Benefit finding in first-ever young and middle-aged patients who had a stroke and their spousal caregivers in China: a longitudinal mixed-methods study protocol

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ABSTRACT

Introduction The global burden caused by stroke is shifting to young and middle-aged people. Researchers have emphasised the significance of benefit finding (BF) in psychological health. However, current research has paid little attention to stroke and has discussed BF from only a single perspective, that is, that of either patients or caregivers. Our study aims to understand the changing trajectory, predictors and dyadic interaction of BF in dyads of patient who had a stroke and caregiver.

Methods and analysis This study is a longitudinal mixed-methods, multicentre study. A total of 142 patients who had a stroke and 142 spousal caregivers will be investigated. Participants will be recruited from four large public hospitals in northern China. Quantitative and qualitative data will be collected at five time points (near discharge and 1, 3, 6 and 12 months following discharge). Validated and reliable questionnaires will be used in quantitative studies. Information on sociodemographic data, BF, functional status, perceived stress, coping styles and mutuality will be collected from the dyads. Qualitative data will be collected via semistructured interviews and observations. The growth mixture model will be used to analyse quantitative data, and Colaizzi’s seven-step analysis method will be used to analyse qualitative data. We plan to conduct parallel but separate quantitative and qualitative data analyses and ultimately integrate the data sets to determine confirmation, expansion or discordance.

Ethics and dissemination All participants will be provided with an informed consent form. This study will encode all identifiable data and store all recorded data on a secure research server. This study has been approved by the Ethics Review Committee of the College of Nursing and Health, Zhengzhou University (ZZUIRB2020-53). The results of the longitudinal study will be published in peer-reviewed journals and presented at national conferences.

Trial registration number ChiCTR2000039509.

INTRODUCTION

Stroke is the leading cause of death and disability worldwide, and one concern emerging is that the age of onset of stroke is decreasing. Stroke incidence among people aged 18–50 has increased by 40% worldwide. The highest reported incidence of stroke is in China, with an estimated 331–378 people affected per 100 000 life years. Among the 423 603 patients who participated in follow-up in China in 2017, the proportion of patients who had a stroke aged 40–59 years was as high as 56.8%. A 3-year longitudinal study showed that 16.8% of young and middle-aged patients who had a stroke had depressive symptoms and 23.0% had anxiety symptoms, and that these symptoms persisted 10 years after stroke. These psychological issues have a number of adverse effects on the health of patients who had a stroke, such as poorer recovery, more pronounced cognitive deficits, an increased chance of mortality and a decline in social participation. Within 1 year of suffering a stroke, patients who had a stroke with spousal care had a 51% lower
hospitalisation rate than patients who had a stroke without spousal care.\textsuperscript{7} Depressive symptoms affect up to 55\% of spousal caregivers.\textsuperscript{8} Stroke is associated with increased depressive symptoms among spouses, and caregiver depressive symptoms are connected with post-stroke depression.\textsuperscript{9,10} The majority of previous research has concentrated on identifying the symptoms and risk factors for psychological illness.\textsuperscript{11,12}

Stroke events do not merely have negative effects. A large number of studies have confirmed the prevalence of benefit finding (BF) among patients who had a stroke and their caregivers.\textsuperscript{13,14} BF is defined as a cognitive and behavioural response process in which individuals discover personal, social, psychological and spiritual benefits in the context of negative life events such as traumas or misfortunes.\textsuperscript{15} BF alleviates negative emotions and enhances positive emotions and happiness, effectively promoting individual mental health.\textsuperscript{16} BF is also linked to the physiological system, and a higher level of BF is related to a healthier cortisol circadian rhythm.\textsuperscript{17} According to studies, the BF of patients who had a stroke is at a moderate level; scale scores varied from 26 to 130, with the mean BF score of patients who had a stroke found to be 97.47±17.64.\textsuperscript{18} In contrast, the BF of stroke caregivers is at a low to medium level; scale scores varied from 22 to 110, and the mean BF score of spousal caregivers was found to be 69.35±15.46.\textsuperscript{19} A Chinese study discovered a link between BF of patients with cancer and that of their caregivers, patients were more likely to receive support from their spouses, and even good support from others, such as friends or family members, did not compensate for a lack of spousal support.\textsuperscript{20} With respect to the Chinese cultural background, it is essential to understand the BF of both patients and their spousal caregivers. Our study will focus on the BF from a dyadic perspective, which may provide a blueprint for the development of preventive interventions.

