, the lowest

health functionaries in the district also do not seem to visit such households, indicating the poor quality of follow up care. This speaks of the compounding effects of poverty on the AES survivors' ability to seek care and persist with it. The lack of follow up care, except through the initiative of the parents and care givers points to the lack of a health system link to these families who are severely affected both by having AES affecting their children and the dependency that it leaves in its wake. When such dependency is severe, a care giver would need to devote themselves to care, restricting the ability of such a person to earn. This would exacerbate poverty that was already a characteristic of most of the households with afflicted children. Dependency is more in children, who went to two more other health facilities either because of lack of knowledge or because of absence of effective primary health care facility nearby for the effective treatment of initial AES.

5.5 Policy Implications

To reduce the mortality due to AES in children quick access to the treatment center is necessary. AES is prevalent among poorer with resource constrained families. So, in order to prevent AES among them, proper awareness in the community is needed. Govt. has started awareness campaign but effective implementation is necessary. AES is prevalent in children with under nutrition. So, policy should be made to address this in effective way and food supplement for children in weaning ages should be provided free of cost so that mortality among children of under five year of age due to AES can be reduced. For dependent children more care is needed. So, care center for such children should be provided with free of cost. Specialist treatment facilities and rehabilitation centers in the affected region should be operationalised. It should be free of cost, so that treatment of the children with persistent AES is not adding extra burden to the family. After discharge from the hospital, regular monitoring through ASHA should be done to

know the condition of the children. Dependency is more in children, who went to two more other health facilities for the effective treatment of initial AES. So adequate health assistance and provisioning of follow up care across the district, particularly for BPL families is needed.

5.6 Recommendation for future research

Research determining the extent of borrowings that households made to seek access for follow up care is needed. Many of the households gave up on follow up care even after persistent AES. Some did so because the treatment was not seen as resolving the problem. But several did so because of the cost involved. The exact reasons for not persisting in care seeking needs to be explored.

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Annexure- I

**Achutha Menon Centre for Health Science Studies (AMCHSS)
Sree Chitra Tirunal Institute for Medical Sciences & Technology (SCTIMST)
Trivandrum -11
Post effects of acute encephalitis syndrome (AES) among 1- 15 year old children in
Muzaffarpur district, Bihar**

Research subject information sheet

I am Dr. Shruti Sarika, currently pursuing Master of Public Health course at Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala. I am doing a study on “Post effects of Acute Encephalitis Syndrome (AES) among 1- 15 year old children in Muzaffarpur district, Bihar” as part of my course work.

Purpose of study:

The purpose of the research is to find out the probable complications after AES among AES survivors. I also aim to find out the health seeking practices towards the health problems due to the illness after recovery from the illness.

About the study:

In this study, I will interview survey 135 parents/guardians of children who have recovered from AES. This study is being conducted by me as Principal Investigator (PI) under supervision of Dr Mala Ramanathan, Professor at Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala. The ethics approval for this study has been obtained from Institutional Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum, Kerala.

What participation will be required from your side?

Participation involves answering some questions regarding the health problems faced by the children due to AES after recovery. If you agree to participate in the study, then I will interview you for about 30 to 60 minutes. The information given by you will be

documented. After the interview you may be contacted again only if it is found that the information documented is either incomplete or any further clarification is needed with your permission.

Benefits from the study:

You or your child may not derive any benefit from participation. However, the results of the study can be helpful in further research and policy making which may benefit the children having complications after recovery from AES.

Possible harms from the study:

Some of the questions will be of a personal nature which may make you uncomfortable. In such case you are free to take time to answer or if you are not willing to answer, you can ask me to skip the question. If still you are not willing to answer further, you will be free to terminate the interview without any obligation.

Confidentiality of your data:

Whatever information you share will be kept highly confidential and will only be accessible to me and my supervisor. All the information that is being collected will be used solely for research. Your personal details will not be shared with anyone at any stage. The data other than your personal identifiers will be used for analysis of the study. The results of the study will be published and presented in public forums but neither you nor your child/ward will be individually identified.

Withdrawal from the study:

Your participation in the study will be completely voluntary. You are free and have right to withdraw during the interview at any time. There will be no penalty for withdrawal or not participating in the study.

Is there any query or doubt you want to ask?

I will try to clarify it to best of my ability.

Name of the Principal Investigator: Dr.ShrutiSarika

Signature of Principal Investigator:

Contact No. of Principal Investigator: 7209016733

If you have any doubt/query on the authentication of this study, you may contact the
SCTIMST

Institutional Ethics Committee Member Secretary

Dr. Srinivasa G Contact Details: 0471 - 2524689

Are you willing to participate in the study? - Yes / No.

If yes – please fill up and give signature on the informed consent provided

If no – can you please tell the reason for not participating in the study?

Annexure- II

Consent form

I----- have read/ heard and understood all the information provided in the research information sheet. I understand that my participation in this study is entirely voluntary. By signing/ putting thumb impression I confirm my voluntary participation in this study. I agree to be contacted again if any missing information or further clarification is needed. I understand that I can withdraw my participation at any time during the interview without any explanation and I also understand that my identity and personal information will be kept confidential. I have been informed who should be contacted for further clarifications.

I agree to take part in this study.

Name of the Participant:

Signature of the Participant:

Thumb Impression (if unable to sign):

Date:

Annexure-III

ASSENT FORM FOR CHILDREN (ORAL CONSENT FORM) [to be attached to consent form from parent/guardian)

Title of the study: A study on post effects of acute encephalitis syndrome (AES) among 1- 15 year old children in Muzaffarpur district, Bihar

My name is Shruti Sarika. I am studying in a college at Thiruvananthapuram, Kerala. I am going to do a study to find out if you are having any problems due to AES or not. I will ask you to do five activities like sitting, standing, walking, putting hands on your head and picking up something. It will take only 3 to 5 minutes. Your parent/guardian will be with you when you try to do this, all the time. If you don't want any of these things, you can say no. If you decide to stop after we begin, that's also okay. Your parents know about the study.

If you decide you want to be in this study, please sign your name.

I, ----- am ready to participate in this research study.

Signature of the Participant:

Thumb Impression (if unable to sign):

Date:

Annexure- IV

GENERAL INFORMATION ABOUT THE STUDY

Provisional title: A study on post effects of acute encephalitis syndrome (AES) among 1-15 year old children in Muzaffarpur district, Bihar

Principal investigator: Dr Shruti Sarika

Guide: Dr Mala Ramanathan

Objectives:

To assess the health problems experienced by the survivors of AES in Muzaffarpur district, Bihar

To describe the health seeking practices among the survivors of AES who continue to experience health problems

Methods

- **Study design:** cross sectional survey
- **Study participants:** Children who survived after AES
- **Sample size:** 135 at 5 percent precision,
- **Inclusion Criteria:** Children who obtained treatment in any hospital after AES were diagnosed.
 - Children who had recovered from AES at least one year before this study
 - Children who did not have any neurological disorder from birth or after birth before AES
 - Children who did not have any mental disorder before AES.
 - Parents of AES affected child who are willing to participate
- **Exclusion Criteria:** Death after recovery from AES
- Children who have not been hospitalized due to AES
- Children having some neurological or mental disorder before AES manifestation.

