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# Preferences for long-termcare among elderly patients who had a stroke with disabilities in Eastern China: protocol for a ditscrete choice experiment study

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## ABSTRACT

**Background** Stroke is a leading cause of disability among older adults worldwide, often resulting in significant physical, cognitive and emotional impairments that require long-term care. With ageing populations and increasing stroke prevalence, the demand for appropriate and sustainable long-term care is growing. However, designing care models that align with the complex needs and preferences of elderly patients who had a stroke remains a challenge. This study employs a discrete choice experiment (DCE) to measure and quantify patients' preferences for long-term care. The primary objectives of this study are as follows: (1) identify and examine the key attributes and levels of long-term care that are most valued by this patient population, (2) assess patients' preferences for long-term care and explore the role of each attribute on overall preference and (3) explore heterogeneity in preferences based on participants' characteristics through subgroup analyses.

**Methods** The research was conducted in accordance with the design programme of the DCE study. Seven attributes were developed through a systematic literature review, in-depth interviews and experts consultation. A partial factorial survey design was generated through an orthogonal experimental design to optimise the choice scenario sets. We plan to conduct a DCE questionnaire survey in Suzhou, Jiangsu Province, China, and recruit at least 500 participants. The final data will be analysed through a mixed logit model and a latent class model to explore the preference of elderly patients who had a stroke with disabilities for long-term care.

**Ethics and dissemination** This study was approved by the Ethics Committee of Nanjing Medical University-Affiliated Suzhou Hospital (K-2024-096 K01). All participants will be required to provide informed consent. The findings of this study will be disseminated and shared with interested patient groups and the general public through a variety of channels, including online blogs, policy briefs, national and international conferences, and peer-reviewed journals.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study employs a discrete choice experiment (DCE) to systematically quantify the preferences of elderly patients who had a stroke with disabilities regarding long-term care.
- ⇒ The attributes and levels included in the DCE were developed through a rigorous process, including a systematic literature review, in-depth interviews and expert consultation, enhancing the study's methodological robustness.
- ⇒ A partial factorial design was used to optimise the choice sets, ensuring a balance between statistical efficiency and respondent burden.
- ⇒ The findings may not be directly generalisable to other cultural or healthcare contexts as differences in long-term care resources, insurance coverage and healthcare policies exist both across countries and within different regions of China.

## INTRODUCTION

Stroke represents a significant global health challenge, characterised by its high incidence, prevalence and substantial burden on healthcare systems.[1] It is the leading cause of mortality and long-term disability, affecting millions of individuals annually.[2] According to the Global Burden of Disease study,[3] there are currently 101 million people worldwide experiencing stroke, with about 12.2 million new cases each year, and about 6.55 million deaths caused by stroke, accounting for 11.6% of all deaths, which has now become the second leading cause of death. In China, the ageing of the population has contributed to the prevalence of unhealthy lifestyles, which have led to a significant increase in the number of individuals exposed to risk factors for cardiovascular and cerebrovascular diseases.[4] Consequently, the burden of stroke in China has exhibited an alarming growth trend. A report published in *JAMA* on the burden of stroke in China[5] indicated that the estimated prevalence, incidence and mortality rate of stroke were 2.6%, 505.2 per 100 000 person-years and 343.4 per 100 000 person-years, respectively. These figures illustrate the significant disease burden among this disease group.

The burden of stroke extends beyond immediate medical consequences. Survivors frequently confront long-term challenges, and studies[6 7] have shown that 60% of patients who had a stroke have varying degrees of cognitive impairment, speech, swallowing or physical mobility disorders, depressive symptoms or social dysfunction, resulting in the loss of daily activities and self-care ability, and the quality of life is severely affected. Nowadays, the reported disabilities rate among patients who had a stroke in China is 12.5 (95% CI 12.4 to 12.5), as defined by a modified Rankin scale.[8] The disability-adjusted life-years caused by stroke are higher than a majority of other diseases.[9] In this context, long-term care emerges as a crucial element of comprehensive healthcare, with the objective of enhancing the quality of life of elderly stroke survivors with disabilities and of alleviating the medical burden on families and society.[10] With an ageing population and increasing prevalence of stroke, the demand for appropriate and sustainable long-term care is expected to increase significantly in the coming years.[11]

