

Factors associated with delayed health-seeking behaviour and disease severity on admission among patients diagnosed with acute encephalitis syndrome: an observational study from North India

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ABSTRACT

Introduction Acute encephalitis syndrome (AES) poses a significant health challenge to children across India. Late arrival at tertiary care hospitals is a primary contributor to disease severity and poor outcomes. This study identifies the determinants of delayed health seeking and disease severity in AES cases.

Methods We interviewed the parents/guardians/caregivers of 242 patients with AES admitted at a tertiary care centre. Multivariable analyses identified factors for delayed health seeking, defined as >3 days spent at home after symptom onset; and disease severity on admission, defined as need for oxygen support. 131 patients were evaluated for long-term outcomes after 3 years using the Liverpool Outcome Score.

Results 90 (37.2%) patients had delayed health seeking and 202 (83.5%) had severe disease on admission. Lack of awareness about AES was a significant risk factor (OR 2.4, 95% CI 1.2 to 5.0, $p=0.01$) for delayed health seeking. Disease severity was associated with seeking treatment from uncertified medical practitioners (UMPs) (OR 7.3, 95% CI 2.7 to 19.8, $p<0.01$) and ≥ 2 days of time spent between the first healthcare provider and tertiary care admission (OR 3.0, 95% CI 1.3 to 7.3, $p=0.01$). At follow-up, disability was observed in 18.3% ($n=24$) of the patients.

Conclusion Delayed health seeking, treatment from UMPs and multiple healthcare consultations contributed to disease severity in patients with AES on admission at tertiary care health facilities.

INTRODUCTION

Acute encephalitis syndrome (AES) is a neurological condition characterised by inflammation of the brain, resulting in significant mortality and disability. In India, several viral, bacterial and fungal agents have been identified as the aetiologies of AES.^{1 2} In the eastern part of Uttar Pradesh, AES poses a significant public health challenge, with

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Globally, delayed health seeking and referral is a major contributor to death and disability among patients with acute encephalitis syndrome (AES).
- ⇒ Limited data are available on the factors associated with delayed health seeking among patients with AES and their caregivers.

WHAT THIS STUDY ADDS

- ⇒ This study identifies modifiable risk factors for delayed health-seeking behaviour among patients with AES or their caregivers and highlights health system-related factors associated with delayed referral and poor outcome.
- ⇒ Consulting uncertified medical practitioners during the acute phase of an illness is a major risk factor for delayed treatment, resulting in severity, mortality and disability in AES cases.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The findings of this study will guide policy makers in devising effective strategies to improve health-seeking behaviour in AES endemic regions and reduce the dependency on uncertified medical practitioners.

seasonal outbreaks in the monsoon and post-monsoon months, primarily affecting children and leading to high mortality and disability.² Scrub typhus and Japanese encephalitis have been identified as the major aetiologies of AES in eastern Uttar Pradesh.²

The management of AES primarily relies on symptomatic care. To mitigate severe morbidity and mortality, it is crucial to promptly recognise early warning signs and facilitate referral of patients to health-care facilities. Additionally, it is essential to

educate healthcare workers at the grassroots level on the initial steps in managing these conditions. In view of this, the National Center for Vector Borne Diseases Control (NCVBDC) (formerly National Centre for Vector Borne Disease Control Programme (NVBDCP)) developed an AES management guideline in 2007, revising it in 2009.³ Earlier studies have documented that majority of children affected with AES were from rural areas,⁴ belonged to lower socioeconomic status,⁴ often sought care from informal healthcare providers⁵ and experienced delayed referrals to tertiary health facilities.⁶ This delay in treatment initiation has the potential to increase the risk of severe disease and mortality due to disease progression and the development of complications.