**Achutha Menon Centre for Health Science Studies (AMCHSS)
Sree Chitra Tirunal Institute for Medical Sciences & Technology (SCTIMST)**

Trivandrum -11

**Post effects of acute encephalitis syndrome (AES) among 1- 15 year old
children in Muzaffarpur district, Bihar**

Tool: Interview schedule

Title of the study: Post effects of acute encephalitis syndrome (AES) among 1- 15
year old children in Muzaffarpur district, Bihar

Q.No	Question	Answer options	Skip option
1.	Patient serial No.	
2.	Name of the child with AES (as per records)[Needs to be entered from hospital records in pencil and corrected after verification]		
3.	Verified address of the child with AES [entered as per hospital records in pencil and corrected after verifying in the field]		
4.	Date of interview		

	dd/mm/yyyy		
	Thank you very much for agreeing to talk about the child who had AES. I am going to ask a few questions about you and the child now.		
5.	Can you tell me your name? (enter name)	
6.	How are you related to the child who had AES? [Identity of the care taker providing responses regarding the child]	Mother: 1 Father : 2 Mother and father: 3 Others (Specify).....4	
7.	Which month and year was this child born(the one who had AES)	Month. Don't know month..... Year Don't know year.....	If the respondent is unable to give an answer, skip to question no. 8
8.	How old was the child on the last birthday	Age in completed years	
9.	Sex of the child [note in keeping with name and cultural norms]	Male: 1 Female: 2 Other: 3	
10.	What is the religion followed by members of this household?	Hinduism: 1 Islam: 2 Christianity: 3 Sikhism 4 Jainism 5 Buddhism 6 Zoroastrianism 7 Others 8	

11.	What is your Caste?	General 1 OBC 2 SC 3 ST 4	
12.	Have you heard about AES? (ChamkiBukhar)	Yes 1 No 2	
13.	How many children were born to you or the mother of this child? By that I mean, how many children did you give birth to?	Son Daughter..... Total.....	
14.	Have any of these children died?	Yes 1 No 2	If No, go to question 16
15.	How many children that were born to you are alive now?	Son..... Daughter..... Total.....	
16.	What did the child die of?	No of deaths due to AES 1 Others 2	
17.	Of all the children born to you/mother of this child, what was the number of this child who is affected by AES?[By		

	that, I mean, what order of birth is this child if your first born is 1, second born is 2 and so on]		
18.	Which month and year did this child get AES? (Check against given hospital data and cross verify. If not matched, clarify and correct accordingly).	Month..... Year.....	
19.	Have you ever gone to school?	Yes 1 No 2	If No, skip Q 20
20.	What is the highest class you passed while in school or in college?	Below primary 1 Primary 2 Upper primary/middle 3 Secondary 4 Higher secondary 5 Diploma/certificate course (up to secondary) 6 Diploma/certificate course (higher secondary) 7 Diploma/certificate course (graduation & above) 8 Graduate 9 Postgraduate and above10	
21.	Has your spouse ever	Yes 1	If No, skip Q 22

	gone to school?	No	2	
22.	What is the highest education attained by your spouse (husband or wife)	Below primary	1	
		Primary	2	
		Upper primary/middle	3	
		Secondary	4	
		Higher secondary	5	
		Diploma/certificate course (up to secondary)	6	
		Diploma/certificate course (higher secondary)	7	
		Diploma/certificate course (graduation & above)	8	
		Graduate	9	
		Postgraduate and above	10	
23.	What is the category of your family's ration card? Please answer in keeping with which type of ration card your family has (affinal family).	APL	1	
		BPL	2	
24.	What kind of work do you mainly do for livelihood? That is the work you did for more than 180 days last year.	self-employed in: agriculture	1	
		non-agriculture	2	
		regular wage/salary earning	3	
		casual labour in: agriculture	4	
		non-agriculture	5	
		Unable to work due to child care requirement	6	
		others (specify).....	7	

25.	<p>What kind of work does the head of the household do for a livelihood? This is the work done for more than 180 days in the last year.</p>	<p>self-employed in: agriculture 1 non-agriculture 2 regular wage/salary earning 3 casual labour in: agriculture 4 non-agriculture 5 Unable to work due to child care requirement 6 others (specify)..... 7</p>	
26.	<p>What is the monthly income of your household? Consider all those who live under this roof and eat in the kitchen. But do not consider the salaries of resident workers.</p>		
27.	<p>According to you, what are the early symptoms of AES?[multiple responses are possible]</p>	<p>Fever 1 Unconsciousness 2 Drowsiness 3 Seizures 4 Vomiting 5 Diarrhoea 6 Any other (specify) 7</p>	
28.	<p>When that child was afflicted by AES, where did you seek treatment? That I mean where</p>	<p>Public health care facilities sub-centres 1 PHC's 2</p>	

	did you go for the treatment initially?	CHC's 3 Hospital 4 AYUSH 5 Anganwadi 6 Private sector Hospital 7 Clinic 8 AYUSH 9 Pharmacist 10 Others (specify)..... 11	
29.	Was that effective?	Yes 1 No 2	If No then ask 30
30.	Where else did you go from the list above mentioned?		
31.	What is the distance of nearby treatment centre, where your child was seeking treatment at the time of acute illness?	Distance in kilometer..... Distance meter.....	
32.	When did you finally reach the hospital where you got treatment for the child [the hospital from where records		

	were obtained]dd/m m/yyyy		
33.	How many health facilities and health care providers had you visited before reaching that hospital?	None, we went straight to that hospital: 1 one other health facility/provider: 2 two other health facilities/providers: 3 three or more health facilities/providers: 4	
34.	What were the symptoms your child experienced at the time of illness?		
35.	Does your child experiencing any of the same symptoms till now?	Yes 1 No 2	If NO, skip Q 36
36.	What are those symptoms?		
37.	Has your child experience any new symptom after getting discharge from Hospital?	Yes 1 No 2	If NO, skip Q38, 39
38.	Since when did the new symptoms start?(After got discharged from hospital)		

