

Original Research Article

Barriers and facilitators to seeking care for persons with acute brain infections: a cross sectional study

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ABSTRACT

Background: Acute brain infections including encephalitis are less common but serious conditions characterized by the inflammation of the brain requiring immediate accurate diagnosis and management. For many infections appropriate therapies exist, but the outcome is often less desirable because of failure to receive appropriate treatment on time due to multiple factors. The aim of the study was to understand the barriers and facilitators towards receiving care for persons with acute brain infections in a low resource setting.

Methods: The study design was cross sectional exploratory study. Consecutive patients presenting to neurology department of a tertiary referral care center for Neuropsychiatry in South India from July 2020 to September 2020 with the diagnosis of acute brain infections were assessed using the modified Kuppaswamy scale, Glasgow coma scale, the pathway scale: encounter form, patient centered health services in India and client socio-demographic and service receipt inventory.

Results: A total of 110 participants, both male and female, were recruited for the study. The average age was 39.64±16.5 years, with more female (65.45%) representation. 29% of individuals reported continued use of traditional practices while seeking care for the brain infections. Costs associated with care increased with the increase in duration of infection. There are major barriers and facilitators which either prohibit or facilitate care for persons with acute brain infections.

Conclusions: Acute brain infections continuing to be a public health challenge in developing country context, and the recognition that the delay in treatment causes significant disability, it becomes imperative to focus on the social, cultural, economic, environmental factors to understand the barriers and facilitators to health seeking among this population.

Keywords: Acute brain infections, Encephalitis, Meningitis, Psychosocial research, Barriers and facilitators, Social determinants of health

INTRODUCTION

Acute neurological infections, such as meningitis and encephalitis, are a major cause of death and disability

globally and have a disproportionately large impact in many countries. Encephalitis is a less common but serious condition characterized by the inflammation of the brain requiring immediate, accurate diagnosis and care, and

significantly contributes to the global burden of disease {5.3% (3.7-8.9)}.^{1,2}

For many infections appropriate therapies exist, but outcome is often poor because of failure to receive appropriate treatment due to multiple factors.³ In the industrialized countries, acute encephalitis syndrome (AES) cases were reported to have a minimum incidence of 10.5 per 100,000 among children and 2.2 per 100,000 for adults.⁴ Japanese encephalitis (JE) is the major cause of AES, which many countries, including India, have been battling with since 1955, with 3,595 cases reported in 2021.⁵⁻⁷ With a global burden of 30% and a morbidity rate of 0.3 to 1.5 in 1,00,000, in India, more number of cases are found majorly in northern India.⁸⁻¹⁰ Thirty percent of the individuals with brain infections never receive a diagnosis with close to a third dying due to the illness leaving behind economic burden on the caregivers from the often protracted, expensive and extensive investigations.⁸ Intensive care units have nearly half of the patients with inflammatory conditions going undiagnosed causing humongous levels of economic, emotional and national burden thereby affecting the quality of life of the individuals living with the condition and increasing the disability adjusted life years at large.¹¹ Social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels.¹² An interference with these can trigger various stress pathways thereby affecting health seeking behaviour. This can also affect the outcomes by influencing affordability and availability of medications for continued treatment.¹³

Developing an understanding of health determinants which could include both social and cultural factors and could interact with the person's life and shape their health behaviours in the context of illness is an acknowledged factor but little explored in the context of Brain infections. Inclusion of the components of the 'one health' by exploring the factors informed by biopsychosocial model shall help in the long run to successfully implement healthcare interventions, especially from a public health and policy planning perspective.¹⁴

The present study is an exploration of these factors with the aim of providing the context for developing interventions for acute brain infections.

METHODS

A cross sectional, exploratory study was conducted to explore the costs, barriers and facilitators towards receiving care for persons with acute brain infections. The objectives were to profile the patients with acute brain infections and their families, to understand the care-pathways and pathways leading to their treatment, to assess the costs associated with the acute brain infections and to explore the barriers and facilitators to seeking care for persons with acute brain infections. Consecutive patients

with the diagnosis of acute (defined as duration within 4 weeks) brain infections presenting to Neurology services in a national tertiary referral care centre for Neuro psychiatry in South India from July-September 2020 were recruited for the study. Standardised scales and the content analysis on the open-ended questions were employed. Of the total of 110 participants, majority (N=98) were recruited from the Neurology casualty- emergency services.