Data are limited on the involvement of uncertified medical practitioners (UMPs) in delayed health seeking among patients with AES and its ill effect on clinical severity. UMPs, defined as informal healthcare providers (commonly known as quacks) who have not received formal training, degree and licence to practise medicine, are a threat to regional, national and global healthcare systems.⁷ They are significantly present in developing nations where healthcare infrastructures are limited and inefficient. Economic and social factors are major contributors to the thriving of UMPs within existing health systems.⁸ In India, evidence suggests that UMPs provide more than 70% of all primary healthcare services; however, the quality of healthcare services they provide remains unclear and is dangerous.⁹

To address this knowledge gap, we conducted a study among the parents or guardians or caregivers of patients with AES to understand their health-seeking behaviour. Specifically, we aimed to identify the factors associated with delayed treatment and clinical severity at the time of hospitalisation at a tertiary care facility in eastern Uttar Pradesh.

MATERIALS AND METHODS

Study design and participants

We conducted a cross-sectional study among parents/guardians/caregivers of patients with AES hospitalised in the paediatric (≤18 years of age) and medicine (>18 years of age) wards of Baba Raghav Das (BRD) Medical College, Gorakhpur, Uttar Pradesh, India, the major tertiary care hospital in the region, from January to December 2019. BRD Medical College is the only tertiary care hospital in the region catering to patients from a wider geographical area. We tried to recruit all patients with AES during the study period to avoid non-response bias.

Sample size and sampling

A total of 617 patients with AES were hospitalised from January to December 2019. We were able to recruit 242 (39.2%) patients with AES for the first phase of the study (figure 1), with a non-response rate of 60.8%. Patients with AES of all age groups hospitalised at the BRD Medical College Gorakhpur from January to December 2019 and whose parents/guardians/caregivers provided consent were included in the study.

Data collection

Patients presenting with acute onset of fever and 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) were considered as AES cases, according to the WHO definition.¹⁰ The parents/guardians/caregivers of patients with AES were interviewed at BRD Medical College Gorakhpur at the time of hospital admission.

On arrival of patients with AES at the AES ward, assessment of the airway, breathing and circulation is the essential first step,¹¹ and at the paediatric department of the BRD Medical College the Pediatric Assessment Triangle is employed to determine the child’s clinical status and