39.	What are these new symptoms?		
40.	When any of your family members get sick where do they go for treatment?	Public health care facilities sub-centres 1 PHC's 2 CHC's 3 Hospital 4 AYUSH 5 Anganwadi 6 Private sector Hospital 7 Clinic 8 AYUSH 9 Pharmacist 10 Others (specify)..... 11	
41.	Is this the same place where the child with AES is getting treated?	Yes 1 No 2	
42.	Where would you prefer to treat your child?	Public health care facilities sub-centres 1 PHC's 2 CHC's 3 Hospital 4 AYUSH 5 Anganwadi 6 Private sector	

		Hospital 7 Clinic 8 AYUSH 9 Pharmacist 10 Others (specify)..... 11	
43.	If this is different from the one they are going to: Why are you not using that centre?	Stated reason(s):	
44.	At which facility (from the above list) is the child getting treated now?		
45.	What is the distance of the treatment center from your residence, where your child is seeking treatment now?		
46.	For how long have you been treating the child at this place?		
47.	Is the child is on medication?	Yes 1 No 2	If NO, skip Q 48, 49
48.	List of medicines		

49.	Are there any medicines that have been prescribed, but the child is not taking now?	Yes 1 No 2	If NO, skip Q 50
50.	What is the reason for not taking these medicines now?	Costly medicine 1 I decided it not needed now2 Not available in the 3 pharmacy 4 Child refuses to take 5 Others decided to not given those medicines to the child 6 Other Reasons.....7	
51.	According to you, is there any improvement in the condition of the child?	Yes 1 No 2	
52.	Are you spending money for medicines for the child with AES?	Yes: 1 No: 2	If No, go to Q 54
53.	How much money are you spending on medicines per month?	Rs:	
54.	Are you spending	Yes: 1	If no, go to

	money for diagnostic tests like x-ray, ECG, pathological tests for the child?	No: 2	Q57
55.	How much money are you spending on diagnostics like X ray, ECG, pathological tests etc per month	Rs:	
56.	Are you spending any money for doctors' fees for this child?	Yes: 1 No: 2	If no, go to Q58
57.	How much money are you spending on doctors' fees per month for this child?	Rs:	
58.	Have you spent any additional money, after the initial hospitalisation for hospital based care for this child?	Yes: 1 No: 2	If no, go to Q60
59.	How much money did you spend on any additional hospital based care for this child in the last one month?	Rs.:	

60.	Have you spend any money for health care of this child other than those mentioned above during the last month?	Yes: 1 No: 2	If no, go to Q63
61.	For what did you spend money on for health care needs of the child?	Reasons for additional expenditure during the last one month:	
62.	How much money did you spend for this reason during the last one month?	Rs:	
63.	On the whole, after the initial hospitalisation, approximately how much money have you had to spend for the overall care of the child?	Rs:	
64.	How do you pay for the medicines?	Household income/ savings 1 Borrowings 2 Sale of physical assets 3 Contributions from friends and relatives 4 Other sources 5	
65.	How is the child now? By that mean whether he/she		

	is able to continue his normal life (playing, schooling, expressing etc.)		
66.	What are the difficulties you are facing to manage the health needs of the child		
67.	Why you are not taking the child for treatment?	Availability of treatment center 1 Availability of doctors 2 Affordability 3	
68.	Does ASHA visit your house?	Yes: 1 No: 2	
69.	Does the child have health card under RBSK program?	Yes: 1 No: 2	
LIVERPOOL OUTCOME SCORE - For assessing simple cognitive & behavioural functions, basic motor and self- care skills			
70.	<u>1. Speech or communication</u> Compared with before the illness, is the child's speech or communication :	The same as before (5) Changed or reduced (3) Not speaking or communicating (2) _____	

71.	<u>2. Feeding</u> The child's feeding is:	The same as before illness (5) Occasionally needs help (3) Always needs more help (2)	
72.	<u>3. Leaving Alone</u> Before the illness, could this child be left alone without coming to harm? If Yes , can this child now be left alone?	Yes (5) Yes briefly in familiar environment (3) No (2)	If No score 5 (5)
73.	<u>4. Behaviour</u> Compared with before the illness do the caregivers think the child's behaviour is altered?	No completely normal (5) Gets angry easily (4) Other behavioural problems (4) Severely abnormal (2) If abnormal give details: _____ _____ _____	
74.	<u>5. Recognition</u> Could the child recognise their family members, other than their main carer, before the illness? If Yes , can this child now	Yes (5) Some (3) None (2)	If No , score 5 (5)

	recognise their family members, other than their main carer?		
75.	<p><u>6. School and working</u></p> <p>Before the illness, was the child at school or working?</p> <p>If Yes, do the carers think the child will go back to school or work?</p>	<p>Yes (5)</p> <p>No (3)</p>	<p>If No, do the carers think the child will still be able to do the same tasks at home, follow the same routine, or play normally?</p> <p>Yes (5)</p> <p>Not able to (3)</p>
76.	<p><u>7. Epilepsy/ Seizures</u></p> <p>Did the child have any seizures during this illness?</p> <p>If Yes, is the child still having seizures?</p>	<p>No seizures and not on anti-epileptic drugs (5)</p> <p>No seizures and on anti-epileptic drugs (4)</p> <p>Yes still having seizures (3)</p> <p>Yes, seizures most days (2)</p>	<p>If No, score 5 (5)</p>
77.	<p><u>8. Dressing</u></p> <p>Can other children of this age dress</p>	<p>Yes, the same as before illness (5)</p> <p>Occasionally needs extra help (3)</p> <p>Needs more help than before (2)</p>	<p>If No, score 5 (5)</p>

	<p>themselves?</p> <p>If Yes, can the child dress themselves since their illness?</p>		
78.	<p><u>9. Bladder and Bowel control</u></p> <p>Is urinary and faecal continence:</p>	<p>The same as before the illness (5)</p> <p>Occasionally needs more help or occasionally is incontinent (4)</p> <p>Needs more help or is incontinent of bowel or bladder (2)</p>	
79.	<p><u>10. Hearing</u></p> <p>Does the parent think this child's hearing is:</p>	<p>Normal (5)</p> <p>Reduced in one or both ears (4)</p> <p>Cannot hear at all (3)</p>	
80.	<p><u>Observation of the child's abilities</u></p>		
81.	<p><u>11. Sitting</u></p> <p>Could the child sit before the illness?</p>	<p>Yes independently (5)</p> <p>Needs help (3)</p> <p>Not at all (2)</p>	<p>If No, score 5 (5)</p>
82.	<p><u>12. Standing up</u></p> <p>Could the child get from sitting to standing before the illness?</p>	<p>Yes, independently (5)</p> <p>Needs help (3)</p> <p>Not at all (2)</p>	<p>If No, score 5 (5)</p>