WHO[12] defines long-term care as a range of care activities provided by professional caregivers or non-professional caregivers (such as family members) to ensure a satisfactory quality of life for individuals with chronic health conditions or disabilities. According to the different places of care services, long-term care in different countries is basically divided into three models: institutional care with different types of institutions as the platform, community care with each community as the platform and home care with the family as the platform, each offering distinct advantages and challenges.[13 14] Institutional care, which includes hospitals and nursing homes, provides access to professional medical staff and medical infrastructure. However, it is often associated with higher costs, greater financial burden, personnel shortages and uneven regional availability.[15] In contrast, home-based care and community-based care offer long-term care in familiar environments, which may improve patient comfort and well-being. Under this circumstance, family members often serve as primary caregivers, many of whom lack formal training in healthcare.[16] This dual responsibility—caring for patients who had a stroke with disabilities while managing other household and childcare duties—can place significant psychological, emotional and financial strain on families.[17] Thus, the optimal configuration of long-term care for stroke survivors remains a pressing concern, especially in countries like China where the ageing population is rapidly expanding.[18]

Developing effective long-term care services requires a thorough understanding of patient preferences as long-term care options vary in structure, content and payment.[19] Previous research in China[20] has examined the preferences for long-term care among older adults, and the results demonstrated that home-based care remains the predominant option for older people, which is closely related to Chinese cultural traditions (eg, filial piety). But the study also points to a gradual increase in demand for community and institutional care as China goes through a period of change in terms of family structure and social norms. In addition, demographic, psychological, physical condition and economic factors were all correlated with patients' preference. Research[21] suggests that there may be significant differences in patients' care preferences when care needs are high, and that policymakers should be flexible in developing resource allocation strategies according to the needs and health status of different groups. However, little attention has been paid to disabled stroke survivors, and there is a lack of research on the long-term care preferences of this population.

To address this gap, this study employs a discrete choice experiment (DCE) to explore and quantify the preferences of elderly patients who had a stroke with disabilities regarding long-term care. DCE is a robust quantitative method that assesses individual trade-offs between different attributes, offering valuable insights into which content is most valued by patients[22] . By presenting respondents with hypothetical long-term care scenarios composed of varying attributes and levels, this study will reveal the relative importance (RI) of specific service features and identify the optimal configurations of long-term care services. Specifically, the study pursues three key objectives: (1) it aims to identify the essential components of long-term care for elderly patients who had a stroke with disabilities; (2) it seeks to measure patients' preferences for long-term care and evaluate the RI of each attribute, providing insights into the factors most highly valued by this population; and (3) the study explores heterogeneity in individual preferences through subgroup analyses across different demographic and clinical categories. The findings are expected to inform policymakers, healthcare providers and caregivers in tailoring care options that better align with the values and expectations of elderly patients who had a stroke with disabilities.

## METHODS AND ANALYSIS

### Study design

DCE-stated preference method is a technique that presents hypothetical scenarios, characterised by attributes and their associated levels, to study participants in order to assess their preferences and marginal rates of substitution in healthcare.[23] DCEs are primarily founded on the theoretical framework of random utility. In accordance with this framework, it is assumed that an individual respondent will select the alternative that they perceive to offer the greatest utility.[23] A DCE survey was conducted in this study, in accordance with the guidance set forth in a report by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Conjoint Analysis Good Research Practices Task Force.[24] Respondents were required to make trade-offs between their preferred and less preferred attribute level for each choice set. A DCE comprises four main stages: (1) identifying and