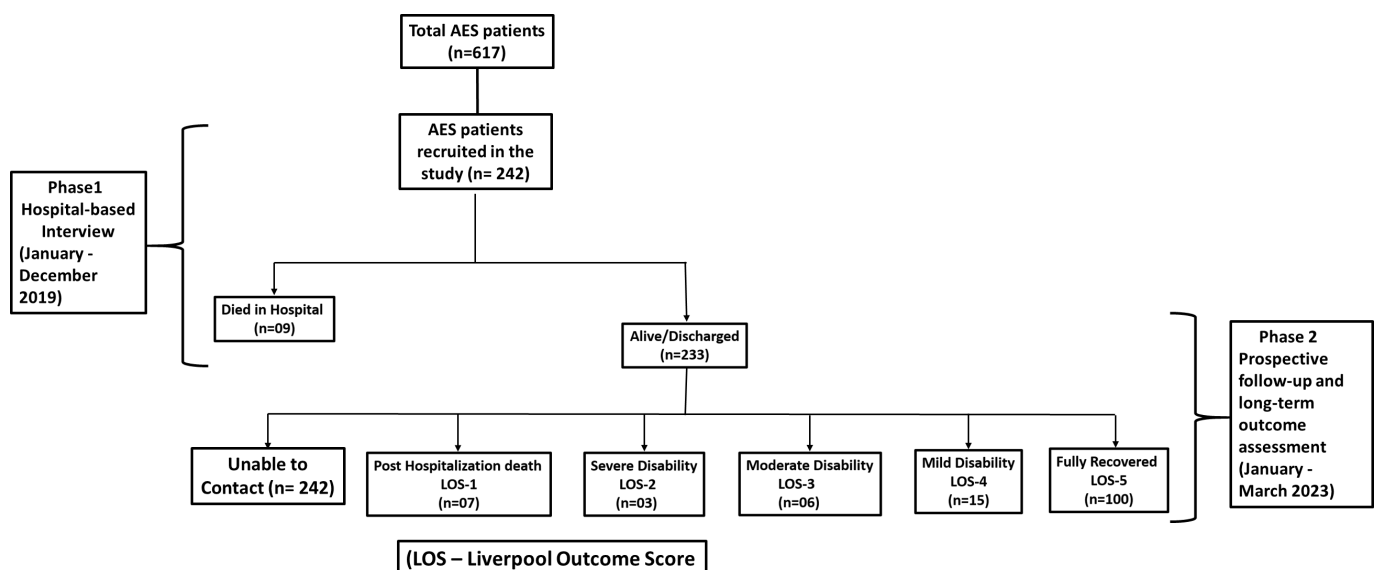


Figure 1 Flow chart of patient screening, recruitment and assessment. AES, acute encephalitis syndrome.

prioritise initial management.¹² Since patients with AES typically arrive unconscious and exhibit signs of shock, immediate oxygen support is often required shortly after admission (according to the Consensus Guidelines on Evaluation and Management of Suspected Acute Viral Encephalitis in Children in India).¹³ Our assessment protocol includes evaluating the level of consciousness using the Glasgow Coma Scale, assessing hydration status and measuring capillary refill time (CRT), with a CRT >3s indicating concern. Hence, in the current study, we used necessity for oxygen support as an indicator of severity of the condition at the time of hospital admission.

We also collected information on the patient's outcomes on discharge from the hospital. After obtaining informed consent from the parents/guardians/caregivers of patients with AES, we conducted an interview using a structured questionnaire to collect data on socio-economic and demographic characteristics, date of onset of febrile illness, treatment sought from different health-care providers, mode of transportation to the tertiary care hospital, time taken to reach the hospital, symptoms on admission and awareness about AES campaigns.

The definition for uncertified rural practitioners or UMPs, locally called quacks, is inconsistent.⁹ However, in this article, we defined UMPs as informal healthcare providers who have not received formal training, degree and licence to practise medicine.

From January to March 2023, we visited patients with AES discharged from the hospital at their homes. We interviewed the parents/guardians/caregivers to collect information about posthospitalisation deaths and disability among the survivors using the Liverpool Outcome Score (LOS).¹⁴ We further categorised the LOS questionnaire, which contains 15 questions, into four domains of disability, that is, cognition (speech/communication, behaviour, hearing, recognition), mobility (sitting, standing up, walking, ability to put hands on head, picking up), self-care (feeding/eating, leaving alone, dressing) and life activities (school and working).¹⁵ We used the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for reporting this study.¹⁶

Statistical analysis

Continuous variables were presented as mean and SD or median with IQR. Categorical variables were presented as numbers with percentages. Bivariate logistic regression analysis was used to explore the association between dichotomous dependent variables and categorical independent variables. We defined delayed health-seeking behaviour as patients who visited a healthcare provider more than 3 days after the onset of their first symptom. Oxygen requirement on admission was the primary indicator of disease severity. We conducted logistic regression analysis to identify factors associated with delayed health seeking as well as disease severity on admission. Variables with a p value of 0.2 in the univariate analysis were included in the backward stepwise multivariable

regression model to compute the adjusted OR (aOR) along with 95% CI. A p value of <0.05 was considered significant. All statistical analyses were performed using STATA V.17 software.

Patient and public involvement

Patients or members of the public were not directly involved in this research study.

RESULTS

Sociodemographic details of patients with AES

We included 242 patients with AES in our study, with a mean (SD) age of 8 (6.7) years and of whom 114 (47.1%) were male. All patients with AES were from rural areas. Parents/guardians/caregivers of most of the patients with AES (142 out of 242, 58.7%) were either illiterate or had studied up to eighth standard, 47.9% (116 out of 242) were labourers and 95.9% (232 out of 242) were below poverty line (income less than 10 000 Indian rupees per month) (table 1).