83.	<u>13. Walking</u> Could the child walk before the illness?	Normally (5) Abnormally, but independently +/- crutches/stick (3) Not able to walk (2)	If No, score 5 (5)
84.	<u>14. Hands on head</u> Put both your hands on your head, and ask the child to copy you. Child is:	Too young (5) Normal both hands (5) Abnormal one or both hands (4) Unable one or both hands (3)	
85.	<u>15. Picking Up</u> Ask child to pick up pea-sized ball of paper or small coin. Child is:	Too young (5) Normal pincer grasp both hands (5) Unable one hand (3) Abnormal one hand or both hands (3) Unable both hands (2)	
86.	Have you consulted any Therapists?	Yes: 1 No: 2	If NO skip Q87, 88 If yes skip Q89
87.	specify	
88.	For how long you sought Treatment?	Month..... Year.....	
89.	What are the reasons for not consulting any special therapy?		
90.	Can I contact your for clarifications	Yes: 1	

	if any are needed?	No: 2	
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Thank you for sparing your time.



Annexure- V

**Achutha Menon Centre for Health Science Studies (AMCHSS)
Sree Chitra Tirunal Institute for Medical Sciences & Technology (SCTIMST)
Trivandrum -11**

**Post effects of acute encephalitis syndrome (AES) among 1- 15 year old children in
Muzaffarpur district, Bihar**

अनुसंधान विषय सूचना पत्र

मैं डॉक्टर श्रुति सारिका हू, जो वर्तमान में अच्युता मेनन सेंटर फॉर हेल्थ साइंस स्टडीज, श्री चित्रा तिरुनल इंस्टीट्यूट फॉर मेडिकल साइंसेज एन्ड टेक्नोलॉजी, तिरुवनंतपुरम, केरल में मास्टर ऑफ पब्लिक हेल्थ कोर्स कर रही हूँ. मैं अपने पाठ्यक्रम कार्य के भाग के रूप में "बिहार के मुजफ्फरपुर जिले में 1 से 15 वर्ष के बच्चों में एक्यूट इंसेफेलाइटिस सिंड्रोम (ए इ स) के बाद के प्रभाव" पर एक अध्ययन कर रही हूँ.

अध्ययन का उद्देश्य:

शोध का उद्देश्य चमकी बुखार से बच्चों में चमकी बुखार के बाद संभावित स्वस्थ सम्बंधित जटिलताओं का पता लगाना है. मेरा उद्देश्य बीमारी से उबरने के बाद बीमारी के कारण होने वाली स्वास्थ्य समस्याओं के प्रति इलाज के लिए प्रयास करने वाले तरीकों का पता लगाना है.

अध्ययन के बारे में:

इस अध्ययन में, मैं से एक्यूट इंसेफेलाइटिस सिंड्रोम (चमकी बुखार) से उबर चुके बच्चों के 135 माता-पिता/अभिभावकों का सर्वेक्षण करूंगी. यह अध्ययन मेरे द्वारा प्रधान अन्वेषक (पीआई) के रूप में डॉक्टर माला रामनाथन, अच्युता मेनन सेंटर फॉर हेल्थ साइंस स्टडीज, श्री चित्रा तिरुनल इंस्टीट्यूट फ़ोर मेडिकल साइंसेज एन्ड टेक्नोलॉजी, तिरुवनंतपुरम, केरल में प्रोफेसर की देखरेख में किया जा रहा है. इस अध्ययन के लिए नैतिक अनुमोदन श्रीचित्रा तिरुनल आयुर्विज्ञान और प्रौद्योगिकी संस्थान, त्रिवेंद्रम, केरल की संस्थागत आचार समिति से प्राप्त किया गया है.

आपकी ओर से किस भागीदारी की आवश्यकता होगी?

भागीदारी में एक्यूट इंसेफेलाइटिस सिंड्रोम (चमकी बुखार) से स्वस्थ होने के बाद के कारण बच्चों को होने वाली स्वास्थ्य समस्याओं के बारे में कुछ सवालों के जवाब देना शामिल है। यदि आप अध्ययन में भाग लेने के लिए सहमत हैं, तो मैं आपका लगभग 30 से 60 मिनट तक साक्षात्कार करूंगी। आपके द्वारा दी गयी जानकारी का दस्तावेजीकरण किया जाएगा। साक्षात्कार के बाद आपसे केवल तभी संपर्क किया जा सकता है जब यह पाया जाए की प्रलेखित जानकारी या तो अधूरी है या आपके अनुमति से किसी और स्पष्टीकरण की आवश्यकता है।

अध्ययन से लाभ:

हो सकता है की आपको या आपके बच्चे को भागीदारी से कोई लाभ न मिले। हालांकि, अध्ययन के परिणाम आगे के शोध और नीति निर्माण में सहायक हो सकते हैं जिससे एक्यूट इंसेफेलाइटिस सिंड्रोम (चमकी बुखार) से उबरने के बाद जटिलताओं वाले बच्चों को लाभ हो सकता है।

अध्ययन से संभावित नुकसान:

कुछ प्रश्न व्यक्तिगत प्रकृति के होंगे जो आपको असहज कर सकते हैं। ऐसे मामले में आप उत्तर देने के लिए समय लेने के लिए स्वतन्त्र हैं या यदि आप उत्तर देने के इच्छुक नहीं हैं, तो आप मुझसे प्रश्न को छोड़ने के लिए कह सकते हैं। यदि फिर भी आप आगे उत्तर देने के इच्छुक नहीं हैं, तो आप बिना किसी बाध्यता के साक्षात्कार को समाप्त करने के लिए स्वतन्त्र होंगे।

आपके द्वारा दी हुई जानकारी की गोपनीयता :

आप जो भी जानकारी साझा करते हैं उसे अत्यधिक गोपनीय रखा जाएगा और केवल मेरे और मेरे पर्यवेक्षक के लिए ही पहुँच योग्य होगा। जो भी जानकारी एकत्र की जा रही है उसका उपयोग केवल शोध के लिए किया जाएगा। आपका व्यक्तिगत विवरण किसी भी शर्त पर किसी के साथ साझा नहीं किया जाएगा। अध्ययन के विश्लेषण के लिए आपके व्यक्तिगत पहचानकर्ताओं के अलावा अन्य जानकारी का उपयोग किया जाएगा। अध्ययन के परिणाम सार्वजनिक मंचों पर प्रकाशित और

प्रस्तुत किए जाएंगे लेकिन न तो आप और न ही आपके बच्चे/वार्ड की व्यक्तिगत रूप से पहचान की जाएगी.