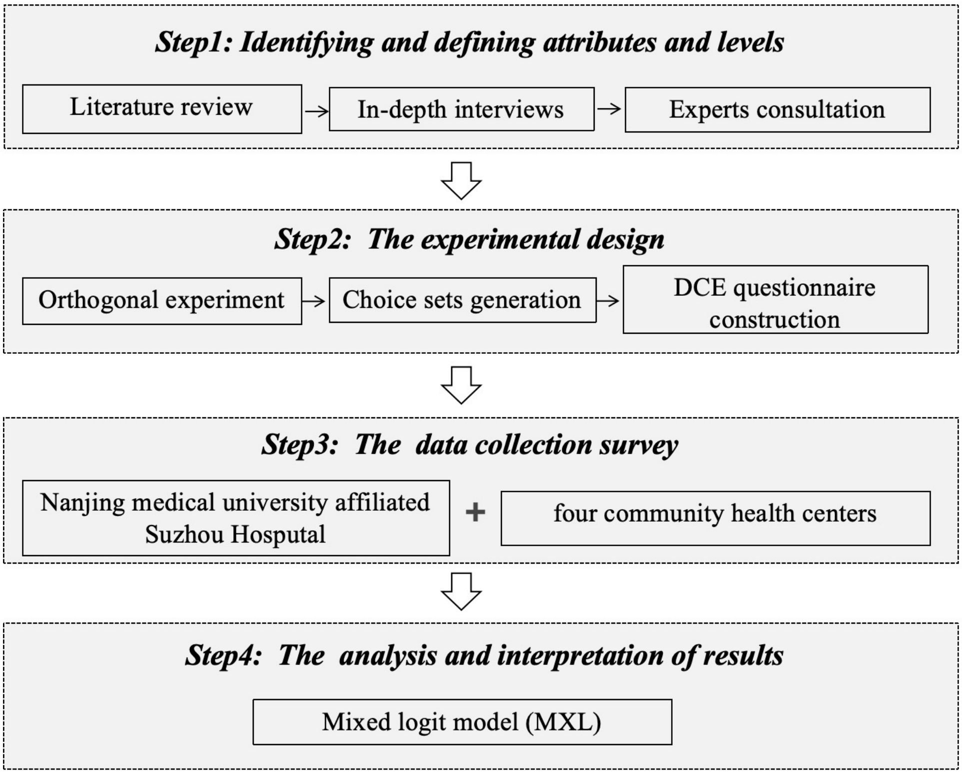

**Figure 1** The procedure of discrete choice experiment (DCE).

defining attributes and levels; (2) the experimental design; (3) the data collection survey and (4) the analysis and interpretation of results.[4] The procedure of DCE is shown in figure 1.

## Identify attributes and their levels

To design a DCE questionnaire for understanding long-term care preferences of elderly patients who had a stroke with disabilities, identifying specific attributes and their levels is a crucial step. These attributes should reflect the factors that are most likely to influence the patients' preferences for long-term care services. In the domain of health, the number of attributes is typically 4–6, and the ideal number of choice sets is 8–16.

### Literature review

To determine the key attributes of long-term care in this research, first, we performed a literature search for eligible studies before 1 October 2024 on global databases such as PubMed, EMBASE, Web of Science, along with Chinese journal literature databases, including CNKI and Wanfang. The inclusion criteria included (1) studies focusing on long-term care preferences or needs among elderly individuals with disabilities and (2) studies employing qualitative, quantitative or mixed-methods approaches to explore preferences. The key words included “elderly”, “stroke”, “preference”, “long-term care”, “LTC”, “disabilities” and “disabled”. Concurrently, to gain a more comprehensive understanding, we undertook a review of the references cited in the retrieved documents. We restricted our search to articles published in English and Chinese to capture a comprehensive range of literature while maintaining language accessibility. Two independent reviewers screened articles based on title, abstract and full text. Any discrepancies were resolved through discussion with a third reviewer. After screening and discussing, we selected attributes such as location of care, type of care, provider of care, duration of care, content of care, support and cost for a broader retrieval of patients who had a stroke with disabilities. A list of potential attributes and levels were established, which will serve as the basis for the forthcoming discussion of qualitative research.