The majority of BF studies are cross-sectional in nature, with patients with cancer serving as the primary study population. BF has been shown in cross-sectional research to enhance mental health.\textsuperscript{21} However, cross-sectional studies are evaluated at a certain time point and cannot observe dynamic changes in BF, making it difficult to make causal inferences.\textsuperscript{22} Stroke is a dynamic process that changes over time. BF is a cognitive and behavioural response process that changes dynamically throughout the disease process.\textsuperscript{23} Patients may pay more attention to the response results, while spousal caregivers may pay more attention to the response process when coping with the disease. Therefore, couples’ BF may change over time.\textsuperscript{24} Longitudinal studies are thus required to follow the BF of dyads of patient who had a stroke and caregiver. To the best of our knowledge, no longitudinal study has investigated the BF of patients who had a stroke or caregivers. The first year after a stroke is the most challenging for dyads.\textsuperscript{25,26} Stroke has a unique disease path that lasts for 1 year from onset to sequelae.\textsuperscript{27} Further, the year following a stroke is a time when patients’ physical and mental functions change greatly.\textsuperscript{28}

Both quantitative and qualitative methods can be used to conduct longitudinal research.\textsuperscript{29} Although quantitative longitudinal study can shed light on the development trend of BF,\textsuperscript{30} it cannot provide an in-depth examination of psychological variables or explain the internal and subjective factors that affect BF changes. Qualitative longitudinal research can address research questions and provide new insights concerning previous waves of data collection,\textsuperscript{31} but it cannot provide intuitive data and development trends. Researchers are becoming more aware of the benefits of collecting data using a mixed-methods approach in the same study.\textsuperscript{32} Mixed-methods research can integrate findings from different methods.\textsuperscript{33}

METHODS AND ANALYSIS

Study purpose and objectives

This study aims to investigate changes in BF among first-ever young and middle-aged patients who had a stroke and their spousal caregivers within the first year after a stroke. The specific research objectives are as follows:

1. To identify the distinct trajectories of BF in dyads of patient who had a stroke and caregiver at five mutually exclusive time points.
2. To investigate the association of BF in dyads of patient who had a stroke and caregiver using a longitudinal mixed-methods approach.
3. To explore the predictors of BF in patients who had a stroke and their spousal caregivers from the patient, caregiver and dyadic perspectives.

Theoretical framework

The revised stress and coping theory and the theory of dyadic illness management will be used to guide this study. The revised stress and coping theory was developed by Folkman et al.\textsuperscript{34} Individuals’ responses to stress are influenced by a variety of factors, such as coping style, social support and cognitive evaluation. The most notable aspect of this theory is the introduction of a meaning-centred coping style.\textsuperscript{35} The theory highlights the fact that BF is the most common meaningful response. It has been discovered that BF reduces individual suffering while also promoting positive emotions. The impact of BF on positive or negative emotions will be observed via a qualitative study. These positive emotions can provide coping resources as well as the motivation needed to sustain a problem-centred long-term response.

The theory of dyadic illness management was proposed by American scholar Lyons in 2018.\textsuperscript{36} The theory of dyadic illness management is developed on the premise that illness management is a dyadic phenomenon. The predictors of BF among patients who had a stroke and their spousal caregivers can be considered from the perspectives of the patient, caregiver and dyads. BF promotes dyadic mental health by reducing negative emotions and stimulating positive emotions. This dyadic mental health status can provide feedback, which further affects the responses of the dyads to stress events. The theoretical
framework for this study is built by combining these two theories (figure 1).

**Study design**

A longitudinal mixed-methods approach will be used in this study. Both quantitative and qualitative data will be collected on the participants at each data collection point. The participants in both the quantitative and qualitative studies will be the same. This study will intend to conduct parallel but separate quantitative and qualitative data analyses. Following each interview, the information will be carefully analysed to determine which areas require additional attention in subsequent interviews. Quantitative data will be analysed only after all follow-up visits have been completed. Finally, the quantitative and qualitative data will be integrated in this study to conduct a more targeted mixed analysis. Figure 2 shows a diagram of the longitudinal mixed-methods design. The survey began in January 2022 and is scheduled to end in September 2023 (figure 3).