अध्ययन से वापसी:

अध्ययन में आपकी भागीदारी पूर्णतः स्वैच्छिक होगी. आप स्वतन्त्र हैं और किसी भी समय साक्षात्कार के दौरान वापस लेने का अधिकार है. अध्ययन में भाग लेने या वापस लेने के लिए कोई दंड नहीं होगा.

क्या कोई प्रश्न या संदेह है जो आप पूछना चाहते हैं?

मैं अपनी क्षमता के अनुसार इसे स्पष्ट करने का प्रयास करूंगी.

प्रधान अन्वेषक का नाम: डॉक्टर श्रुति सारिका

प्रधान अन्वेषक के हस्ताक्षर:

प्रधान अन्वेषक का संपर्क नंबर: 7209016733

यदि आपको इस अध्ययन के प्रमाणीकरण पर कोई संदेह/प्रश्न है, तो आप से संपर्क कर सकते हैं
संस्थागत आचार समिति सदस्य सचिव

डॉक्टर श्रीनिवास जी. संपर्क विवरण: 0471 - 2524689

क्या आप अध्ययन में भाग लेने के इच्छुक हैं? - हाँ नहीं.

यदि हाँ - कृपया भरें और प्रदान की गयी सूचित सहमति पर हस्ताक्षर करें

यदि नहीं - क्या आप कृपया अध्ययन में भाग न लेने का कारण बता सकते हैं?

Annexure- VI

शोध सूचना पत्र

मैंने ----- शोध सूचना पत्र में दी गयी सभी सूचनाओं को पढ़/सुन और समझ लिया है . मैं समझता/ समझती हूँ की इस अध्ययन में मेरी भागीदारी पूरी तरह से स्वैच्छिक है . हस्ताक्षर करके /अंगूठे का निशान लगाकर मैं इस अध्ययन में अपनी स्वैच्छिक भागीदारी की पुष्टि करता/ करती हूँ . यदि कोई छूटी हुई जानकारी या आगे स्पष्टीकरण की आवश्यकता है तो मैं फिर से संपर्क करने के लिए सहमत हूँ . मैं समझता/ समझती हूँ की मैं साक्षात्कार के दौरान किसी भी समय बिना किसी स्पष्टीकरण के अपनी भागीदारी वापस ले सकता/ सकती हूँ और मैं यह भी समझता हूँ की मेरी पहचान और व्यक्तिगत जानकारी को गोपनीय रखा जाएगा. मुझे सूचित किया गया है की अधिक स्पष्टीकरण के लिए किससे संपर्क किया जाना चाहिए. मैं इस अध्ययन में भाग लेने के लिए सहमत हूँ .

प्रतिभागी का नाम :

प्रतिभागी का हस्ताक्षर :

अंगूठे का निशाँ (यदि हस्ताक्षर करने में असमर्थ हो):

दिनांक :

Annexure- VII

ASSENT FORM FOR CHILDREN (ORAL CONSENT FORM) [to be attached to consent form from parent/guardian]

Title of the study: A study on post effects of acute encephalitis syndrome (AES) among 1- 15 year old children in Muzaffarpur district, Bihar

मेरा नाम श्रुति सारिका है। मैं केरल के तिरुवनंतपुरम के एक कॉलेज में पढ़ रही हूँ। आपको एईएस के कारण कोई समस्या हो रही है या नहीं मैं यह पता लगाने के लिए एक अध्ययन करने जा रही हूँ। मैं आपको पाँच गतिविधियाँ करने के लिए कहूँगी जैसे बैठना, खड़ा होना, चलना, अपने सिर पर हाथ रखना और कुछ उठाना। इसमें सिर्फ 3 से 5 मिनट का समय लगेगा। जब आप ऐसा करने का प्रयास करेंगे तो आपके माता-पिता/अभिभावक हर समय आपके साथ रहेंगे। यदि आप इनमें से कुछ भी नहीं चाहते हैं, तो आप नहीं कह सकते हैं। अगर आप हमारे शुरू करने के बाद रुकने का फैसला करते हैं, तो यह भी ठीक है। आपके माता-पिता अध्ययन के बारे में जानते हैं।

यदि आप तय करते हैं कि आप इस अध्ययन में शामिल होना चाहते हैं, तो कृपया अपना हस्ताक्षर करें।

मैं, ----- इस शोध अध्ययन में भाग लेने के लिए तैयार हूँ।

प्रतिभागी के हस्ताक्षर:

अंगूठे का निशान (यदि हस्ताक्षर करने में असमर्थ हो):

तारीख:

Annexure- VIII

Achutha Menon Centre for Health Science Studies (AMCHSS)

Sree Chitra Tirunal Institute for Medical Sciences & Technology (SCTIMST)

Trivandrum -11

**Post effects of acute encephalitis syndrome (AES) among 1- 15 year old children in
Muzaffarpur district, Bihar**

टूल: इंटरव्यू शेड्यूल

अध्ययन का शीर्षक: बिहार के मुजफ्फरपुर जिले में १ से १५ साल के बच्चों में एक्यूट इंसेफेलाइटिस सिंड्रोम (चमकी बुखार) के बाद के प्रभाव

प्रश्न संख्या	प्रश्न	उत्तर विकल्प	छोड़ने का विकल्प
1.	रोगी क्रमांक संख्या	
2.	चमकी बुखार वाले बच्चे का नाम (हॉस्पिटल रिकॉर्ड के अनुसार)		
3.	बच्चे का पता [entered as per hospital records in pencil and corrected after verifying in the field]		
4.	इंटरव्यू की तारीख dd/mm/yyyy		
ए इ स से प्रभावित बच्चे के बारे में बात करने के लिए धन्यवाद. अब मैं आपसे आपके और आपके बच्चे के बारे में कुछ प्रश्न पूछने वाली हूँ			
5.	आपका नाम क्या है ? (enter name)	
6.	ए इ स प्रभावित बच्चे से आपका क्या सम्बन्ध हैं?[Identity of the care taker providing responses regarding the child]	माता: 1 पिता: 2 माता और पिता: 3 अन्य (विवरण दें): 4	
7.	इस बच्चे का जन्म किस महीने और साल में हुआ था? (the one who had AES)	महीना..... महीना पता नहीं..... साल..... साल पता नहीं.....	यदि उत्तर देने में असमर्थ हैं तो प्रश्न संख्या 8 पर जाएँ
8.	इसके पिछले जन्मदिन पर इस बच्चे की आयु कितनी थी?	आयु पूर्ण वर्षों में	
9.	बच्चे का लिंग [note in keeping with name and cultural norms]	पुरुष : 1 महिला: 2 अन्य: 3	