### In-depth interviews

Second, based on the results of the literature review, we conducted nine one-on-one semistructured in-depth interviews. The purpose of one-on-one interviews is to further explore the conceptual attributes derived from the literature review and obtain new and contextual attributes from the perspective of disabled strokes. The participants were recruited from the geriatrics and neurology wards of Nanjing Medical University-Affiliated Suzhou Hospital (n=5) and its affiliated Runda Community Health Centre (n=4). All respondents participated in the study on a voluntary basis and provided written informed consent prior to being included in the study. The interviewers were two researchers from Nanjing Medical University-Affiliated Suzhou Hospital who had previously undergone training and were experienced in conducting interviews. Each participant was assigned a unique number, which was used to identify them during both the completion of the demographic questionnaires and the interviews. Detailed information about the interviewed patients is provided in online supplemental file A2.

Three authors (HZ, WM and XT) analysed the qualitative data from the records of the in-depth interviews using content analysis,[25] aided by coding and aggregation using Nvivo V.14.0 software. The results include two parts: one to collate and summarise patients' ranking of attribute priorities to determine the attributes for inclusion, and the other to refine the levels corresponding to each attribute based on patients' statement.

### Expert consultation

Third, we invited six experts from the fields of neurology, geriatric care, long-term care and disability care for an expert consultation to refine the attributes and their corresponding levels. This process followed a Delphi method, which involved two rounds of consultation to ensure consensus on the suitability, definitions and expression of the attributes and levels. In the first round, experts reviewed and rated the relevance of the proposed attributes, suggesting refinements where necessary. Experts suggested that the original attribute 'provider of care' should be revised to 'qualification of staff' to more accurately reflect the levels below. In addition, the experts suggested that the attribute support should be limited to technical support and the corresponding levels should be revised. In the second round, the revised attributes were reviewed, and full agreement was reached. This iterative process was crucial for clarifying the meanings of the attributes and ensuring their comprehensiveness. Finally, seven attributes were identified, including location of care, type of care, qualification of staff, personalisation of care plan, duration of care, technical support and cost, each encompassed three levels. The details of attributes and corresponding levels are shown in table 1.

### Construction of the DCE questionnaires

Once the discrete experimental attributes and corresponding levels have been identified, hypothetical scenario choices comprising different combinations of attributes and levels must be constructed using an experimental design. The predetermined attributes and levels ($3^7$) will result in 2187 choice sets (ie, a full factorial design). However, in practice, it is often impractical to provide respondents with all hypothetical scenario choices. Huber and Zwerina[26] posited that the most effective experimental design is achieved when the four principles of orthogonality, level balancing, minimal overlap and utility balancing are met. Consequently, this study employed a partial factorial design of experimental design methodology to optimise the design of choice scenario sets using SPSS V.28.0 software. A partial factorial design of experimental design methodology was also conducted to optimise the design of the choice set of options, thereby reducing the number of options for respondents while ensuring the DCE design met the requisite statistical efficiency standards. The following two points were also taken into consideration during the choice set design process[27]: (1) in order to avoid any exaggeration of the relative weights of the attributes and improve the efficiency of the questionnaire, this study did not incorporate the opt-out exit option; and (2) despite the partial factorial design, there were still 18 choice sets with a total of 9 sets of options created. The results of the orthogonal experiment on the choice preference of patients who had a stroke with disabilities are provided in online supplemental file A3. To assess the internal consistency of the participants' choices, a random number method was employed to repeat the inclusion of the fifth choice set. However, the data from this choice set were not included in the final data analysis, and the final questionnaire comprised 10 choice sets. An example of the choice set is provided in table 2.

Finally, the questionnaire was presented in four sections. Section 1 described the purpose of the study and obtained informed consent from participants. Section 2 comprised the respondents' sociodemographic characteristics (age, gender, marital status, educational level, occupation, family income status, primary caregivers and payment of medical expenses) and disease-related data (time of first stroke, recurrence and comorbidities), which may influence patients' preferences for long-term care. Section 3 collected Barthel Index scores to assess the severity of the participant's disability. Section 4 comprised an introductory script designed to familiarise respondents with the hypothetical nature of the DCE. Subsequently, participants were presented with 10 sets of choice tasks.