**Quantitative part**

**Data collection**

Patients who had a stroke and their spousal caregivers will be recruited from the neurology nursing units of four large public hospitals in northern China using a convenience sampling strategy. According to the disease stages associated with stroke and the disease trajectory proposed by Kirkevold, the time points of the longitudinal study are the duration of hospitalisation (near discharge, time 0), 1 month following discharge (time 1), 3 months following discharge (time 2), 6 months following discharge (time 3) and 12 months following discharge (time 4). During hospitalisation, quantitative data on patients who had a stroke and their spousal caregivers will be collected using standardised questionnaires. The researchers will double-check the information and make any necessary corrections once the questionnaires have been recovered. Following discharge, face-to-face follow-up will be conducted in the hospital department's reception area or a location specified by the participants based on their preferences and needs. If participants are unable to participate in face-to-face follow-up owing to physical problems or for any other reason, telephone follow-up will be conducted in this study. Quality control will be ensured in telephone follow-up: (1) This study will provide standardised research team training to each investigator to ensure that the investigator is extremely familiar with the unique content of the survey instruments and has good communication skills. (2) During the follow-up procedure, participants in this study will be interviewed when they have sufficient free time to engage in in-depth communication with us. (3) At the end of the interviews, this study will double-check some important information with the participants to make sure that their intentions are understood correctly.

**Population and sampling**

G*Power software V.3.1 will be used to calculate the number of participants. Multiple regression analysis with a power of 80% and an alpha value of 0.05 will be performed. The average effect value is 0.15, according to the definition by Cohen. Due to a 10% rate of invalid questionnaires and a 20% attrition rate for longitudinal follow-up, the estimated number of participants is 142 dyads.
The inclusion criteria for patients who had a stroke are as follows: (1) males aged 22–59 years and females aged 20–59 years; (2) patients who have suffered a first-ever stroke and meet various cerebrovascular diagnostic criteria; (3) patients with a certain level of language communication ability and cognitive function; and (4) patients who agree to participate in the study. The inclusion criteria for spousal caregivers are as follows: (1) males aged 22–59 years and females aged 20–59 years; (2) husband or wife of the patient; (3) identification by the patient as the principal unpaid, informal caregiver; and (4) agreement to participate in the study. Prior to being considered for inclusion, both patients and their spousal caregivers will agree to participate in the study.

The exclusion criteria for patients who had a stroke and their spousal caregivers are as follows: (1) patients or spouses with severe heart, liver or kidney dysfunction, respiratory failure or malignant tumours; (2) patients with a history of dementia, mental illness or mental retardation; and (3) participation in other studies.

Shedding criteria: one of the following events occurs: (1) participants are contacted more than three different times (not on the same day) by the researchers via telephone, short message service (SMS), WeChat or other methods and cannot be reached; (2) during the study, participants express a wish to terminate follow-up.

Study measures
The validity, reliability and usability of all the scales used in this study have been verified by other researchers. Studies have assessed the relationships between demographic and medical variables and BF. However, future research must investigate the link between BF and psychosocial outcomes. The outcomes of the predictors of BF are still debatable. This study will analyse the predictors of BF from the perspectives of the patient, caregiver and dyads.

From the patient’s perspective, predictors of BF include sociodemographic characteristics, disease-related indicators and psychosocial variables. Generally, women, elderly individuals and those with a higher level of education and a better socioeconomic status are associated with more BF. Severity, stage, diagnosis and time of illness are disease-related predictors of BF. A higher level of BF is related to optimism, a positive coping style and a lower level of perceived stress.

Figure 2  Flow chart of a longitudinal mixed-methods study design. T0: duration of hospitalisation (near discharge); T1: 1 month following discharge; T2: 3 months following discharge; T3: 6 months following discharge; T4: 12 months following discharge. → indicates the flow of activities; ←→ indicates activities occurring simultaneously. GMM, growth mixture model.
Predictors of caregivers’ BF are sociodemographic characteristics and psychosocial variables. Unmarried people, those who live in rural areas and religious caregivers have higher levels of BF. Younger caregivers are more likely to recognize the advantages of caregiving than older caregivers, but some studies have found that older caregivers benefit more. Positive coping style, optimism, less perceived stress and social support are important predictors of caregivers’ BF.

This study will focus on the important predictive effects of dyadic-related factors on BF. The relationship quality between patients and caregivers, as well as the perception of marital quality, was shown to be significantly positively connected with BF among dyads in studies involving heart failure and patients with Parkinson’s. In summary, the variables in this study are chosen based on the literature, theoretical research frameworks and expert consultation. The variables, measurement tools and measurement time involved in this article are shown in Table 1. The specific scales used are as follows.

**Sociodemographic and clinical data**

Specific questionnaires will be used to collect sociodemographic and clinical data from patients and their spousal caregivers.