10	आपलोग किस धर्म को मानते हैं?	हिन्दू धर्म: 1 इस्लाम: 2 क्रिस्चन धर्म : 3 सिख धर्म 4 जैन धर्म 5 बौद्ध धर्म 6 पारसी धर्म 7 अन्य 8	
11	आपकी जाती या जनजाति क्या है?	सामान्य वर्ग 1 अन्य पिछड़ा वर्ग 2 अनुसूचित जाती 3 अनुसूचित जनजाति 4	
12	क्या आपने चमकी बुखार के बारे में सुना है?	हाँ 1 नहीं 2	
13	आपने या इस बच्चे की माता ने अपने जीवनकाल में कितने बच्चों को जन्म दिया है?	पुत्र पुत्री कुल	
14	क्या उनमें से किसी की मृत्यु हुई है?	हाँ 1 नहीं 2	If No, go to question 16
15	जन्म दिए बच्चों में से कितने अभी जीवित हैं?	पुत्र पुत्री कुल	
16	मृत्यु का कारन क्या था?	चमकी बुखार के कारन मृत्यु की संख्या 1 अन्य 2	
17	आपने या इस बच्चे की मिटाने जितने बच्चे को जन्म दिया है उसमें से		

	इस बच्चे जो चमकी भुखार से प्रभावित हुआ उसका क्रमांक क्या है? जैसे की पहला जन्मा बच्चा १, दूसरा जन्मा बच्चा २		
18	किस महीने या साल में इसको चमकी बुखार हुआ था? (Check against given hospital data and cross verify. If not matched, clarify and correct accordingly).	महीना साल	
19	क्या आप कभी स्कूल गए हैं?	हाँ 1 नहीं 2	If No, skip Q 20
20	आपने स्कूल या कॉलेज में कौन सा उच्चतम दर्जा उत्तीर्ण किया है?	प्राथमिक से नीच 1 प्राथमिक 2 उच्च प्राथमिक/मध्य 3 माध्यमिक 4 हायर सेकेंडरी 5 डिप्लोमा/सर्टिफिकेट कोर्स (माध्यमिक तक) 6 डिप्लोमा/सर्टिफिकेट कोर्स (हायर सेकेंडरी) 7 डिप्लोमा / सर्टिफिकेट कोर्स (स्नातक और ऊपर) 8 स्नातक 9 स्नातकोत्तर और ऊपर 10	
21	क्या आपके पति/ पत्नी कभी स्कूल गए हैं?	हाँ 1 नहीं 2	If No, skip Q 22
22	आपके पति/ पत्नी ने स्कूल या कॉलेज में कौन सा उच्चतम दर्जा उत्तीर्ण किया है?	प्राथमिक से नीच 1 प्राथमिक 2 उच्च प्राथमिक/मध्य 3	

		माध्यमिक 4 हायर सेकेंडरी 5 डिप्लोमा/सर्टिफिकेट कोर्स (माध्यमिक तक) 6 डिप्लोमा/सर्टिफिकेट कोर्स (हायर सेकेंडरी) 7 डिप्लोमा / सर्टिफिकेट कोर्स (स्नातक और ऊपर) 8 स्नातक 9 स्नातकोत्तर और ऊपर 10	
23	आपके परिवार में कौन सा राशन कार्ड है?	APL 1 BPL 2	
24	आप अपने जीवन यापन के लिए क्या काम करते हैं? जो काम आपने पिछले साल १८० दिन से अधिक क लिए किया.	स्वरोजगार में: कृषि 1 गैर-कृषि 2 नियमित वेतन/वेतन अर्जन 3 कैजुअल लेबर इन: कृषि 4 गैर-कृषि 5 चाइल्ड केयर आवश्यकता के कारण काम करने में असमर्थ 6 अन्य (विवरण दें) 7	
25	इस घर के मुखिया जीवन यापन के लिये कौन सा काम करते हैं? जो काम पिछले साल १८० दिन से अधिक क लिए किया.	स्वरोजगार में: कृषि 1 गैर-कृषि 2 नियमित वेतन/वेतन अर्जन 3 कैजुअल लेबर इन: कृषि 4 गैर-कृषि 5 चाइल्ड केयर आवश्यकता के कारण काम करने में असमर्थ 6 अन्य (विवरण दें) 7	
26	आपके परिवार का मासिक आय क्या है? सभी जो एक छत के नीचे रहते हैं और एक		

	रसोई में खाना कहते हैं उनका विचार करें परन्तु श्रमिक का विचार मत करें.		
27	आपके अनुसार चमकी बुखार के शुरुआती लक्षण क्या हैं? [एक से अधिक जवाब संभव हैं]	बुखार 1 बेहोशी 2 सुस्ती 3 मिर्गी, दौरा 4 उलटी 5 दस्त 6 अन्य (विवरण दें) 7	
28	जब बच्चे को चमकी बुखार हुआ था तब आपने कहाँ इलाज करवाया था? मतलब आप शुरुआत में इलाज के लिए कहाँ गए थे?	सार्वजनिक स्वास्थ्य देखभाल सुविधाएं उप-केंद्र 1 पीएचसी 2 सीएचसी 3 अस्पताल 4 आयुष 5 आंगनबाड़ी 6 निजी क्षेत्र अस्पताल 7 क्लिनिक 8 आयुष 9 फार्मासिस्ट 10 अन्य (विवरण दें)..... 11	
29	क्या वो प्रभावशाली था?	हाँ 1 नहीं 2	If No then ask 30
30	ऊपर दिए गए लिस्ट में से और कहाँ गए इलाज के लिए?		

31	चमकी बुखार के समय जहाँ आपके बच्चे का इलाज हुआ उसकी आपके घर से दूरी कितनी है?	दूरी किलोमीटर में दूरी मीटर में	
32	जहाँ आपके बच्चे का इलाज हुआ वह आप कब पहुँचे? [the hospital from where records were obtained]dd/mm/yyyy		
33	जहाँ बच्चे का इलाज हुआ वहाँ पहुँचने से पहले आप और कितने स्वस्थ केन्द्रों गए?	कोई नहीं, हम सीधे उस अस्पताल गए: 1 एक अन्य स्वास्थ्य सुविधा/प्रदाता: 2 दो अन्य स्वास्थ्य सुविधाएं/प्रदाता: 3 तीन या अधिक स्वास्थ्य सुविधाएं/प्रदाता: 4	
34	चमकी बुखार के समय बच्चे के क्या लक्षण थे?		
35	क्या उनमें से कोई भी लक्षण अभी तक बच्चे में हैं?	हाँ 1 नहीं 2	If NO, skip Q 36
36	वो कौन से लक्षण हैं?		
37	अस्पताल से छुट्टी के बाद आपके बच्चे में कोई नया लक्षण आया है?	हाँ 1 नहीं 2	If NO, skip Q38, 39
38	अस्पताल से छुट्टी के बाद नया लक्षण कब से आना सुरु हुआ?		
39	नए लक्षण कौन कौन से हैं?		