Health-seeking behaviour of patients with AES

Patients with AES consulted their first healthcare provider after a median of 2.8 (IQR: 1–5) days of onset of illness. Out of the 242 patients, 152 (64%) consulted their first healthcare provider within 3 days, while 90 (37.2%) patients sought care after 3 days or more and thus were considered delayed health seekers. 117 (48.4%) consulted UMPs, while 70 (28.9%) and 55 (22.7%) consulted registered medical practitioners (RMPs) in the public and private health facilities, respectively (table 1). Patients with AES sought care from a median of three healthcare providers (IQR: 2–3) before being referred to a tertiary care hospital in Gorakhpur. We identified four patterns of health seeking and referral to the tertiary care facility. 59 patients who first consulted an RMP (47.5%, n=28, from private-sector RMPs and 52.5%, n=31, from government-sector RMPs) were directly referred to the tertiary care facility, whereas 66 (40.9%, n=27, from private-sector RMPs and 59.1%, n=39, from government-sector RMPs) patients consulted a UMP before reaching the tertiary care hospital. Of 117 patients with AES who first consulted a UMP, 15 (12.8%) were directly referred to the tertiary care facility, whereas 102 (87.2%) consulted an RMP (39.2%, n=40, in the public sector; 60.8%, n=62, in the private sector) before admission to the tertiary care hospital (figure 2). The median treatment duration with UMPs, private-sector RMPs, and government-sector RMPs was 1 day (IQR: 0–2), 1 day (IQR: 0–3) and 0 day (IQR: 0–1), respectively. Patients with AES spent a median of 2 (IQR: 1–2.5) hours on transportation to reach the tertiary care hospital.

Clinical details of patients with AES on admission

Patients with AES presented with fever (100%), history of seizures (88%) and altered sensorium (64.5%). Other symptoms included vomiting (76.9%), headache (36.6%) and abdominal pain (27.7%) (table 1). A total of 144

Table 1 Characteristics of patients and presentation of the findings (N=242)

| Characteristics | n (%) or mean±SD |
|---|------------------|
| Gender | |
| Male | 114 (47.1) |
| Female | 128 (52.9) |
| Residence | |
| Rural | 242 (100) |
| Urban | Nil |
| First contact of patient with a healthcare provider | |
| UMP | 117 (48.3) |
| RMP | 125 (51.7) |
| RMP | |
| RMP, private hospitals | 55 (44.0) |
| RMP, government health facility (district hospital/CHC/PHC/Encephalitis Treatment Centre (ETC)) | 70 (56.0) |
| Symptoms at the time of admission to tertiary care hospital | |
| Fever | 242 (100.0) |
| Seizures | 213 (88.0) |
| Vomiting | 186 (76.9) |
| Altered sensorium | 156 (64.5) |
| Headache | 87 (36.0) |
| Abdominal pain | 67 (27.7) |
| Patients with seizures and altered sensorium before the referral | 144 (59.5) |
| Patients with seizures and altered sensorium before referral from: | |
| UMP | 82 (56.9) |
| Private hospitals | 25 (17.4) |
| Government peripheral health facility (CHC/PHC/ETC) | 37 (25.7) |
| Patient arrived with an intravenous drip at the time of admission to BRD Medical College | |
| Yes | 136 (56.2) |
| No | 106 (43.8) |
| Awareness about disease (AES/JE campaign) | |
| Yes | 49 (20.2) |
| No | 193 (79.8) |
| Patient sought help from ASHA | |
| No | 207 (85.5) |
| Yes | 35 (14.5) |
| ASHA | |
| Provided medicine | 15 (42.9) |
| Referred to hospital | 16 (45.7) |
| Both | 4 (11.4) |
| Mode of patient transportation to tertiary care hospital | |
| Ambulance 108 | 96 (39.7) |
| Self/private | 146 (60.3) |