Measures

All participants were assessed on clinical profile, with the help of Glasgow coma scale which is a neurological scale which gives a score on the level of consciousness, calculated between 3 to 15 based on eye, verbal and motor movements.¹¹ A semi-structured interview schedule with close and open-ended questions were used to explore the participant's experiences of health seeking. The modified Kuppaswamy scale commonly used to measure socio-economic status in urban and rural areas consisting of a composite score which includes the education and occupation of the family head along with the income per month of the family, yielding a score of 3-29 was used to understand the Socio economic status.¹⁵

The pathways of care were defined as the path that a patient and/or caregiver travels during his/her/their referral process to a health care professional and was assessed using the pathway scale: encounter form, 1987.¹⁶

The care pathways were defined as the understanding of the clients' perception of the treating hospital and the treating team for the mutual decision-making and organisation of care for a well-defined period in the tertiary care hospital and were assessed using Patient centred health services in India scale along with the client sociodemographic and service receipt inventory.^{17,18}

Ethics approval for the study was taken from the Institute review board in the month of April 2020. The participants were recruited while they were receiving treatment either in the emergency or the inpatient settings. They were informed about the study and consent to participate was taken in person. The caregivers (the participants) were interviewed over telephone or face to face, with 1-2 sessions per participant's availability at their convenience.

RESULTS

Socio-demographic details

The mean age of the participants was 39.6±16.5 years with a gender representation of 1:2, with more females (72; 65%). A significant proportion of the participants were illiterate or were not formally educated (41; 37%), with 35.5% (39) being daily wage labourers and 30.9% (34) homemakers. 62.7% (69) of the participants were married and the majority with 69.1% (76) following Hinduism.

Clinical characteristics

The clinical diagnosis was encephalitis as the majority (29; 26.4%), meningoencephalitis (27; 24.5%) while an equal number of participants (14; 12.7%) had the diagnosis of bacterial meningitis and encephalomyelitis (Figure 1). Most common presenting symptoms reported were headache, seizures, and fever. On Glasgow coma scale, majority were found to be having mild level of altered consciousness (84; 76.3%), though a minority (2; 1.2%) were severely affected.

Help seeking

The majority (78; 70.9%) sought allopathic treatment, a process often involving a tortuous route (figure 2) of the individual travelled from home, had the first referral at a primary health centre (PHC; the first level of public health facility in India), second referral at the district level or community level hospital and then had been referred to the referral care centre.

A significant minority (32; 29.1%) of the participants went from home to traditional healing methods from where they have been referred to a general practitioner. Despite being given treatment from the general practitioner, they have gone to a priest in the church or temples who has referred them back to the general practitioner who then referred them for neurological care. In terms of care pathways, majority (65; 59.1%) stated that the care provided was good.

Cost and welfare assistance for treatment

Majority of the participants in the current study (69; 62.8%), belonged to the LSES (lower socio-economic status) on the Modified Kuppuswamy scale while 6.4% belong to the HSES (higher socio-economic status). The individuals reported a range of 2 to 20 days' of history of symptoms before reaching care. While seeking care, they have met several people (e.g.: local pharmacists) who have facilitated the care in the primary and secondary care

centers, for which 20,000 to 2 lakh INR was spent. In their period of admission, several available welfare schemes, namely below poverty line, Arogya Karnataka, Ayushman Bharath scheme, Rastriya Arogya Nidhi and Sarojini Damodar Fund were availed. Duration of illness and cost involved were found to have significant positive correlation ($\rho = 0.463$, $p < 0.001$). The costs involved in treatment increased with the longer duration of illness ($\rho = 0.463$, $p < 0.001$). The duration of illness significantly differed between rural and urban participants with the participants from rural areas having significantly higher duration of illness (Mann Whitney $U = 834$; $p = 0.006$). The GCS score differed significantly across the different types of illnesses (Chi-square score = 22.278 ($p < 0.001$)). Severity of illness (as assessed through GCS score) differed significantly between the different types of infections, with the meningoencephalitis having more severe illness.

Barriers and facilitators to treatment

In order to explore the barriers and facilitators, two open ended questions were asked in the interview focusing on barriers and facilitators and the results were then content analysed.

Major barriers while seeking care for brain infections included poor awareness and understanding, fear of stigma, magico-religious practices, inadequate support, non-availability of care personnel, misinformation, affordability of care, accessibility and accessibility to the care and lack of adequate policy planning have been stated.

Major facilitators while seeking care for brain infections: doctor shopping, accessibility to a primary or secondary level care centre, limited to adequate awareness and understanding, availability of a general physician, availability of para-medical members, acknowledging the disability and damage caused, reduced confusion and distress in the caregiver, understanding of the medical model by the priests of different faiths or a desperate need for an answer.

