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The trajectory and influencing factors of disability acceptance in patients with hypertensive intracerebral haemorrhage: a protocol for prospective longitudinal cohort study in Heyuan City, China

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ABSTRACT

Introduction China is one of the countries with the highest burden of hypertensive intracerebral haemorrhage (HICH), and its morbidity and mortality rates are almost twice the world average. Most survivors experience negative emotions such as anxiety and depression due to symptoms such as speech disorders, dysphagia, cognitive impairment, hemiplegia and ataxia. While evidence has emerged, supporting the acceptance of disability is a major factor in psychosocial adjustment of patients with disabilities. However, most relevant studies mainly focus on cross-sectional design, and the impact of disability on physical and mental health is a complex and comprehensive process, and its mechanism is still unclear. Therefore, we aimed to use the latent growth mixture model (LGMM) and the decision tree model to analyse the trajectory and predictors of disability acceptance in patients with HICH from stable hospitalisation to 2 years after discharge.

Methods and analysis The objective of this prospective study will be to examine the 2-year trajectory of disability acceptance in a cohort of persons with HICH. 180 participants will be recruited, and baseline general data collection, disability acceptance, family caring index and self-efficacy of chronic disease will be conducted. All of them will be followed up at the stable hospitalisation period, 6 month, 1 year and 2 year after discharge using the same protocol. As a major result, disability acceptance trajectories and potential categories will be analysed using LGMM. Additionally, the independent variables with statistical significance will be included in the decision tree model, and the Classification And Regression Trees (CART) algorithm programme will be used to construct the prediction model of influencing factors of disability acceptance trajectory. The exploratory outcome will provide scientific basis for the optimal intervention time point and the formulation of rehabilitation measures for this population.

Ethics and dissemination Ethical approval was obtained from the medical research ethics committee of Heyuan People's Hospital (YXYJLL-2022S58). The results will be disseminated nationally and internationally through the publication of research papers.

Trial registration number ChiCTR2300071778.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Unlike cross-sectional studies, this prospective cohort study will use longitudinal follow-up to determine the psychological mechanisms of disability acceptance in patients with hypertensive intracerebral haemorrhage.
⇒ Another strength of this study is its data analysis design, as the growth mixture model will allow for a deeper understanding of the influencing factors corresponding to different categories of patients.
⇒ CART decision tree has the advantage of being structured at a glance and easy to understand.
⇒ Potential limitation is that the current protocol can only follow up patients in and around Heyuan City, Guangdong Province, China, so the generality of the results is limited to this urban area.
⇒ The follow-up time of this study is relatively short (only 2 years).

INTRODUCTION

Hypertensive intracerebral haemorrhage (HICH) is one of the subtypes of stroke, accounting for 20%–30% of acute cerebrovascular diseases.[1] According to the 2020 global disease analysis report,[2] as a widespread global health problem, cerebral haemorrhage occurs in about 2–3 million people on average every year, with a total incidence of 24.6 people per 100 000 population per year, featuring high morbidity, high mortality rate, high disability rate and heavy economic burden.

Although the survival rate of patients with cerebral haemorrhage has been increased with the improvement of medical level, most survivors may have anxiety, depression, pessimism, disappointment, stigma and other negative emotions,[3–5] even suicidal ideation,[6] due to speech disorders, swallowing disorders, cognitive disorders, hemiplegia, ataxia and other symptoms.[7] A Korean meta-analysis

of depression-related factors in stroke patients[8] showed that patients' acceptance of disability was highly correlated with the occurrence of depression. Cao and Gao[9] compared the the psychological status of 82 stroke patients in ten aspects, including sensation, emotion, thinking, consciousness, behavior, lifestyle habits, interpersonal relationships, diet and sleep, with the norm using SymptomChecklist90 (SCL-90), and the results showed that the scores in nine dimensions of physical discomfort, compulsion, interpersonal relationship, depression, anxiety, hostility, terror, paranoia and psychosis were higher than the norm. Other literature[10 11] showed that the stigma of patients with hemiplegia was at a medium high level. It can be seen that disability seriously affects the physical and mental health of patients and leads to a series of psychological and social adaptation problems.