1. Patients who had a stroke section: sociological data (age, gender, place of residence, educational level, religious affiliation, etc) and disease-related data (main symptoms, complications, rehabilitation exercise

### Table 1 Variables, measurement tools and measurement time

| Variables                              | Measured by                          | Individual measure | Measured in (month) |
|----------------------------------------|--------------------------------------|--------------------|--------------------|
|                                        |                                      | Patient who had a stroke | Spousal caregiver |                     |
| Sociocultural contextual factors       | Sociodemographic questionnaire        | ×                  | ×                  | 0                  |
| Proximal contextual factors            | Sociodemographic questionnaire        | ×                  | ×                  | 0                  |
| Ability to engage in daily living      | MBI                                  | ×                  |                    | 0, 1, 3, 6, 12     |
| Benefit finding                        | BFS                                  | ×                  |                    | 0, 1, 3, 6, 12     |
|                                       | CBFS                                 | ×                  |                    | 0, 1, 3, 6, 12     |
| Perceived stress                       | CPSS                                 | ×                  | ×                  | 0, 1, 3, 6, 12     |
| Coping style                           | SCSQ                                 | ×                  | ×                  | 0, 1, 3, 6, 12     |
| Mutuality relationship                 | MS                                   | ×                  | ×                  | 0, 1, 3, 6, 12     |

BFS, Benefit Finding Scale; CBFS, Caregiver Benefit Finding Scale; CPSS, Chinese Perceived Stress Scale; MBI, modified Barthel Index; MS, Mutuality Scale; SCSQ, Simplified Coping Style Questionnaire.
adherence, rehabilitation progress, recurrences during follow-up, etc).

2. Spousal caregivers section: sociological data (age, gender, income, occupation, etc), health status (co-morbidities, etc) and follow-up information (the presence or absence of other caregivers, daily patient care hours, etc).

**Functional status**
The modified Barthel Index will be used to evaluate the functional status of stroke. This scale includes 10 items: eating, personal hygiene, dressing, walking, bathing, toilet, stairs, bed and chair transfer and control of large or small urine. Each item is graded as follows: failure to complete the task, attempting the task but not safely, needing moderate help, needing a small amount of help and complete independence. The total score of the scale is 100. The higher the score, the better the patients' independence and abilities.

**Benefit finding**
The BF of patients will be measured via the Benefit Finding Scale. This scale has six dimensions and a total of 22 items. The six dimensions are acceptance, family relationships, world outlook, personal growth, social relationships and health behaviour. Each item is rated from 1 (not at all) to 5 (very much). The total score ranges from 22 to 110, with a higher score indicating better BF. The Cronbach’s alpha coefficient of the scale in this study is 0.925, and the item-level content validity index is 0.88–1.00.

The 26-item Caregiver Benefit Finding Scale will be used to measure perceived caregiving benefits for family caregivers of patients with stroke. The scale includes four dimensions of personal growth, health promotion, family growth and self-sublimation and is scored from 1 (very strongly disagree) to 5 (very strongly agree). The total score ranges from 26 to 130 points. The Cronbach’s alpha coefficients range from 0.885 to 0.953 for each dimension of this scale.

**Stress**
The Chinese Perceived Stress Scale will be used to measure the degree of perceived stress. This scale consists of 14 items divided into two dimensions: tension and out of control. A 5-point Likert scale is used for scoring. The out-of-control dimension is graded negatively, whereas the tension dimension is scored positively. Standardised scores (range 0–56) are computed, with higher values indicating greater perceived pressure.

**Coping style**
The Simplified Coping Style Questionnaire was revised to produce a simplified version for use in China in 1998 to measure the coping styles of patients and their spousal caregivers. The questionnaire employs a self-assessment method, with a total of 20 items covering both positive and negative coping dimensions. The positive coping score ranges from 0 to 36, the negative coping score ranges from 0 to 24 and the total score ranges from 0 to 60. When the scores of the two dimensions are compared, the higher the score, the more likely the patient will use this coping style.

**Mutuality**
The Mutuality Scale was developed on the basis of interviews conducted by Archbold et al with 76 elderly patients and their caregivers in 1990. Shyu et al adapted this scale into Chinese, and it is used to measure the quality of the interaction between patients and their spousal caregivers. The scale has 15 items with scores ranging from 0 to 4, including the four dimensions of love and affection, sharing joy, common values and reciprocity.

**Quantitative data analysis**
The IBM SPSS V21.0 software package will be used for data entry and analysis. The Mplus V8.3 software will be used to perform a growth mixture model (GMM) fitting analysis, and the test level will be treated according to bilateral α=0.05.