Table 1: Duration of illness and cost involved at $p < 0.001$.

Cost involved	Cost involved	Duration of illness	GCS score	Age (years)
	1			
Duration of illness	0.463	1		
GCS score	0.886	0.261	1	
Age (years)	0.183*	0.870	0.054	1

Note: *- $p < 0.001$.

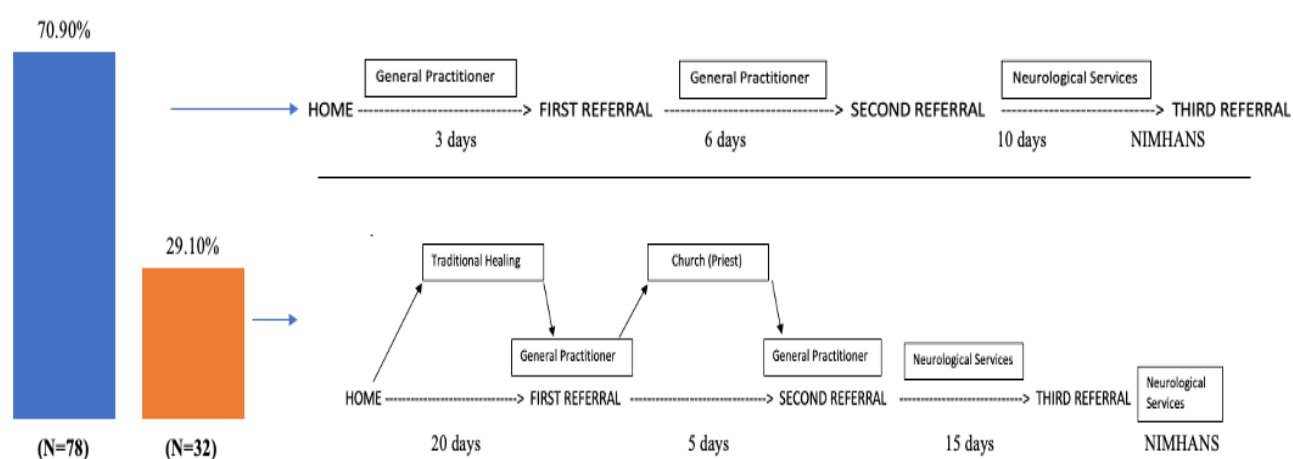
Table 2: Duration of illness and domicile.

Variables	N	Rank average	Rank total	U	Z value	P value
Rural	32	68.44	2190.00	834.000	0.834	0.006
Urban	78	50.19	3915.00			
Total	110					

Table 3: Severity of illness and Glasgow coma scale score in the cohort.

Type of infection	N	Mean rank	Chi square	P value
Encephalitis	29	58.84	22.278	<0.001
Autoimmune encephalitis	3	6.33		
Bacterial meningitis	14	55.14		
Encephalomyelitis	13	39.42		
TBM	24	48.96		
Meningo-encephalitis	27	71.11		
Total	110			

■ Medical Model ■ Traditional model

**Figure 2: Pathways of care.**

DISCUSSION

The present study is a novel attempt, which has tried to explore the social factors affecting the treatment seeking behaviour of Persons with Acute Brain Infections and their family members in a low resource setting. The social determinants of health are commonly understood as the milieu in which humans are born, live, work, reproduce, worship, and age that profoundly affect physical and mental health indicators and overall quality of life.¹⁹ The WHO considers health care one of the five pillars of the social determinants of health.²⁰ They have been studied across many psychiatric conditions and general health conditions but have not been explored into the area of brain infections.

There are more females than males in participant group, which is contrary to the existing literature stating the sex distribution of patients seeking care that shows a male preponderance.²¹ 29.10% of individuals continued to use the traditional practices while caring for the Brain Infections. This is in congruence with the study done by Desmond et al in 2013, which estimated that 37% of illness

episodes are managed at home without external advice and an additional 16% seek help from traditional healers.²²

Indian healthcare scenario presents a contrasting landscape throughout. The care system is often fragmented with differential access across the socioeconomic strata. Thereby 5 'A' considered as challenges to healthcare which are: awareness which states as to how aware is population about health conditions, accessibility which deals with the connectedness of healthcare to civilians, absence of trained professionals in the healthcare setting, affordability of care at the local and national levels and accountability for the management of care.⁵ Health care seeking behaviour is the set of actions taken by an individual to a health problem or a set of problems to rectify ill-health. These are influenced by factors in the environment, interpersonal relationships and intrapersonal relationships.²³ Rural-urban divide in terms of health care seeking behavior has been linked to internal and external factors which range from socio-demographic to type of symptoms.^{24,25} The rural urban divide in delay in seeking care has been found in the study as well to have caused a significant difference in their response and attitude towards

adherence towards the management of care. It was understood that these practices have been linked to type of symptoms that were noticed by the family members or relatives in the affected person, their understanding and attitudes towards ill-health or as basic as the unavailability of a qualified health care personnel at the primary and/or secondary institutes, difficulty in affording the care or the difficulty in making the choice to go and earn the daily wage for the day or to seek treatment.