40	क्या नए लक्षण में कोई परिवर्तन हो रहा है?	कोई परिवर्तन नहीं 1 लक्षणों में कमी आ रही है 2 लक्षणों में वृद्धि हो रही है 3	
41	आपके परिवार में कोई बीमार होता है तो आपलोग इलाज के लिए कहाँ जाते हैं?	सार्वजनिक स्वास्थ्य देखभाल सुविधाएं उप-केंद्र 1 पीएचसी 2 सीएचसी 3 अस्पताल 4 आयुष 5 आंगनबाडी 6 निजी क्षेत्र अस्पताल 7 क्लिनिक 8 आयुष 9 फार्मासिस्ट 10 अन्य (विवरण दें)..... 11	
42	क्या ये वही स्थान है जहाँ चमकी बुखार में बच्चे का इलाज हुआ था?	हाँ 1 नहीं 2	
43	आप बच्चे के इलाज के लिए कहाँ जाना पसंद करते हैं?	सार्वजनिक स्वास्थ्य देखभाल सुविधाएं उप-केंद्र 1 पीएचसी 2 सीएचसी 3 अस्पताल 4 आयुष 5 आंगनबाडी 6 निजी क्षेत्र अस्पताल 7 क्लिनिक 8	

		आयुष 9 फार्मासिस्ट 10 अन्य (विवरण दें)..... 11	
44	आप अभी जहाँ से इलाज करवा रहे हैं क्या ये उससे भिन्न है? अलग स्वाथ्य क्रेन्द्र जाने का कोई विशेष कारन?	बताया गया कारण:	
45	बच्चे का इलाज अभी ऊपर दिए लिस्ट में से कहाँ करवा रहे हैं?		
46	अभी जहाँ बच्चे का इलाज हो रहा है उसकी आपके निवास स्थान से दुरी कितनी है?		
47	इस स्थान पर कितने समय से इलाज करवा रहे हैं?		
48	क्या बच्चा कोई दवाई ले रहा है?	हाँ 1 नहीं 2	If NO, skip Q 49
49	कौन कौन सी दवाइयां अभी ले रहा है?		
50	क्या ऐसी कोई दवाई है जो डॉक्टर द्वारा लिखी गयी हो लेकिन ये नहीं ले रहा?	Yes 1 No 2	If NO, skip Q 51
51	दवाई नहीं लेने का कोई कारन?	महंगी दवा 1 मैंने तय किया कि अब इसकी जरूरत नहीं है2 फार्मसी में उपलब्ध नहीं है 3 बच्चे ने लेने से मना किया 4 बच्चे को वो दवाएं दूसरों ने नहीं देने का फैसला	

		किया 5 अन्य कारण6	
52	आपके अनुसार बच्चे के स्थिति में कोई सुधार हो रहा है?	हाँ 1 नहीं 2	
53	क्या आप इस बच्चे के दवाई पर पैसे खर्च कर रहे है?	हाँ 1 नहीं 2	If No, go to q 55
54	हर महीने आप इस बच्चे की दवाई पर कितना खर्च करते हैं?	Rs:	
55	क्या आप बच्चे के जाँच जैसे X रे, ECG, खून की जाँच पर खर्च करते हैं?	हाँ 1 नहीं 2	If no, go to q 57
56	हर महीने आप इस बच्चे की जाँच जैसे X रे, ECG, खून की जाँच पर कितना खर्च करते हैं?	Rs:	
57	क्या आप इस बच्चे के लिए डॉक्टर के फीस पर खर्च करते हैं?	हाँ 1 नहीं 2	If no, go to q59
58	हर महीने आप इस बच्चे के लिए डॉक्टर के फीस पर कितना खर्च करते हैं?	Rs:	
59	चमकी बुखार के कारन अस्पताल में भर्ती होने के बाद से अभी तक अस्पताल में इलाज के लिए आपने क्या कभी अतिरिक्त पैसे खर्च किये हैं?	हाँ 1 नहीं 2	If no, go to q 61
60	चमकी बुखार के कारन अस्पताल में भर्ती होने के बाद से अभी तक अस्पताल में इलाज के लिए आपने कितने अतिरिक्त पैसे खर्च किये	Rs.:	

	हैं?		
61	क्या आपने ऊपर उल्लेखित स्वास्थ्य विकल्प के अतिरिक्त किसी स्वस्थ देखभाल पर पैसे खर्च किये हैं?	हाँ 1 नहीं 2	If no, go to q64
62	किस प्रकार के स्वास्थ्य देखभाल के लिए आपने पैसे खर्च किये हैं?	पिछले एक महीने के दौरान अतिरिक्त खर्च के कारण:	
63	इस प्रकार के स्वास्थ्य देखभाल के लिए आपने पिछले महीने कितने पैसे खर्च किये?	Rs:	
64	आपने अभी तक चमकी बुखार के कारण अस्पताल से छुट्टी के बाद इस बच्चे के इलाज पर कितने पैसे खर्च किये हैं?	Rs:	
65	आप दवाई के लिए पैसे का भुगतान कैसे करते हैं?	घरेलु आय/ बचत 1 उधार लेकर 2 संपत्ति को बेचकर 3 मित्रों और रिश्तेदारों के योगदान से 4 अन्य स्रोत 5	
66	अभी आपका बच्चा कैसा है? ये अपने स्कूल, खेलकूद, भावनाओं के अभिव्यक्ति के सामर्थ्य है?		
67	इस बच्चे के स्वास्थ्य सम्बन्धी आवश्यकताओं को पूरा करने में आपको क्या क्या तकलीफ होती है?		