For quantitative data, descriptive statistics (mean, SD, median, IQR, frequency, percentage, t-test, etc) will be used to summarise the characteristics of patients and their spousal caregivers. Multivariate logistic regression analysis and Spearman correlation analysis will be used to analyse the influencing factors. The Mplus V8.3 software will be used to analyse the GMM. This method of analysis has significant advantages because it can describe the overall development trajectory of data and allows us to examine the heterogeneity of that trajectory. The parameter estimation method used in this study is the robust maximum likelihood estimator (MLR). The single category growth model is established first. Then, two and three potential types are established for model fitting. The model’s number of categories is expanded until the data no longer support it. The main fitting indicators are (1) the log likelihood; (2) the information evaluation index: the Akaike information criterion; the Bayesian information criterion (BIC) and the sample size-adjusted BIC, they judge the model fit by comparing the difference between expected and actual values; (3) the entropy index, which evaluates accuracy of classification with values ranging from 0 to 1, with 0.80 indicating that classification accuracy is better than 90%; and (4) the Lo-Mendell-Rubin adjusted likelihood ratio and the bootstrap likelihood ratio test, which are the most sensitive indicators of latent class classification, and they are used to compare the differences in fit between different latent class models, with p<0.05 indicating that k class models are significantly better than k-1.

**Qualitative part**
**Data collection**
This study will employ the descriptive phenomenological research method proposed by Husserl and Boyce. The essence of this method is to advocate for and pursue a direct understanding of things without incorporating inherent knowledge or prejudices. Semistructured
interviews and observations will be used to collect qualitative data. Face-to-face interviews will be conducted in a peaceful and safe room in the participant’s home or in the departmental reception room, allowing participants to express their true feelings in a relaxed and trusting environment. The location will be determined by the participants. The interview questions will be developed initially by studying existing research results and expert assistance, and the interview guides will be constantly updated to meet the situations encountered during the research process. Separate interviews will be conducted with patients and their spousal caregivers. Each participant’s interview will last approximately 40–60 min, and all interviews will be recorded. The interviews will be conversational, and there will be no need for strict order in the discussion of topics, which will emerge naturally during the discussion. One researcher will conduct the interviews, while the other will record the expressions, actions and emotional responses of the interviewees. Following the interviews, the two researchers will listen to the recordings independently and transcribe them within 24 hours. Timely analysis can help researchers achieve a better overall understanding of the interview content, collect sufficient data to answer research questions and provide a better basis for determining when data saturation is reached. In the process of conducting interviews across multiple time points, the following points will be focused on: (1) the content of the later repeated interview is largely driven by the results of the previous interview, and (2) this study will focus on ‘change’, that is, how the participants’ experience (BF) changes over time, the factors that affect these changes and the new influences that emerge. The interview outline includes the following questions (box 1).

Population and sampling

In terms of qualitative data, repeating qualitative interviews with each participant at each time point will significantly increase the workload of the researchers and the burden on participants. This protocol will employ a purposive sampling strategy. The participants will be drawn from the quantitative studies, and the number of participants will be determined based on when the interviews no longer reveal new themes and the data have reached saturation (the point when only repeated or non-substantial information emerges from the interviews). Participants who can provide rich and key information will be selected for our study. The following criteria will be used in the study: (1) gender representation in patients and caregivers; (2) diversity in sociodemographic and clinical information (rural/urban locations; religious beliefs/no religious beliefs; high income/low income; disease severity; disease type, etc); (3) participants can contribute a wealth of information, such as information about the quality of marital relationships and coping styles; and (4) sufficient reach to provide data saturation.

Box 1 Interview schedule

| Interview outline for patients who had a stroke | Interview outline for stroke spousal caregivers |
|-------------------------------------------------|--------------------------------------------------|
| ⇒ What changes have you noticed in your family, work and life since your illness (during this period)? | ⇒ What were your inner feelings when your spouse had a stroke? |
| ⇒ How have your feelings changed as a result of your illness (during this period)? What changes in your mood or sentiments have occurred since the last interview? | ⇒ What changes have you noticed in your family, work and life as a result of a family illness (during this period)? |
| ⇒ Have any benefits or positive outcomes developed as a result of experiencing stroke events? Have these positive outcomes (benefits) changed over time, and if so, what has caused these changes? | ⇒ What positive changes have occurred in your own feelings (or behaviour) while caring for a patient with stroke? Have these positive outcomes (benefits) changed over time, and what has caused these changes? |
| ⇒ What factors affected and supported your response to the stroke? Has anything changed in the things that helped you cope with the stroke? | ⇒ What factors do you think will have an effect on these positive changes? Have any of these factors changed throughout this time? |
| ⇒ What changes have taken place in your relationship with your spouse (during this period)? | ⇒ What changes have taken place in your relationship with your spouse while you have been providing care (during this period)? |
| ⇒ If you meet similar patients, how will you enlighten them? | |

