

Quality of life among outpatients with autoimmune encephalitis at Bach Mai National Institute of Neuroscience

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ABSTRACT

Objective: To describe health-related quality of life characteristics in outpatients with autoimmune encephalitis at Bach Mai National Institute of Neuroscience, Bach Mai Hospital.

Subjects and Methods: A cross-sectional study was conducted at Bach Mai National Institute of Neuroscience, Bach Mai Hospital. Study participants were outpatients with autoimmune encephalitis who attended follow-up visits from March to May 2026, were able to communicate, had a Montreal Cognitive Assessment (MoCA) score of 18 or higher, and agreed to participate in the study. Data were collected using a structured questionnaire comprising demographic and clinical information, the SF-36, and the MoCA. Data were entered in Excel and analyzed using SPSS version 27.0 with descriptive statistical methods.

Results: The study included 31 patients. The median age was 27 years (IQR: 15), and women accounted for 61.3%. The median length of hospital stay was 27.0 days (IQR: 27.0), and 54.8% of patients had returned to their previous work or study. Among the SF-36 domains, the highest mean score was observed for Bodily Pain (79.84 ± 22.40), whereas the lowest was observed for Role Emotional (37.63 ± 42.81). The Physical Component Summary (PCS) score was higher than the Mental Component Summary (MCS) score (64.24 ± 8.89 vs. 44.01 ± 6.74).

Conclusion: In this group of outpatients with autoimmune encephalitis, the physical component of quality of life tended to be better preserved than the mental component. Role Emotional was the most affected domain. The findings suggest that persistent emotional and mental health impairments may remain after hospital discharge.

Keywords: autoimmune encephalitis, quality of life, SF-36, MoCA, Bach Mai Hospital.

I. INTRODUCTION

Autoimmune encephalitis is a group of serious disorders characterized by acute or subacute brain inflammation caused by a specific immune response against neural structures.¹ The disease commonly presents with cognitive impairment, psychiatric symptoms, or seizures developing over several weeks to three months. Over the past two decades, autoimmune encephalitis has been increasingly recognized owing to advances in modern paraclinical techniques, expansion of the spectrum of neuronal antibodies, and a more comprehensive understanding of immune-mediated pathogenesis.²

Although some patients may show clinical improvement after treatment, recent studies have demonstrated that persistent impairments in mental health, social functioning, and the ability to reintegrate into daily life may remain for many years after disease onset. Many previous studies have primarily focused on clinical outcomes during the acute treatment phase, with less attention to long-term quality of life. However, current evidence emphasizes that long-term outcomes should be assessed more comprehensively.³

Yokota et al. reported that after a median follow-up of 63 months, no more than 71% of patients with autoimmune encephalitis had returned to their previous work or study, and 48% had social quality-of-life scores below the normal threshold.⁴ Ramanuj et al., using the SF-36 and SF-10 instruments in a general encephalitis population, also showed that most survivors had quality-of-life scores lower than those of the reference population.⁵ Hirose et al. further demonstrated that patients with anti-N-methyl-D-aspartate receptor encephalitis may achieve favorable neurological recovery while still experiencing persistent impairment

in quality of life.⁸

The Short Form-36 (SF-36) questionnaire is a standardized instrument widely used to assess health-related quality of life. It enables multidimensional assessment across physical, social, and emotional domains and is therefore suitable for evaluating patient-centered outcomes after autoimmune encephalitis.

In Vietnam, studies on autoimmune encephalitis remain limited in number and have mainly focused on clinical and paraclinical characteristics. No comprehensive study has used a standardized instrument such as the SF-36 to assess quality of life in patients with autoimmune encephalitis after hospital discharge. Therefore, this study was conducted to describe health-related quality of life characteristics in outpatients with autoimmune encephalitis at Bach Mai National Institute of Neuroscience, Bach Mai Hospital.

II. SUBJECTS AND METHODS

2.1. Study setting and period

- Study setting: Bach Mai National Institute of Neuroscience, Bach Mai Hospital.
- Study period: from January 1, 2026 to June 25, 2026.
- Data collection period: from March 1, 2026 to May 31, 2026.

2.2. Study participants

Inclusion criteria:

- Patients diagnosed with autoimmune encephalitis who attended follow-up visits to receive medication between March 1, 2026 and May 31, 2026.
- Patients able to communicate and with a Montreal Cognitive Assessment (MoCA) score of 18 or higher.
- Patients or their legal guardians who agreed to participate in the study.

Exclusion criteria:

- Patients with severe chronic diseases in advanced or end-stage phases, or with other life-threatening conditions.

2.3. Research methods

Study design

Cross-sectional descriptive study

Sample size and sampling method

Convenience sampling was used. A total of 31 patients who met the inclusion and exclusion criteria were enrolled in the study.