Continued

Table 1 Continued

| Characteristics | n (%) or mean±SD |
|--|------------------|
| Time taken (hours) to reach tertiary care hospital | |
| ≤1 | 79 (32.6) |
| 1.1–3.5 | 148 (61.2) |
| >3.5 | 15 (6.2) |
| Average time spent (days) at different referral points | |
| Self-treatment/home treatment | 3.7±3.8 |
| UMP | 1.8±2.8 |
| Private facilities | 1.7±2.2 |
| Peripheral health facilities (CHC/PHC/ETC) | 1.0±1.6 |
| Socioeconomic status | |
| Education of parents/guardians | |
| Graduate | 20 (8.3) |
| Senior secondary | 21 (8.7) |
| Secondary | 59 (24.4) |
| Upper primary | 47 (19.4) |
| Primary | 31 (12.8) |
| Illiterate | 64 (26.5) |
| Occupation of parents/guardians | |
| Private/government job | 34 (14.1) |
| Self-employed | 40 (16.5) |
| Farmer | 31 (12.8) |
| Labour | 116 (47.9) |
| Unemployed | 21 (8.7) |
| Monthly income of the family (Indian rupees) | |
| >10 000 (APL) | 10 (4.1) |
| ≤10 000 (BPL) | 232 (95.9) |

AES, acute encephalitis syndrome; APL, above the poverty line; ASHA, accredited social health activist; BPL, below the poverty line; BRD, Baba Raghav Das; CHC, community health centre; JE, Japanese encephalitis; PHC, primary health centre; RMP, registered medical practitioner; UMP, uncertified medical practitioner.

(59.5%) patients had seizures and altered sensorium before referral. Of these, 82 (56.9%) were referred from UMPs and 62 (43.1%) from RMPs. We did not find any statistical significance (p=0.09) between patients referred by a UMP and an RMP. 202 (83.4%) patients required oxygen on admission and were classified as having severe illness. Of 242 patients with AES, 9 died, with a case fatality of 3.7% (figure 1).

Factors associated with delayed health seeking

In the multivariable logistic regression analysis, patients with AES whose parents were unemployed (aOR=2.5, 95% CI 1 to 6.2) and who were not aware of Dastak Abhiyan, a mission mode project of the Government of Uttar Pradesh to increase awareness about AES (aOR=2.4,