Qualitative data analysis

Qualitative data will be summarised and analysed using Colaizzi’s seven-step analysis method,64 and NVivo V.10.0 software will be used to assist in this analysis. Qualitative data analysis will follow the steps described by Colaizzi: (1) familiarisation, which requires the researchers reading the collected data and becoming fully familiar with and understanding all of the associated contents; (2) identification of significant statements, since the purpose of word-by-word analysis is to identify and extract significant and pertinent statements about the research issues; (3) formulation of meanings, in which researchers encode the meaning of repeated points of view while bracketing pre-existing hypotheses as much as possible; (4) clustering themes, such that the encoded views are assembled to discover meaningful common concepts and develop the theme prototype; (5) the development of an exhaustive description in which, based on step 4, the researchers describe each topic in greater detail and extract typical original statements from the participants; (6) production of the fundamental structure through the development of a short intensive theme; and (7) seeking to verify the fundamental structure, which requires the researchers to return the generated thematic structure to the participants for verification.

Bracketing is an important premise in the research process, because it requires researchers to do as much as possible throughout the research process without being
affected by previous knowledge and experience to return to the things themselves. The following approaches will be used to ensure the rigour of this study. First, during the data collection process, research diaries will be used to record important details of the qualitative interviews. Second, two researchers who are not involved in the study but are familiar with qualitative research methods will be invited to read the transcripts independently and refine the themes to ensure the objectivity and authenticity of the study. In addition, each researcher will be instructed to avoid injecting his or her personal values into the themes. Finally, the qualitative research results will be compared with the experiences of non-participating dyads of patient who had a stroke and caregiver. The coding will feature a combination of manual coding and NVivo V.10.0 software. Following joint discussions among study group members, the controversial aspects of theme extraction will be determined. To better manage a large amount of qualitative data and conduct qualitative analysis over time, the trajectory method will be used to analyse the qualitative data. We will use the time-ordered, sequential matrices described in the study by Grossoehme and Lipstein.65

Integrating quantitative and qualitative data
At the conclusion of the longitudinal follow-up process, the quantitative and qualitative data will be integrated using a joint display method,66 and the data will be presented visually through charts, tables and graphics. There are three possibilities regarding the results of integration: (1) the quantitative and qualitative results are consistent or similar, which will be confirmed; (2) there is disagreement between the quantitative and qualitative results, indicating that they might be complementary; and (3) discordance occurs when the quantitative and qualitative results are inconsistent.

Patient and public involvement
Neither patients nor the public are involved in the design, conduct, reporting or dissemination plans associated with this research.

Ethics and dissemination
This study has been approved by the Ethics Review Committee for Life Sciences, Zhengzhou University in October 2020 (ZZUIRB2020-53) and is in keeping with the Declaration of Helsinki.

At the beginning of the survey, patients and their spousal caregivers will be made aware of the purpose, content, methods and significance of this study (including the form, time and purpose of the follow-up process). They will also be made aware that they should adhere to the follow-up. The advantages and risks of participating in this study will be clearly communicated to participants, who voluntarily agree to participate and sign written informed consent forms. This study will take a people-oriented approach. If the participants experience negative emotions or other adverse reactions while completing the questionnaire, this study will provide them with timely comfort, record participants who are missing or request to leave during the process and reflect on and optimise the research process in a timely manner. Participants have the right to choose to participate, refuse to participate or leave the process at any time, and their medical rights will not be jeopardised as a result of their choices.

The principle of confidentiality will be observed by all researchers during the course of this study. All participants’ health information and privacy will be kept private. The paper version of the data will be kept in an office cabinet, and the key to the cabinet will be kept by a designated person. To ensure that participants’ information is not accessible by third parties, the data will be kept in a separate database that only the researchers will be able to access. The recorded content from the qualitative research will be transcribed anonymously, and all public information will be kept anonymous. There are no ethical, legal or security concerns with any data collection, storage or dissemination associated with this study. The final results of this protocol will be presented at national conferences and published in peer-reviewed journals. The results of the study will also be shared with our partner hospitals that are taking part in the study.

DISCUSSION AND RELEVANCE OF THE STUDY DESIGN
To the best of our knowledge, this will be the first longitudinal study of BF among patients who had a stroke and spousal caregivers. A 1-year longitudinal study allows us to better investigate the causal relationships among variables.