There are different barriers to seeking care that emerged from the current study and existing literature emphasising infections as one of the emerging debilitating diseases with severe morbidity and mortality as well as difficulty in treating the patients involved, these need special attention. It is the leading cause of neurodevelopmental delay.²⁶ Facilitators have also been reported which has helped in bringing individuals to seek care early resulting in better prognosis and management in the presence of a paramedical professionals. In the tertiary care center where the study is conducted, apart from the medical management, interventions focused on psychosocial care, wherein psychoeducation, supportive work focused on knowledge, attitudes and practices, drug adherence and follow up were focused. The literature too states that the need for establishment of a multidisciplinary approach for the evaluation and management.²⁷

Uni-disciplinary disease control strategies may have limited in efficacy when planned without due recognition of underlying social determinants of health. Studies from middleeast countries have demonstrated better outcomes in the treatment of tuberculosis with the use of vaccines when delivered in tandem with a focus on the housing and social conditions.²⁸ The recent COVID-19 pandemic and subsequent management strategies are another example of the need for a multicomponent approach in prevention and care.

Implications of the study

The barriers and facilitators in seeking care range from awareness, availability, accessibility, and affordability of care across different levels which either increases or decreases the delay, disability, and the residual damage of the acute brain infections. While it is understood that social factors have a role to play in help seeking behaviour, the findings from the study helps to empirically support this understanding.

In terms of strengths, this is a novel study. A study of this kind is important for clinicians to design their interventions for the person with brain infections and their families. While public health professionals could use this understanding for understanding the epidemiological details for the conditions which could together inform the policy planning and reforms for the prevention of brain infections and promotion of better health seeking behavior for the condition.

In terms of limitations, this study done in a tertiary health care center shows results from a hospital with an established equipment for diagnosis and management in place. The findings may not be representative of the community level practices in ABI health seeking. Hence there is a need to explore the patient journey's and their pathways of care in at different public healthcare systems, or in a private setting where the larger population seeks care. Also, it's important to note that the current study has not covered the treatment outcomes and follow-up schedules of the persons who sought care.

CONCLUSION

Health is stated as one of the major pillars of care in terms of social determinants by the WHO with areas focusing economic stability, education, social context, and the built environment as equally important factors for a well-functioning personal and public health profile. The studies primarily explore the prevalence, functional and socioeconomic impact of the Brain Infections. Whereas, the barriers and facilitators in seeking care are less evident in literature. These factors range from awareness, availability, accessibility and affordability of care across levels which either increases or decreases the delay, disability and the residual damage of the acute brain infections.

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REFERENCES

1. NHP. Acute encephalitis syndrome, 2014. Available at: <https://www.nhp.gov.in/disease/commune/acute-encephalitis-syndrome>. Accessed on 06 March 2023.
2. Tan K, Patel S, Gandhi N, Chow F, Rumbaugh J, Nath A. Burden of neuroinfectious diseases on the neurology service in a tertiary care center. *Neurology*. 2008;71(15):1160-6.
3. GBD 2016 DALYs and HALE Collaborators. Global, regional, and national disability-adjusted life-years (DALYs) for 333 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet*. 2017;390(10100):1260-344.
4. Jmor F, Emsley HC, Fischer M, Solomon T, Lewthwaite P. The incidence of acute encephalitis syndrome in Western industrialised and tropical countries. *Virol J*. 2008;5:134.
5. Kasthuri A. Challenges to Healthcare in India - The Five A's. *Indian J Community Med*. 2018;43(3):141-3.
6. Kumar P, Pisudde PM, Sarthi PP, Sharma MP, Keshri VR. Status and trend of acute encephalitis syndrome and Japanese encephalitis in Bihar, India. *Natl Med J India*. 2017;30(6):317-20.