68	आप इस बच्चे को इलाज के लिए क्यों नहीं ले जाते हैं?	स्वस्थ केंद्र की उपलब्धता 1 डॉक्टर की उपलब्धता 2 सामर्थ्य 3	
69	क्या आशा आपके घर पर आती है?	हाँ 1 नहीं 2	
70	क्या इस बच्चे का हेल्थ कार्ड राष्ट्रीय बाल स्वस्थ कार्यक्रम के अंतर्गत बना है?	हाँ 1 नहीं 2	
लिवरपूल आउटकम स्कोर: सरल संज्ञानात्मक और व्यवहारिक कार्य, बुनियादी मोटर कौशल और स्वयं देखभाल का आकलन करने के लिए			
71	<u>1. भाषा या वार्तालाप</u> बिमारी से पहले की तुलना में बच्चे की भाषा या वार्तालाप है	पहले के जैसा (5) बदला हुआ या पहले से कम (3) बोलना या वार्तालाप नहीं करना (2)	
72	<u>2. खिलाना</u> बच्चे का खाना खिलाना:	पहले के जैसा (5) कभी कभी मदद की जरूरत होती है (3) हमेशा मदद की जरूरत होती है (2)	
73	<u>3. अकेला छोड़ना</u> क्या बीमारी से पहले इस बच्चे को बिना किसी नुक्सान के अकेला छोड़ा जा सकता था अगर हाँ, क्या इस बच्चे को अभी अकेला छोड़ा जा सकता है?	हाँ (5) हाँ कुछ समय के लिए परिचित वातावरण में (3) नहीं (2)	अगर नहीं स्कोर (5)
74	<u>4. व्यवहार</u> बीमारी से पहले की तुलना में क्या बच्चे की देखभाल करने वाले	नहीं पूरी तरह से सामान्य है (5) जल्दी गुस्सा हो जाता है (4)	

	सोचते हैं की बच्चे का व्यवहार बदल गया है?	अन्य व्यवहार सम्बन्धी समस्याएं (4) गंभीर रूप से असामान्य (2) यदि असामान्य हो तो विवरण दें: _____ _____ _____	
75	<u>5. पहचानना</u> क्या बच्चा बीमारी से पहले अपने मुख्य देखभालकरता के अलावा अपने परिवार के अन्य सदस्यों को पहचान सकता था? अगर हाँ, क्या अभी यह बच्चा अपने मुख्य देखभालकरता के अलावा अपने परिवार के अन्य सदस्यों को पहचान सकता है?	हाँ (5) कुछ (3) किसी को नहीं (2)	अगर नहीं, स्कोर 5 (5)
76	<u>6 स्कूल और काम</u> क्या बीमारी से पहले बच्चा स्कूल में था या काम कर रहा था? अगर हाँ तो क्या देखभाल करने वालो को लगता है की बच्चा वापस से स्कूल जायेगा या काम करेगा?	हाँ (5) नहीं (3)	अगर नहीं, क्या देखभाल करने वालो को लगता है की बच्चा अभी भी घर पर वही काम कर पायेगा, वही दिनचर्या का पालन कर पायेगा या सामान्य रूप से खेल पायेगा? हाँ (5) सक्षम नहीं है (3)
77	<u>7. मिर्गी / दौरे</u> क्या बच्चे को इस बीमारी के दौरान दौरे	कोई दौरा नहीं, मिर्गी रोधी दवाई पर नहीं है (5) कोई दौरा नहीं, मिर्गी रोधी दवाई पर है (4)	अगर नहीं, स्कोर 5 (5)

	<p>परते हैं?</p> <p>अगर हाँ, तो क्या बच्चे को अभी भी दौरे परते हैं?</p>	<p>हाँ, अभी भी दौरे पर रहे हैं (3)</p> <p>हाँ, अधिकांश दिनों में दौरे परते हैं (2)</p>	
78	<p><u>8. कपडे पहनना</u></p> <p>क्या इस उम्र के अन्य बच्चे खुद कपडे पहन सकते हैं?</p> <p>अगर हाँ, तो क्या बच्चा बीमारी के बाद खुद कपडे पहन सकता है?</p>	<p>हाँ, बिमारी से पहले की तरह हि (5)</p> <p>कभी कभी अतिरिक्त सहायता की आवश्यकता होती है (3)</p> <p>पहले से ज्यादा मदद की जरूरत है (2)</p>	अगर नहीं, स्कोर 5 (5)
79	<p><u>9. मूत्राशय और आंत्र नियंत्रण</u></p> <p>मल और मूत्र की निरंतरता है?</p>	<p>बिमारी से पहले की तरह हि (5)</p> <p>कभी कभी अतिरिक्त सहायता की आवश्यकता होती है या कभी कभी असंयम होता है (4)</p> <p>ज्यादा मदद की जरूरत है या हमेशा असंयम होता है (2)</p>	
80	<p><u>10. सुनना</u></p> <p>क्या माता, पिता को लगता है की इस बच्चे की सुनने की क्षमता है:</p>	<p>सामान्य (5)</p> <p>एक या दोनों कानो में कम (4)</p> <p>बिलकुल नहीं सुन सकता (3)</p>	
81	<p>बच्चे की क्षमता का अवलोकन</p>		
82	<p><u>11. बैठना</u></p> <p>क्या बच्चा बीमारी के पहले बैठ सकता था?</p>	<p>हाँ, बिना किसी सहायता के (5)</p> <p>मदद की आवश्यकता होती है (3)</p> <p>बिलकुल नहीं बैठ सकता (2)</p>	If No , score 5 (5)
83	<p><u>12. खड़े होना</u></p> <p>क्या बच्चा बीमारी के पहले बैठने से लेकर खड़े हो सकता था?</p>	<p>हाँ, बिना किसी सहायता के (5)</p> <p>मदद की आवश्यकता होती है (3)</p> <p>बिलकुल नहीं खड़े हो सकता (2)</p>	If No , score 5 (5)

84	<u>13 चलना</u> क्या बच्चा बीमारी से पहले चल सकता था?	सामान्य (5) असामान्य रूप से, लेकिन स्वतंत्र रूप से +/- बैसाखी/ छड़ी (3) बिलकुल चल नहीं सकता (2)	If No , score 5 (5)
85	<u>14. सर पर हाँथ</u> अपने दोनों हाँथ सर पर रखे और बच्चे को नक़ल करने को बोले बच्चा है	बहुत छोटा (5) दोनों हाँथ सामान्य (5) असामान्य एक या दोनों हाँथ (4) एक या दोनों हाँथों में असामर्थ्य (3)	
86	<u>15. उठाना</u> बच्चे को मटर के दाने के आकर के कागज़ या छोटा सिक्का उठाने को कहें बच्चा है	बहुत छोटा (5) सामान्य पकड़ दोनों हाँथों में (5) एक हाँथ से असमर्थ (3) असामान्य एक या दोनों हाँथ (3) दोनों हाँथ असामान्य (2)	
87	क्या आपने किसी थेरेपिस्ट से सलाह ली है?	हाँ 1 नहीं 2	If NO skip Q 88, 89 If yes skip Q90
88	विवरण दे	
89	कितने समय से आप वह इलाज करवा रहे हैं?	महीना साल	
90	किसी भी थेरेपिस्ट से सलाह नहीं लेने का क्या कारन है?		
91	यदि कोई आवश्यकता हुई तो क्या मैं आपसे स्पष्टीकरण के लिए संपर्क कर सकती हूँ?	हाँ 1 नहीं 2	