Data collection instruments and procedures

Data were collected using a structured questionnaire comprising administrative information, clinical information, the SF-36 questionnaire, and the MoCA. Patients attending follow-up visits were initially screened for cognitive status using the MoCA and were then assessed against the inclusion and exclusion criteria. Eligible patients were enrolled and interviewed directly. Relevant information was subsequently cross-checked against archived medical records. Throughout data collection, the research team performed data quality control, coding, secure information storage, and review of missing or inconsistent data when necessary. After data collection was completed, all data were standardized, coded, and prepared for analysis.

Data management and analysis

Data were entered using Microsoft Excel 2019 and analyzed with SPSS version 27.0. Descriptive statistics, including frequency, percentage, mean, standard deviation, median, and interquartile range, were used to describe demographic characteristics, clinical characteristics, and quality of life. The Shapiro-Wilk test was used to assess the distribution of SF-36 domain scores.

III. RESULTS

3.1. General characteristics of study participants

The study included 31 outpatients with autoimmune encephalitis at Bach Mai National Institute of Neuroscience, Bach Mai Hospital. The median age of the study participants was 27 years (IQR: 15), ranging from 15 to 74 years. Men accounted for 38.7%, whereas women accounted for 61.3%. Regarding marital status, the never-married group represented the highest proportion.

Table 1. General characteristics of the study participants

Variable	n	%
Sex		
Male	12	38.7
Female	19	61.3
Occupation		
Student	4	12.9
Currently working	26	83.9
Currently not working	1	3.2
Marital status		
Never married	17	54.8
Married	14	45.2

3.2. Clinical characteristics and post-discharge follow-up

The median length of hospital stay was 27.0 days (IQR: 27.0), ranging from 12 to 75 days. The median number of rehospitalizations was 0 (IQR: 2), ranging from 0 to 7. The median interval from hospital discharge to the interview was 181 days (IQR: 393). The proportion of patients who had returned to their previous work or study was 54.8%. Among those who had returned, the median time from hospital discharge to return to work or study was 30.0 days (IQR: 80.0), ranging from 3 to 365 days.

Table 2. Clinical characteristics and post-discharge follow-up

Variable	Mean ± SD	Median (IQR)	Min-Max
Length of hospital stay (days)	32.3 ± 16.34	27.0 (27.0)	12-75
Number of rehospitalizations	1.00 ± 1.65	0 (2)	0-7
Time from discharge to interview (days)	262.56 ± 250.47	181.0 (393.0)	6-778
Time from discharge to return to work/study (days)*	64.06 ± 92.43	30.0 (80.0)	3-365
Variable	n		%
Return to previous work/study			
Yes	17		54.8
No	14		45.2
MoCA score	n		%
18-25	9		29
≥26	22		71

* Calculated only among patients who had returned to work or study.

3.3. Physical health-related quality of life according to the SF-36

Among the physical domains of the SF-36, the highest mean score was observed for Bodily Pain (79.84 ± 22.40), whereas the lowest was observed for Role Physical (50.81 ± 42.07). PF, RP, and BP were not normally distributed, whereas GH and PCS showed approximately normal distributions. Overall, the PCS score was 64.24 ± 8.89, suggesting that the physical component of quality of life was relatively preserved in this outpatient group.

Table 3. Physical domains of the SF-36 and PCS score

	Mean ± SD	Median (IQR)	Shapiro-Wilk p-value
Physical Functioning (PF)	69.19 ± 26.40	80.00 (35.00)	0.006
Role Physical (RP)	50.81 ± 42.07	50.00 (100.00)	< 0.001
Bodily Pain (BP)	79.84 ± 22.40	90.00 (32.50)	< 0.001
General Health (GH)	54.83 ± 17.54	55.00 (20.00)	0.126
Physical Component Summary (PCS)	64.24 ± 8.89	62.57 (11.52)	0.241

3.4. Mental health-related quality of life according to the SF-36

Among the mental domains of the SF-36, Mental Health had the highest mean score (71.26 ± 13.16), whereas Role Emotional had the lowest (37.63 ± 42.81). The RE domain was not normally

distributed ($p < 0.001$), SF was at the borderline ($p = 0.050$), whereas the other mental domains showed approximately normal distributions (VT: $p = 0.064$; MH: $p = 0.302$; MCS: $p = 0.989$). The MCS score was 44.01 ± 6.74 , lower than the PCS score of 64.24 ± 8.89 .