7. Nath HK. Japanese Encephalitis, Acute Encephalitis Syndrome hit Assam, 120 deaths recorded this year, 2021. Available at: <https://www.indiatoday.in/india/story/japanese-120-deaths-recorded-this-year>. Accessed on 06 March 2023.
8. WHO. Global health risks, 2018. Available at: https://www.who.int/healthinfo/global_burden_disease/GlobalHealthRisks_report_full. Accessed on 06 March 2023.
9. Ravi V, Mani R, Govekar SR, Desai A, Lakshman L. Aetiology and Laboratory Diagnosis of Acute Encephalitis Syndrome with Special Reference to India. *J Commun Dis*. 2014;(46):12-23.
10. Jayaraman Y, Veeraraghavan B, Chethrapilly Purushothaman GK, Sukumar B, Kangusamy B, Nair Kapoor A, et al. Burden of bacterial meningitis in India: Preliminary data from a hospital based sentinel surveillance network. *PLoS One*. 2018;13(5):e0197198.
11. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. *Lancet*. 1974;2(7872):81-4.
12. Bahrami MA, Atashbahar O, Asqari R, Fallahzadeh H. An examination of treatment seeking behavior affecting factors: A qualitative study in Iran. *World Appl Sci J*. 2013.
13. Marmot M, Bell R. Social determinants and non-communicable diseases: time for integrated action. *BMJ*. 2019;364:l251.
14. WHO. One Health, 2014. Available at: <https://www.who.int/newsroom/questionsandanswers/item/one-health>. Accessed on 06 March 2023.
15. Saleem SM. Modified Kuppusswamy socioeconomic scale updated for the year 2019. *Indian J Forensic Community Med*. 2019;6(1):1-3.
16. WHO. The Pathway Study: Encounter Form, 1987. Available at: http://apps.who.int/iris/bitstream/handle/10665/61855/MNH_NAT_87.1.pdf;jsessionid=832429E94744A585B41082722D536705?sequence=1. Accessed on 06 March 2023.
17. Rao KD, Peters DH, Bandeen-Roche K. Towards patient-centered health services in India--a scale to measure patient perceptions of quality. *Int J Qual Health Care*. 2006;18(6):414-21.
18. Chisholm D, Knapp MR, Knudsen HC, Amaddeo F, Gaite L, Wijngaarden B. Client Socio-Demographic and Service Receipt Inventory--European Version: development of an instrument for international research. EPSILON Study 5. *European Psychiatric Services: Inputs Linked to Outcome Domains and Needs*. *Br J Psychiatry Suppl*. 2000;(39):28-33.
19. Morano JP, Holt DA. The social determinants of health contextualized for the Zika virus. *Int J Infect Dis*. 2017;65:142-3.
20. WHO. Closing the gap in a generation: health equity through action on the social determinants of health - Final report of the commission on social determinants of health, 2008. Available at: <https://www.who.int/publications-deredirect/WHO-IER-CSDH-08.1>. Accessed on 06 March 2023.
21. Mwesige A, Mohammed AH, Kristensson K, Juliano SL, Lutwama JJ. Emerging Viral Infections in Sub-Saharan Africa and the Developing Nervous System: A Mini Review. *Front Neurol*. 2018;9:82.
22. Desmond NA, Nyirenda D, Dube Q, Mallewa M, Molyneux E, Lalloo DG, et al. Recognising and treatment seeking for acute bacterial meningitis in adults and children in resource-poor settings: a qualitative study. *PLoS One*. 2013;8(7):e68163.
23. Onyeonoro UU, Ogah OS, Ukegbu AU, Chukwuonye II, Madukwe OO, Moses AO. Urban-rural differences in health-care-seeking pattern of residents of Abia State, Nigeria, and the implication in the control of NCDs. *Health Serv Insights*. 2016;9:29-36.
24. Begashaw B, Tessema F, Gesesew HA. Health care seeking behavior in Southwest Ethiopia. *PLoS One*. 2016;11(9):e0161014.
25. Uddin MJ, Alam N, Koehlmoos TP, Sarma H, Chowdhury MA, Alam DS, et al. Consequences of hypertension and chronic obstructive pulmonary disease, healthcare-seeking behaviors of patients, and responses of the health system: a population-based cross-sectional study in Bangladesh. *BMC Public Health*. 2014;14:547.
26. Abdullahi AM, Sarmast ST, Jahan N. Viral Infections of the Central Nervous System in Children: A Systematic Review. *Cureus*. 2020;12(10):e11174.
27. Nath A. Neuroinfectious Diseases A Crisis in Neurology and a Call for Action. *JAMA Network*. 2023.
28. WHO. The End TB Strategy, 2018. Available at: https://www.who.int/tb/strategy/End_TB_Strategy.pdf. Accessed on 06 March 2023.

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