A pilot survey (n=15) was conducted prior to the formal survey to assess whether the questionnaire content was clearly expressed and easily understood by participants. The data from these 15 patients were not included in the data analysis of the formal investigation. The majority of respondents found the survey to be of appropriate length and the content easy to comprehend. While some participants initially found certain attributes challenging to understand independently, they were able to complete the survey with assistance from the researcher. Based on this feedback, necessary refinements were made before finalising the questionnaire, which is finally provided in online supplemental file B.

### Sample and recruitment

The target population of this study is elderly patients who had a stroke with disabilities. Inclusion criteria are as follows: (1) age≥60 years (as in the context of China, the age of 60 is widely recognised as the threshold for defining 'elderly' in both legal and cultural terms); (2) at least 3 months post-stroke, comprising patients who met the criteria set forth in the China Cerebrovascular Disease Stroke Classification 2015[28] and were diagnosed with stroke by cranial CT or MRI; (3) Barthel Index scores≤100, with varying degrees of disabilities; and (4) provided informed consent and had the ability for clear expression. The exclusion criteria are as follows: (1) currently in the acute stage of stroke with unstable vital

**Table 1** Attributes and levels for discrete choice experiment choice questions

| Attributes | Levels | Description |
|---|---|---|
| Location of care | Institution | Care provided in a hospital or nursing facility |
| | Community | Care provided in a community setting, such as a community health centre |
| | Home | Care provided in the patient's home |
| Type of care | Basic care | Essential care mainly focuses on assisting with daily activities (like eating, bathing and dressing) |
| | Specialised care | Advanced care that addresses specific stroke-related needs, such as rehabilitation therapy or monitoring of stroke complications |
| | Health management | Focus on overall health maintenance, such as chronic disease control, medication management and health education |
| Qualification of staff | Registered nurses | Licensed healthcare professionals with advanced medical training who can manage treatments, administer medication, perform assessments and modify care plans |
| | Nurse aide | Support staff trained to assist with daily activities like feeding, bathing and mobility, mainly focus on personal care but do not perform clinical tasks |
| | Family caregivers | Informal care provided by family members with varying degrees of training and experience |
| Personalisation of care plan | Standardised care | A standardised care plan applied to all patients, with little customisation |
| | Partially standardised care | A care plan that allows some customisation based on the patient's personal needs |
| | Individualised care | A fully customised care plan developed specifically for the patient's individual preferences and clinical requirements |
| Duration of care | 24-hour care | Continuous care provided throughout the day and night, ensuring comprehensive supervision and support |
| | Day care services | Care provided during the day in specialised centres, with patients returning home in the evening |
| | Home visiting care (regular visits) | Periodic care visits to the patient's home for monitoring and support |
| Technical support | Basic technical support | Access to simple medical devices (such as walking aids, blood pressure monitors and blood glucose meter) to help with daily health needs |
| | Advanced technical support | Access to high-level equipment (such as ventilators or telemedicine and monitoring tools) to manage complex medical conditions |
| | No technical support | No specialised medical equipment is provided; care relies mostly on human assistance and personal support |
| Cost | Full reimbursement by health insurance | All care-related expenses are covered by insurance, minimising out-of-pocket costs for the patient |
| | Partial reimbursement by medical insurance | Some costs are covered by insurance, but the patient or family needs to pay a portion of the total care expenses |
| | Self-founded | The patient or family pays all the care costs directly, without financial help from insurance or government programmes |

signs; (2) diagnosed with other severe comorbid cardiovascular or neurological diseases; (3) presence of hearing impairment, mental abnormality or cognitive disorder; and (4) inability to fully understand the objectives and substance of the experiment despite detailed explanation provided by the investigators.