First, most studies have been conducted from the perspective of either patients or caregivers. Stroke can be seen as a dyadic phenomenon that affects the mental health of both patients and their spousal caregivers.36 67 The psychological problems faced by both parties have the characteristics of mutual influence.6 In the context of traditional Chinese culture, family plays an essential part in the concept of ‘spiritual home’. Individual psychological needs are also met by families, which causes people to have a strong dependence on their family.68 Marriage is the most basic familial relationship, and patients and their spouses depend on each other.69 The psychological status of patients and their spousal caregivers is closely linked. Second, research on the mental health of patients who had a stroke or caregivers has mostly focused on stress and negative emotions, with an emphasis on the prevention and treatment of mental diseases. Focusing on the positive effects of BF implies shifting from ‘reducing negative emotions’ to ‘increasing positive qualities’.

Finally, this study will clarify the different trajectories of BF in first-ever young and middle-aged patients who had a stroke and their spousal caregivers. This study will also identify the predictors of BF at the patient, caregiver and dyad levels. This study will take a longitudinal mixed-methods approach to collect and integrate quantitative and qualitative data. By combining the benefits of these...
two methods, this study can investigate the causal relationships between variables and the causes of phenomena and related personal experiences. These results will provide a point of reference for future research on dyadic psychological interventions.

This study may have some limitations. A longitudinal mixed-methods study design and the simultaneous collection of information on patients and their spousal caregivers may place an additional burden on study participants. This difficulty is also a challenge for the research team, and it may require additional time and money. In addition, because of the limitations in terms of regions, races and cultural differences, the results may not be generalisable to other countries. Finally, participant dropout could be another potential limitation of this study. To reduce the occurrence of this situation, this study will establish follow-up files for all patients and their spousal caregivers to understand their situation and schedule follow-up work in their free time. Participants will be provided with service phones so they may call for assistance during the research. Participants can join the WeChat group at their own discretion, and this study will provide health knowledge or other content to participants as needed via SMS (for those who have not joined the WeChat group) or WeChat. Based on these methods, we will maintain positive interactions and communication with the participants to ensure a smooth follow-up and to control the quality of the study. We will also give a gift to the participants following each survey. This study will investigate the specific reasons for participants’ withdrawal of follow-up to enhance our follow-up procedure. This study will continue to provide health counselling and other services in accordance with participants’ desires to protect their rights.

Contributors HL is the first author, and ZZ and YM are the corresponding authors. ZZ and YM obtained funding. HL, ZZ and YM designed the study. HL, LZ, IW and DX collected the data. LZ and DX analysed the data. HL drafted the manuscript. ZZ and YM contributed to the interpretation of the results and critical revision of the manuscript for important intellectual content and approved the final version of the manuscript. All authors have read and approved the final manuscript. HL and LZ are the study guarantors.

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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.

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REFERENCES

1 Ekker MS, Boot EM, Singhal AB, et al. Epidemiology, aetiology, and management of ischaemic stroke in young adults. *Lancet Neurol* 2018;17:790–801.

2 Kuriakose D, Xiao Z. Pathophysiology and treatment of stroke: present status and future perspectives, *Int J Mol Sci* 2020;21:7609.

3 Wang L, Liu J, Yang Y. The prevention and treatment of stroke in China is still facing great challenges - *China Stroke Prevention Report 2018*. Summary. *China Circulation Journal* 2019;34:105–19.

4 Maalouf NAMM, Tonkoski A, Futter-Jacobs CA, et al. Long-term depressive symptoms and anxiety after transient ischaemic attack or ischaemic stroke in young adults. *Eur J Neurol* 2016;23:1262–8.

5 Cai W, Mueller C, Li Y-J, et al. Post stroke depression and risk of stroke recurrence and mortality: a systematic review and meta-analysis. *Ageing Res Rev* 2019;50:102–9.

6 Silva SM, Corrêa JCF, Pereira GS, et al. Social participation following a stroke: an assessment in accordance with the International classification of functioning, disability and health. *Disabil Rehabil* 2019;41:879–86.

7 Tyagi S, Koh GC-H, Nan L, et al. Healthcare utilization and cost trajectories post-stroke: role of caregiver and stroke factors. *BMC Health Serv Res* 2018;18:881.

8 Chung ML, Bakas T, Plue LD, et al. Effects of self-esteem, optimism, and perceived control on depressive symptoms in stroke Survivor Spouse dyads. *J Cardiacovasc Nurs* 2016;31:E8–16.

9 Malhotra R, Chei C-L, Menon E, et al. Short-term trajectories of depressive symptoms in stroke survivors and their family caregivers. *J Stroke Cerebrovasc Dis* 2016;25:172–81.

10 Min J, Jorganson JB, Fast J, et al. The impact of spouse’s illness on depressive symptoms: the roles of spousal caregiving and marital satisfaction. *J Gerontol B Psychol Sci Soc Sci* 2020;75:1548–57.