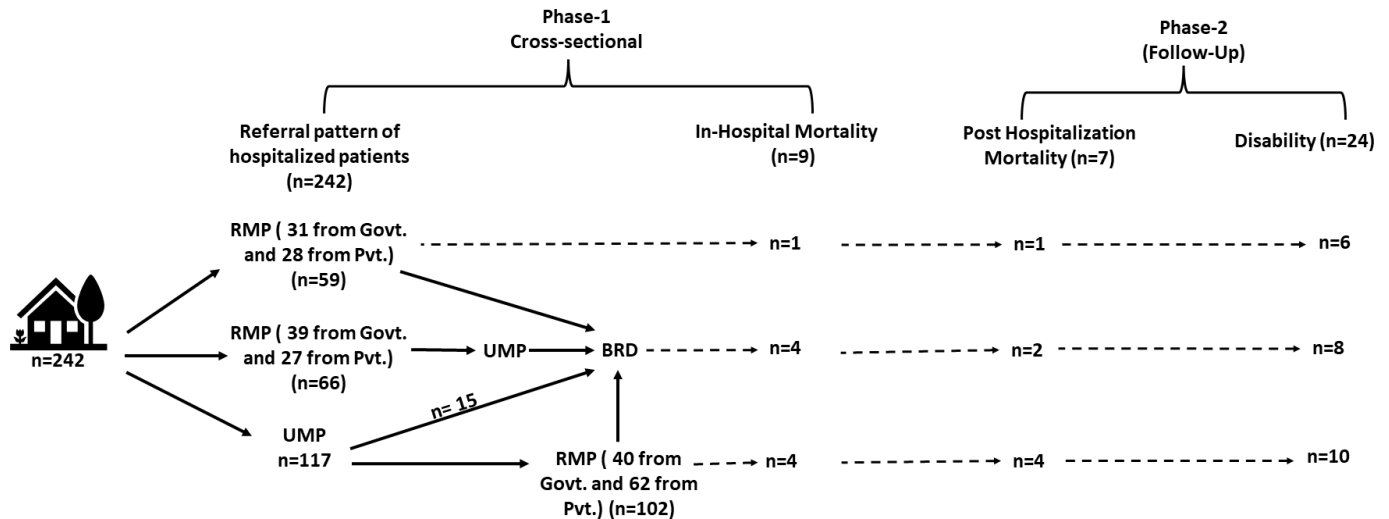


Figure 2 Patients' referral pattern, in-hospital outcomes and outcomes at follow-up. BRD, Baba Raghav Das; Govt, government; Pvt, private; RMP, registered medical practitioner; UMP, uncertified medical practitioner.

95% CI 1.2 to 5.0), were more likely to consult the health-care provider after 3 days or more (table 2).

Factors associated with disease severity on admission

Patients with AES whose initial healthcare contact was with a UMP (aOR=7.3, 95% CI 2.7 to 19.8) and those who consulted three or more healthcare providers before

reaching the tertiary care facility exhibited a higher likelihood of presenting with severe illness on admission. Patients with severe illness spent 2 days or more from their first contact with a healthcare provider to their admission to tertiary care (aOR=3.0, 95% CI 1.3 to 7.3) (table 3).

Table 2 Factors associated with delayed health-seeking behaviour

| Factors | Days spent at home after onset of symptom (N=242) | | Bivariate analysis | | Multivariable analysis | |
|--|---|----------------|--------------------|-------------|------------------------|-------------|
| | ≤3 days (n=152) | >3 days (n=90) | OR (95% CI) | P value | Adjusted OR (95% CI) | P value |
| Patient's gender | | | | | | |
| Male | 75 (49.3) | 39 (43.3) | 1.0 (ref) | – | – | – |
| Female | 77 (50.7) | 51 (56.7) | 1.3 (0.8 to 2.2) | 0.37 | – | – |
| Parent's education | | | | | | |
| Graduate | 12 (7.9) | 8 (8.9) | 1.0 (ref) | – | – | – |
| Secondary/senior secondary | 49 (25.2) | 31 (34.5) | 0.9 (0.3 to 2.6) | 0.92 | – | – |
| Primary/upper primary | 52 (34.2) | 26 (28.9) | 0.8 (0.3 to 2.1) | 0.58 | – | – |
| Illiterate | 39 (25.7) | 25 (27.8) | 0.9 (0.3 to 2.7) | 0.94 | – | – |
| Parent's occupation | | | | | | |
| Private/government job | 22 (14.5) | 12 (13.3) | 1.0 (ref) | – | 1.0 (ref) | – |
| Self-employed | 25 (16.4) | 15 (16.7) | 1.1 (0.4 to 2.8) | 0.84 | – | – |
| Farmer/labour | 96 (63.2) | 51 (56.7) | 0.9 (0.4 to 2.1) | 0.95 | – | – |
| Unemployed | 9 (5.9) | 12 (13.3) | 2.4 (0.8 to 7.4) | 0.12 | 2.5 (0.9 to 6.2) | 0.05 |
| Family monthly income (Indian rupees)* | | | | | | |
| >10 000 (APL) | 8 (5.3) | 2 (2.2) | 1.0 (ref) | – | – | – |
| ≤10 000 (BPL) | 144 (94.7) | 88 (97.8) | 2.4 (0.5 to 11.8) | 0.27 | – | – |
| Awareness about JE/AES | | | | | | |
| Yes | 38 (25.0) | 11 (12.2) | 1.0 (ref) | – | 1.0 (ref) | – |
| No | 114 (75.0) | 79 (87.8) | 2.4 (1.2 to 5.0) | 0.02 | 2.4 (1.2 to 5.0) | 0.01 |

Values in **bold** indicate statistical significance with a p-value less than 0.05.

*Family was categorised as APL and BPL if their monthly income was >10000 and ≤10000 Indian rupees, respectively.