The calculation of the sample size for DCEs in healthcare is dependent on a number of factors, including the desired level of precision of the results, the complexity of the choice tasks, the format of the questions, the availability of the respondents, the heterogeneity of the target population and the necessity for subgroup analysis.[29] To date, researchers have commonly applied a rule of thumb to estimate sample sizes based on the number of attribute levels.[30] In our study, the sample size calculation is based on the rule of thumb proposed by Johnson and Orme,[30] and the calculation formula of the minimum sample size N is as follows: $n>1000\,c/(t\times a)$. In this equation, $t$ represents the number of choice sets faced by each individual (with the exception of the selection set that is repeatedly included), $a$ indicates the number of alternatives within each choice set, while $c$ denotes the number of analysis cells. When considering the main effect, $c$ is equivalent to the maximum level number of any attribute. The minimum sample size required for each version of the questionnaire is 167 ($t$=9, $a$=2, $c$=3). In light of the

**Table 2** Example of the choice task

| Attributes | Long-term care A | Long-term care B |
|---|---|---|
| Location of care | Home | Institution |
| Type of care | Health management | Basic care |
| Qualification of staff | Registered nurses | Registered nurses |
| Personalisation of care plan | Standardised care | Standardised care |
| Duration of care | Day care services | 24-hour care |
| Technical support | Advanced technical support | Basic technical support |
| cost | Partial reimbursement by medical insurance | Full reimbursement by health insurance |
| Which option would you prefer to choose? | ☐ | ☐ |

possibility that 20% of the recovered questionnaires may be invalid, it is prudent to recruit at least 500 elderly patients who had a stroke with disabilities to ensure the inclusion of sufficient data in the analysis and obtain a representative sample.

The research will be conducted in Suzhou, Jiangsu Province, a major city in Eastern China that has a relatively well-developed healthcare system and an ageing demographic structure similar to other cities in the region, such as Shanghai, Nanjing and Hangzhou. Studying long-term care preferences in Suzhou can serve as a reference for other areas within Eastern China that share similar socio-economic characteristics. All participants will be recruited by members of the study team from the Departments of Geriatrics and Neurology in Nanjing Medical University-Affiliated Suzhou Hospital (a tertiary hospital with five hospital districts and nearly 5000 beds) and its four affiliated community health centres. During recruitment, patients who enter the trial site and meet the investigator's inclusion and exclusion criteria for this study will be invited to participate in the survey. Interested volunteers will be briefed in detail by a researcher about the purpose of the study and the process. The survey will be conducted in a separate, quiet room within the clinic or ward. A trained researcher will be present to assist patients and answer all their questions. Questionnaires will be distributed to participants, with the distribution method being face-to-face. If participants requested an electronic questionnaire, they will be provided the questionnaire via WeChat or email. Each patient will only receive the questionnaire once. All questionnaires will be administered in Mandarin, which is a common language throughout China and widely used in daily speaking and writing. The questionnaires will be collected immediately after completion, and the investigator will review the responses for completeness. If any sections are found to be incomplete, participants will have the opportunity to provide the missing information on the spot.

## Study timeline

Data collection commenced on 28 November 2024 and is planned to continue for approximately 4–5 months, with an expected completion around May 2025. During this period, we aim to recruit approximately 500 participants. Following this, data processing and statistical analysis will be conducted.

## Statistical analysis

The final data will be analysed using SPSS V.28.0 and Stata V.18.0. Statistical significance is defined as a two-sided p value of <0.05. A DCE model will be constructed to analyse the following questions: (1) What are the preferences of elderly patients who had a stroke with disabilities for long-term care services? (2) What is the role of each attribute in influencing overall long-term care preference? (3) How do preferences vary across patient subgroups with different demographic and clinical characteristics?

Respondents will be excluded from the final analysis if they have at least one missing DCE task or if the majority of their sociodemographic data are incomplete. Descriptive statistics will be performed to summarise the respondents' sociodemographic and clinical characteristics. The normality of continuous variables will be assessed using the Shapiro-Wilk test, as well as graphical method via histograms. Normally distributed continuous variables will be reported as mean±SD, while non-normally distributed variables will be presented as median and IQR. Categorical variables will be summarised as frequencies (n) and percentages (%).