Table 4. Mental domains of the SF-36 and MCS score

SF-36 domain	Mean $\pm$ SD	Median (IQR)	Shapiro-Wilk p-value
Vitality (VT)	65.00 ± 17.51	60.00 (30.00)	0.064
Social Functioning (SF)	65.31 ± 25.55	74.50 (37.50)	0.050
Role Emotional (RE)	37.63 ± 42.81	33.33 (100.00)	< 0.001
Mental Health (MH)	71.26 ± 13.16	72.00 (20.00)	0.302
Mental Component Summary (MCS)	44.01 ± 6.74	44.27 (8.52)	0.989

IV DISCUSSION

This study provides preliminary data on health-related quality of life among outpatients with autoimmune encephalitis at a tertiary neurology center in Vietnam. The findings showed that the physical component of quality of life was relatively better preserved than the mental component, as reflected by a higher PCS score than MCS score. According to the standardized convention of the Vietnamese version of the SF-36, a score of 50 represents the mean level of the reference population; thus, the MCS in this study was below the reference level, whereas the PCS was above it, suggesting more prominent impairment in the mental component.⁷ Among the SF-36 domains, Bodily Pain had the highest mean score, whereas Role Emotional had the lowest score and the greatest variability.

The pattern observed in our study is generally consistent with previous reports showing that recovery after autoimmune encephalitis is not limited to improvement in motor function or

global neurological function but may also be accompanied by a persistent psychosocial burden.^{4,6,8} Yokota et al. showed that although long-term outcomes were generally favorable, nearly half of patients still had social quality-of-life scores below the normal threshold, and no more than 71% returned to their previous work or study.⁴ Hirose et al. also reported that patients with anti-N-methyl-D-aspartate receptor encephalitis may achieve favorable neurological recovery but still have impaired social quality of life.⁸ In the general encephalitis population, Ramanuj et al. likewise demonstrated lower quality-of-life scores than in the reference population, suggesting that the long-term burden of encephalitis may persist even after the acute phase has passed.⁵ It should be noted that the proportion of patients who were “currently working” and the proportion who had “returned to previous work/study” in our study are not entirely equivalent, because one variable reflects current occupational status whereas the other

reflects the extent to which patients resumed the same role they had before illness.

The finding that Bodily Pain had the highest mean score suggests that pain-related limitations may be less prominent than other dimensions of the post-encephalitic burden in this outpatient group. In contrast, Role Emotional was the domain with the lowest score and the greatest dispersion, suggesting that emotional role functioning remained substantially affected in at least a subgroup of patients. The large standard deviation of RE (42.81), together with the wide interquartile range, indicates marked heterogeneity among patients; some cases had almost no limitation, whereas others were severely affected in emotional role functioning. This finding is consistent with Blum et al. regarding poor long-term psychosocial outcomes in patients recovering from anti-NMDA receptor encephalitis,³ and with the review by Kvam et al., which emphasized that although many patients appear to achieve favorable outcomes on conventional neurological scales, detailed assessments still identify persistent cognitive, psychiatric, and social sequelae.⁶

The lower MCS score compared with the PCS score in our study further supports the view that mental and psychosocial recovery may be slower than physical recovery. This has important clinical implications because it suggests that residual burden after autoimmune encephalitis may be more apparent in emotional, social, and mental health domains than in overt physical disability. Previous studies have also reported that anxiety, depression, fatigue, and reduced social participation may persist after patients become neurologically stable.^{3,6} Therefore, our findings support the incorporation of patient-reported outcome measures such as the SF-36 into long-term follow-up.

Another notable finding was that only 54.8% of patients in the study had returned to their previous work or study. Although direct comparisons across studies should be interpreted cautiously because of differences in disease subtype, severity, and follow-up duration, this finding is generally consistent with previous reports indicating that reintegration after autoimmune encephalitis remains incomplete. Peng et al. reported that only 46.2% of patients with autoimmune encephalitis returned to work within one year after hospital discharge.⁹ These data indicate that social reintegration is an important component of long-term recovery and should be considered a patient-centered outcome alongside traditional neurological indicators.

This study has several limitations that should be acknowledged. First, the small sample size and convenience sampling method limit the generalizability of the findings. Second, the cross-sectional design and substantial variation in the duration of post-discharge follow-up among participants may affect interpretation in relation to the recovery trajectory. Third, the study was conducted at a single tertiary referral center and included only outpatients who were able to attend follow-up visits, communicate, and had a MoCA score of 18 or higher; therefore, the degree of quality-of-life impairment in more severe cases may have been underestimated. Nevertheless, this study contributes preliminary data on health-related quality of life after autoimmune encephalitis. The findings emphasize that outcome assessment in patients with autoimmune encephalitis should not be limited to survival or gross neurological recovery. Long-term follow-up, neuropsychological assessment, and psychosocial support may still be necessary even when patients are clinically stable.

V. CONCLUSION

In this group of outpatients with autoimmune encephalitis, the physical component of quality of life was better preserved than the mental component. Bodily Pain was the domain with the highest mean score, whereas Role Emotional was the most affected domain. More than half of the patients had returned to their previous work or study; however, reintegration remained incomplete in a substantial proportion. These findings suggest the persistence of emotional and mental health impairments after hospital discharge.

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