Disability acceptance theory was first proposed by Grayson in 1950 and summarised by Wright in 1960. He believed that disability acceptance was a major factor in psychosocial adjustment of patients with disabilities[12] and played a role in promoting rehabilitation.[13] A study by Yehene *et al*[14] found that acceptance of disability plays an important role in regulating depression, post-traumatic stress disorder and quality of life. A study by Chai Xuehong[15] found that disability acceptance was positively correlated with the level of life meaning. Therefore, studies had demonstrated that disability acceptance is related to psychological adjustment. At present, cross-sectional studies on disability acceptance focus on brachial plexus injury,[16] ischaemic stroke,[17] post breast cancer radical surgery,[18] burns[19] and permanent stomas.[20] In a few longitudinal studies, evidence of causality between patient's psychological variables is lacking. Only a few studies[21] conducted follow-up investigations on disabled patients to explore the impact of disability acceptance on their mental state, and no studies have been reported on the heterogeneity of longitudinal trajectory of disability acceptance in HICH patients.

On the one hand, the treatment process of cerebral haemorrhage disease includes acute period, transitional period, rehabilitation period, etc, so researchers need to consider the factors of the change in the course of the disease when exploring the acceptance of disability, and to clarify, the psychological changes in different periods is the premise of providing more accurate continuous care and intervention. On the other hand, the nature of disability acceptance is a procedural variable, and cross-sectional studies cannot solve the research problem of observing the changes of individual disability acceptance at different disease stages. Therefore, longitudinal studies must be designed to clarify the mechanism of psychological change. Chinese scholar Chen Liumei[22] *et al* confirmed the above views by conducting follow-up surveys on disability acceptance of burn patients at the time of discharge and 6 months, 1 year and 2 years after discharge, indicating that the development and changes of disability acceptance should be observed more comprehensively through a prospective longitudinal design. To sum up, based on the characteristics of HICH diseases and the requirements of the dynamic attributes of disability acceptance, tracking the changes of disability acceptance of HICH patients during the stable period of hospitalisation, 6 months, 1 year and 2 years after discharge, and exploring related factors are the key and difficult points to overcome at present.

In summary, this study intends to track and evaluate the disability acceptance level of patients with HICH. Researchers will use the LGMM to identify the potential subgroups of disability acceptance trajectory, which can fully consider the possibility of different subgroups with different characteristics in the population, and analyse the differences in development trends of different subgroups. In addition, a decision tree prediction model affecting disability acceptance trajectory will be constructed to clarify the core influencing factors, providing a basis for precise intervention. Specifically, this study will serve as a preliminary step in a randomised controlled trial of rehabilitation protocols for HICH patients.

METHODS AND ANALYSIS

This prospective, longitudinal cohort study was designed in accordance with the STROBE checklist for feasibility studies, which aims to establish an accurate prediction model of HICH individual disability acceptance and to provide information for the formulation of comprehensive and timely rehabilitation guidance. Meanwhile, it is conducive to optimising the reasonable and effective allocation of medical resources. The specific objectives of the study are as follows:

Study objectives

1. To investigate and analyse the changes in disability acceptance level of HICH patients at four time points from acute hospitalisation to 2 years after discharge.
2. To fit the trajectory types of disability acceptance changes, and to analyse its potential categories using the LGMM.
3. To assess the association between disability acceptance and demographic characteristics, disease characteristics, family care index and chronic self-efficacy.
4. To screen the influencing factors in different periods of the disability acceptance trajectory of different potential categories of HICH patients, and construct a decision tree model.
5. To verify the validity and stability of the disability acceptance prediction model through confusion matrix and receiver operating characteristic (ROC) curve .