To analyse the DCE data, this study employs a mixed logit model, which accounts for preference heterogeneity across individuals by treating the coefficients as random variables.[31] Grounded in random utility theory, the mixed logit model assumes that a respondent's choice utility is influenced by a combination of fixed utility derived from observable attributes, stochastic utility components, error terms arising from unobserved attributes and variations in individual preferences.[32] The levels of the seven attributes are encoded using dummy variables. The utility $U$ of respondent $i$ in choice task $t$ for alternative $j$ is formulated as follows: $U_{ijt} = V_{ijt}(X_{ijt}, \beta_i) + \varepsilon_{ijt}$, where $V_{ijt}$ represents the fixed component of $U_{ijt}$, $X$ is a vector of alternative-specific attribute levels, $\beta_i$ denotes the corresponding coefficients, and $\varepsilon_{ijt}$ is the error term. A positive (or negative) $\beta$ coefficient signifies that a particular attribute level is preferred (or not preferred) in comparison to the reference level. The magnitude of the $\beta$ coefficient reflects the strength of preference, with larger absolute values indicating stronger preferences relative to the reference category. Statistical significance of the mean relative utility ($\beta$) and SD is determined based on whether their 95% CIs exclude the null value.

To assess the influence of each attribute on long-term care preferences, the RI of attributes will be calculated. RI quantifies the extent to which each attribute contributes to the total variation in preferences, expressed as the preference weight range.[33] RI values will be obtained by normalising the preference weight range of each attribute such that the total sum of all RI values equals 100%. Higher RI scores indicate that an attribute has greater influence on respondents' choices. The calculation of RI requires effect coding for attributes and levels. The RI of each attribute is derived using the formula: $RI = \frac{\Delta U\ \text{attribute}}{\sum \Delta U\ \text{all attributes}} \times 100$.

Subgroup analysis will be conducted to explore potential variations in preferences across different demographic and clinical characteristic groups. These subgroups include gender (men vs women), age (60–74 years vs 75–90 years vs >90 years), family income (<3000 vs 3000–6000 vs >6000), number of comorbidities (none vs 1–3 vs >3) and activities of daily living scores, categorised as severe disability (0–40), moderate disability (45–60) and mild disability (65–95). The mixed logit model will be estimated separately for each subgroup to assess preference heterogeneity. Interaction terms between subgroup indicators and attribute levels will be introduced to examine statistically significant differences in preferences.

Robustness checks will be performed by re-estimating the models using alternative model specifications, such as the conditional logit model, to ensure consistency in results. Model fit will be assessed using information criteria, including the Akaike information criterion and Bayesian information criterion.

### Patient and public involvement

Patients participated in two phases of DCE development, including qualitative interviews and pilot testing. The involvement of patients was intended to guarantee that the obtained results would reflect the genuine preferences of disabled patients who had a stroke with regard to long-term care services.

## ETHICS AND DISSEMINATION

This study has been approved by the Ethics Committee of Nanjing Medical University-Affiliated Suzhou Hospital (registration number K-2024-096 K01, registration date 3 March 2024). Patient recruitment for this study started from 1 November 2024 and is expected to end before 28 February, 2025. In accordance with the principles of voluntariness and confidentiality, the investigator will provide participants with an explanation of the background, purpose and potential risks associated with the study. This will be done prior to the participants signing a written informed consent form. All interview materials and questionnaires will be used solely for the purposes of this study and will be provided to researchers in an anonymous format to ensure confidentiality. Patients may withdraw from the research at any time. The data will be analysed in accordance with the principles of good scientific research on DCEs, as set forth by the ISPOR. The findings will be disseminated and shared with interested patient groups and the general public through a variety of channels, including online blogs, policy briefs, national and international conferences, and peer-reviewed journals.

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**Competing interests** None declared.

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