AES, acute encephalitis syndrome; APL, above the poverty line; BPL, below the poverty line; JE, Japanese encephalitis; ref, reference.

Table 3 Factors associated with disease severity (oxygen requirement) on admission to tertiary care hospital

| Factors | Oxygen requirement | | Bivariate analysis | | Multivariable analysis | |
|---|--------------------|-----------|--------------------|-----------------|------------------------|-----------------|
| | Yes (n=202) | No (n=40) | OR (95% CI) | P value | Adjusted OR (95% CI) | P value |
| Home treatment (days)* | | | | | | |
| ≤3 | 129 (63.9) | 23 (57.5) | 1.0 (ref) | – | – | – |
| >3 | 73 (36.1) | 17 (42.5) | 0.8 (0.4 to 1.5) | 0.44 | – | – |
| First contact with HCP | | | | | | |
| RMP (government and private) | 90 (44.6) | 35 (87.5) | 1.0 (ref) | – | 1.0 (ref) | – |
| UMP | 112 (55.4) | 5 (12.5) | 8.7 (3.3 to 23.1) | <0.01 | 7.3 (2.7 to 19.8) | <0.01 |
| Total time spent (days) between first HCP and tertiary care hospital† | | | | | | |
| <2 | 21 (10.4) | 12 (30.0) | 1.0 (ref) | – | 1.0 (ref) | – |
| ≥2 | 181 (89.6) | 28 (70.0) | 3.7 (1.6 to 8.3) | <0.01 | 3.0 (1.3 to 7.3) | 0.01 |
| Number of referrals before reaching tertiary care hospital* | | | | | | |
| <3 | 66 (32.7) | 20 (50.0) | 1.0 (ref) | – | – | – |
| ≥3 | 136 (67.3) | 20 (50.0) | 2.1 (1.0 to 4.1) | 0.03 | – | – |
| Helped by ASHA | | | | | | |
| Yes | 23 (11.4) | 12 (30.0) | 1.0 (ref) | – | 1.0 (ref) | – |
| No | 179 (88.6) | 28 (70.0) | 3.3 (1.5 to 7.4) | <0.01 | 1.9 (0.8 to 4.5) | 0.14 |
| Time spent (hours) on patient's transportation* | | | | | | |
| ≤2 | 139 (68.8) | 27 (67.5) | 1.0 (ref) | – | – | – |
| >2 | 63 (31.2) | 13 (32.5) | 0.9 (0.5 to 1.9) | 0.87 | – | – |

Values in **bold** indicate statistical significance with a p-value less than 0.05.

*Median was taken as the cut-off.

†Median of time spent between first HCP and tertiary care hospital was taken.

ASHA, accredited social health activist; HCP, healthcare provider; RMP, registered medical practitioner; UMP, uncertified medical practitioner.

Follow-up of patients with AES after discharge

We were able to contact 131 (56.2%) of 233 patients with AES after a median interval of 42 (IQR 40.8–43.6) months from their discharge from the tertiary care hospital. The remaining 102 (43.8%) patients could not be traced because either their contact numbers were wrong, their phones were switched off or their addresses could not be ascertained. Among the 131 patients evaluated, 100 (76.3%) experienced full recovery, while 31 (23.7%) had unfavourable outcomes with varying severity (online supplemental table 1), including seven posthospitalisation deaths and four patients with severe disability (figure 1). Patients with AES had a disability in different domains, including cognition and behaviour (n=24, 18.3%), life activities (n=11, 8.4%), self-care (n=5, 3.8%) and mobility (n=3, 2.3%) (online supplemental table 2).

DISCUSSION

In eastern Uttar Pradesh, about one-third of patients with AES sought healthcare late, with half of them initially consulting UMPs. On average, these patients consulted three healthcare providers before being admitted to the tertiary care health facility. Most patients with AES were admitted with severe illness, requiring oxygen support. Notably, patients with unemployed parents who lacked awareness of AES were more

likely to delay seeking care. Meanwhile, initial healthcare contact with UMPs and multiple consultations with healthcare providers were associated with presentation with severe illness on admission.