Study location

Geographically, China is located in the east of Asia, on the west coast of the Pacific Ocean. Provincial administrative regions are divided into 23 provinces, 5 autonomous regions, 4 municipalities directly under the central government and 2 special administrative regions. Guangdong Province is one of the provincial administrative

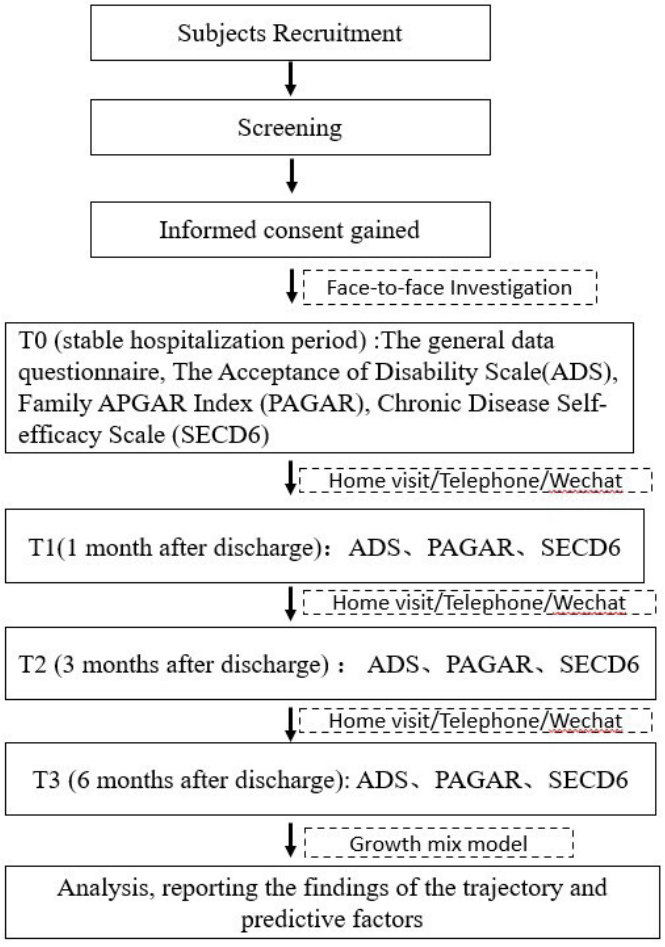

Figure 1 Study participant flow chart.

regions in China, which is located at the southernmost end of the Chinese mainland. The location of this study is in Heyuan City, Guangdong Province, which is a prefecture-level city located in the northeast of Guangdong Province. There is only one tertiary A comprehensive hospital in the local area—Heyuan People's Hospital. In this study, the recruitment of research subjects and the implementation of the plan will be conducted at Heyuan People's Hospital.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting of this research. Patients and/or the public will be informed about the study. A summary of the findings will be made available to the patient and public representatives.

Study design

A prospective, longitudinal cohort study will be conducted among the patients diagnosed with HICH in the Department of Neurosurgery of Heyuan People's Hospital. The trial flowchart and design are presented in figure 1. The research study period started in May 2023 and estimated to be completed in June 2025.

Study participants

At least 180 participants will be recruited through the Department of Neurosurgery. The diagnostic criteria are in accordance with the Chinese guidelines for the diagnosis and treatment of cerebral haemorrhage (2019) issued by the Neurology Branch of the Chinese Medical Association: (1) acute onset; (2) symptoms of focal neurological impairment; (3) skull CT showed high density imaging; and (4) exclude other non-vascular causes. The sample size is in line with recommendations regarding feasibility studies.

Inclusion criteria: (1) at least 18 years of age, (2) combined with basic hypertensive diseases, or a clear diagnosis of hypertension at the time of hospitalisation, and (3) have certain verbal or motor communication ability, without cognitive dysfunction.

Exclusion criteria: (1) have mental illness or severe cognitive dysfunction, accompanied by serious diseases of the heart, kidney, liver and other important organs, (2) have severe aphasia or dysarthria, cannot recognise and understand language well with assistance, (3) have physical defects before the onset of disease, and (4) unexpected circumstances such as loss of contact or deterioration of the condition.

Measurements and instruments

General information

As a general attribute, the socio-demographic characteristics of the participants included gender, age, education level, religious belief, marital status, number of children, occupation, whether they were breadwinners, forms of medical payment, per capita monthly family income and personality.

In addition, disease-related data will also be recorded, including the number of cases of cerebral haemorrhage, the grade of hypertension, the site of bleeding, daily activity ability, treatment methods, whether rehabilitation exercises have been performed, and the status of diseases and injuries. Among them, the disease injury status includes whether there is language dysfunction, swallowing dysfunction, defecation dysfunction, sleep paralysis, neurological impairment degree, etc. Neurological impairment degree is scored by consciousness, horizontal staring function, facial muscle, speech, upper limb muscle strength, hand muscle strength, lower limb muscle strength and walking ability. The score is 0–15 points for light, 16–30 points for medium and 31–45 points for severe. The score can be obtained from the clinical records of patients.

The Acceptance of Disability Scale (ADS)

This scale was developed by Linkowski[23] with the disability acceptance theory as the framework to measure patients' attitudes towards disability acceptance. There are 50 entries, consisting of four dimensions, including the expanded dimension, the dependent dimension, the inclusion dimension and the transformation dimension. It was revised by Groomes and Linkowski[24] and translated into Chinese by Chen *et al*.[16] There were 32 entries in total, of which 22 were inverted scoring entries. The options range from 'strongly

disagree' to 'strongly agree' on a scale of 1 to 4. The total score ranges from 32 to 128, with 97 to 128 indicating high acceptance, 65 to 96 indicating moderate acceptance and 32 to 64 indicating low acceptance. The content validity index of this scale was 0.919, and Cronbach's α value was 0.83, indicating good reliability and validity. At present, the scale has been used in the study of disability acceptance in patients with brachial plexus injury, burn, enterostomy and stroke.

Family APGAR Index (PAGAR)

This scale was developed by Smikstein[25] in 1978 to assess respondents' satisfaction with the five dimensions of family functions, including Partnership, Adaptation, Growth, Affection and Resolve, and was therefore simply referred to as the PAGAR Index. The total score ranges from 0 to 10, with higher scores indicating better family functioning. 0 to 3 is classified as severe family functioning disorder, 4 to 6 as moderate family functioning disorder and 7 to 10 as good family functioning. Lv and Liu[26] verified that the scale had good reliability and validity in the investigation of family function in patients with cerebrovascular diseases.

Chronic Disease Self-efficacy Scale (SECD6)

This scale was compiled by Stanford University scholar Lorig *et al*[27] to reflect the self-efficacy of patients with chronic diseases in symptom control, role function, emotional control, doctor-patient communication and other aspects. There are six items in the scale, which can be divided into two dimensions: symptom management self-efficacy and disease common management self-efficacy. The visual analogue scale (VAS) was used on a scale of 1 to 10, with 1 indicating 'not confident' and 10 indicating 'very confident'. The score ranges from 1 to 10 points, with a higher score indicating a higher level of self-efficacy.

Baseline and follow-up visits

Baseline study visit: During the stable hospitalisation period (T_0), the participants meeting the diagnostic criteria for HICH will be selected by the investigators through the query of medical records, and the participants will be re-evaluated in the ward to ensure that they met the inclusion and exclusion criteria. Meanwhile, written informed consent will be obtained from participants prior to starting the data collection. Baseline data collection of patients will be completed during hospitalisation, among which data related to population sociology and disease can be completed by consulting medical records and inquiring patients. ADS, PAGAR and SECD6 scales are distributed and recovered on site. When the patient's condition permits, all the filling shall be completed by the patient himself. When the patient cannot fill in the filling by himself due to limb dysfunction, reading difficulty or infusion, the researchers shall inquire and record truthfully.