Orientia tsutsugamushi, the causative agent of scrub typhus, is a major contributor to AES in eastern Uttar Pradesh. During the monsoon and post-monsoon months, scrub typhus infections are prevalent among children due to the abundance of infected chigger mites in the environment, as indicated by a high chigger index,¹⁷ and behavioural factors that increase mite exposure.¹⁸ Timely and appropriate treatment with doxycycline or azithromycin is crucial to prevent the infection from progressing to organ involvement. The Government of Uttar Pradesh has launched the Dastak Campaign to raise awareness about AES in the region, emphasising the importance of receiving two doses of the Japanese encephalitis vaccine and seeking prompt treatment for communicable diseases, including common febrile illnesses.² Although the number of AES cases and related mortality have substantially decreased in the last 4–5 years,² our study underscores the continued need for disease awareness, particularly among unemployed and less educated or uneducated population, and to encourage them to seek healthcare from public health facilities.

In rural areas of eastern Uttar Pradesh, many parents of patients with AES initially opted for UMPs as their preferred treatment provider. This preference is often due to the easy availability, accessibility and affordability of UMPs. Previous studies^{4 9 19} have underscored the substantial issue of inadequate health infrastructure particularly affecting healthcare accessibility in AES endemic regions, especially in rural areas. Our study revealed that patients with AES frequently sought care from multiple healthcare providers, resulting in delayed presentation at tertiary care hospitals. These factors were significantly associated with disease severity at the time of admission. This finding aligns with a previous study⁶ that identified multiple and delayed referrals as significant contributors to adverse outcomes in patients with AES.

UMPs are not certified, trained or licensed to provide any healthcare services to people. However, they are an indispensable part of the Indian healthcare system and cater to the health needs of disproportionate number of populations, especially those residing in rural areas.⁹ RMPs are trained physicians who ensure quality healthcare services to the general masses and follow the recommended AES management guidelines of the Government of India, providing appropriate treatment and referral to tertiary care accordingly.³ While RMPs work in collaboration with secondary and tertiary care, UMPs do not collaborate with any public health system and work as a single entity.

Our study also underscores the substantial burden of post-AES disability. Follow-up of patients with AES after discharge revealed that around one-third exhibited long-term sequelae, with the most significant impairments involving cognitive and behavioural issues and limitations in life activities. This is consistent with other studies conducted in this area.^{15 20-23}

This study has certain limitations. First, we could not interview the parents/guardians/caregivers of all patients with AES during the study period due to non-response and could follow up limited number of patients with AES. Thus, we could not establish a statistically significant association between all factors and delayed health-seeking behaviours and poor outcomes. Second, follow-up with all patients with AES could have given us a better understanding of recovery, death and sequelae associated with the disease. Future studies with a large sample size are needed to provide a sound statistical association between independent and dependent factors. The study, however, is the first to provide details on the various factors responsible for delayed health-seeking behaviour and disease severity among patients with AES in this region. This study was done to determine the factors associated with delayed health-seeking behaviour and disease severity on admission among patients with AES in North India. Hence, the findings of this study may not be generalised to other diseases in the region. In addition, it is possible that some critically ill patients may have died or may have been abandoned before reaching the BRD Medical College for treatment.

In light of the delayed health seeking and the observed preference for UMPs along with multiple referrals among parents/guardians/caregivers of patients with AES in the rural areas of eastern Uttar Pradesh, it is necessary to create awareness through AES campaigns, especially among poor and vulnerable populations. Efforts should be directed towards improving the availability and accessibility of certified healthcare providers in these regions. To mitigate delays in reaching tertiary care hospitals and subsequently reducing disease severity, interventions should focus on streamlining the referral processes and enhancing healthcare infrastructure. Collaboration among healthcare providers, awareness campaigns and capacity-building initiatives can contribute to better healthcare outcomes for patients with AES.

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