Follow-up periods: When patients are discharged from the hospital, the research team keep in touch with the participants and follow their whereabouts after discharge, as well as the outcome of their recovery. Follow-up visits are arranged 6 months after discharge (T_1), 1 year after discharge (T_2) and 2 years after discharge (T_3). During the follow-up, disability acceptance survey and the above questionnaire assessment will be conducted again (table 1). Members of our research team will have regular one-to-one contact with the subjects through WeChat or phone or home visits to establish access to the subjects. Information will be sent to participants 1 week and 1 day before the next follow-up to prevent loss of contact. If either the participant or the primary family caregiver is unwilling to cooperate in the study, it is considered disengagement.

Table 1 Details and procedures of the baseline study visit and follow-up periods

	Classification				
Follow-up period	Participant's recruitment	General information	ADS	PAGAR	SECD6
Baseline	√	√	√	√	√
6 month after discharge	–	–	√	√	√
1 year after discharge	–	–	√	√	√
2 year after discharge	–	–	√	√	√

ADS, Acceptance of Disability Scale; SECD6, Chronic Disease Self-efficacy Scale.

Data analysis

1. Construction of trajectory model: Mplus8.0 software will be used to analyse the mixed model of latent variable growth. Model fit test indicators include Akaike information criterion (AIC), Bayesian information criterion (BIC), sample-size adjusted BIC (aBIC), entropy, Lo-Mendell-Rubin (LMR) and bootstrapped likelihood ratio test (BLRT). The smaller the values of AIC, BIC and aBIC, the better the model fitting. LMRT and BLRT are used to compare whether there are significant differences between k and k-1 categories, and a significant p value indicates that the model with k classes is a better fit than the model with k-1 classes. Entropy ranges from 0 to 1 and is used to evaluate the classification accuracy of a category, with a value closer to 1 indicating a higher classification accuracy. This study starts with two potential category models to fit data, and then increases the number of categories according to the situation of two and three potential categories to fit data, and so on. In the fitting process, the specific number of potential trajectory categories will be determined by comparing each fitting index, and the most appropriate fitting model is selected according to the theoretical significance and parameter fitting index.
2. Analysis of influencing factors: Continuous variables with a normal distribution will be compared using t-test or analysis of variance, whereas those with a non-normal distribution will be analysed using a non-parametric test. Categorical variables will be analysed using the χ^2 test.

The independent variables with statistical significance ($p<0.05$) of univariate analysis will be included into the decision tree model, and the prediction model of influencing factors of disability acceptance of HICH patients will be constructed by Classification And Regression Trees (CART) algorithm programme. Repeated analysis of measurement variance will be used to compare the mean score of disability acceptance in HICH patients at different time points. Test level $\alpha=0.05$

3. Validity of the prediction model: We will use prediction accuracy, sensitivity, specificity and area under curve (AUC) ROC to measure the validity of the prediction model.

ETHICS AND DISSEMINATION

Ethical approval was obtained from the medical research ethics committee of Heyuan People's Hospital (YXYJLL-2022S58). The collected electronic data will be kept confidential and can only be accessed by the research group during data statistics. Sensitive paper materials will be stored in a locked cabinet in the project leader's office.

We recognise that HICH patients may experience cognitive and/or physical impairments, resulting in poor health and limited autonomy, posing challenges to research participation. In addition, participants may exacerbate their painful experiences when expressing their own disabilities or living conditions. The research team consists of professional healthcare professionals and rehabilitation practitioners who have the ability to provide relevant information and support in situations where professional assistance is needed.

The study results are planned to be disseminated nationally and internationally through the publication of research papers.

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Contributors JZ and ZZ designed the study protocol and provided revision for intellectual content. XL contributed to manuscript writing.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

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