11 Mitchell AJ, Sheth B, Gill J, et al. Prevalence and predictors of post-stroke mood disorders: a meta-analysis and meta-regression of depression, anxiety and adjustment disorder. *Gen Hosp Psychiatry* 2017;47:48–60.

12 Medeiros GC, Roy D, Kontos N, et al. Post-stroke depression: a 2020 updated review, *Gen Hosp Psychiatry* 2020;66:70–80.

13 Lassmann I, Dinkel A, Marten-Mittag B, et al. Benefit finding in long-term prostate cancer survivors. *Support Care Cancer* 2021;29:4451–60.

14 Schaefer MR, Kenney AE, Hirsheloch AC, et al. A quest for meaning: a qualitative exploration among children with advanced cancer and their parents. *Psychooncology* 2021;30:546–53.

15 Taylor SE. Adjustment to threatening events: a theory of cognitive adaptation. *Am Psychol* 1983;38:1161–73.

16 Tejada-Gallardo C, Blasco-Belled A, Torrelles-Nadal C, et al. Effects of school-based multicomponent positive psychology interventions on well-being and distress in adolescents: a systematic review and meta-analysis. *J Youth Adolesc* 2020;49:1943–60.

17 Wang AW, Hoyt MA. Benefit finding and diurnal cortisol after prostate cancer: the mediating role of positive affect. *Psychooncology* 2018;27:1200–45.

18 Wang XL. Status and influencing factors of benefit finding in elderly stroke patients. Henan: Xinxiang Medical College, 2021.

19 Wang RT. Research on the benefit finding and influencing factors of primary caregivers of patients with ischemic stroke. Zhejiang: Huzhou Normal University, 2020.

20 Lin Y, Luo X, Li J, et al. The dyadic relationship of benefit finding and its impact on quality of life in colorectal cancer survivor and spousal caregiver couples. *Support Care Cancer* 2021;29:1477–86.

21 Mei Y, Wilson S, Lin B, et al. Benefit finding for Chinese family caregivers of community-dwelling stroke survivors: a cross-sectional study. *J Clin Nurs* 2018;27:1419–28.

22 Levin KA. Study design III: cross-sectional studies. *Evid Based Dent* 2006;7:24–5.

23 de Vries AM, Helgeson VS, Schulz T, et al. Benefit finding in renal transplantation and its association with psychological and clinical correlates: a prospective study. *Br J Health Psychol* 2019;24:175–91.

24 Panagopoulou E, Triantafyllou A, Mitziou G, et al. Dyadic benefit finding after myocardial infarction: a qualitative investigation. *Heart Lung* 2009;38:292–2.

25 Krauthof WJ, Post WMM, van Mierlo ML, et al. Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: determinants and prediction. *Patient Educ Couns* 2016;99:1632–40.

26 Segrin C, Badger TA, Silorakki A, et al. A dyadic analysis of stress processes in Latinas with breast cancer and their family caregivers. *Psychooncology* 2018;27:838–46.
27 Neurology Branch Of Chinese Medical Association. Guidelines for the diagnosis and treatment of acute ischemic stroke in China 2014. *Chinese Journal of Neurology* 2015;48:246–57.

28 Limampar P, Wongriratpong W, Kuptniratsaikul V. Depression after stroke at 12-month follow-up: a multicenter study. *Int J Neurosci* 2017;127:887–92.

29 Moseholm E, Fetter MD, Aho I, et al. Study protocol: becoming and being a mother living with HIV - a multicentre longitudinal mixed methods study among pregnant women living with HIV, non-pregnant women living with HIV and pregnant women not living with HIV in a high-income setting (the 2B MOM study). *BMJ Open* 2019;9:e027761.

30 Herts KL, Jorge-Miller A, Beran TM, et al. Appraisal, coping, health status, and psychological symptoms. *J Pers Soc Psychol* 1989;42:31–45.

31 Lytinen K, Lee CS. The theory of Dyadic illness management. *Health Psychol* 2002;22:35–41.

32 Schumacher KL, Plano Clark VL, Eilers J, et al. Methodological considerations for the design and implementation of a fully longitudinal mixed methods study. *Res Nurs Health* 2021;44:571–80.

33 Diaz-Méndez C, Adams J. The combined use of quantitative and qualitative methods in the study of obesity. *Gac Sanit* 2021;35:569–79.

34 Folkman S, Lazarus RS, Gruen RJ, et al. Benefit-finding among cancer patients with and without a spinal cord injury. *J Behav Med* 2002;25:341–52.

35 Folkman S. The case for positive emotions in the stress process. *Gerontologist* 2019;59:e791–801.

36 Lyons KS, Lee CS. The theory of Dyadic illness management. *J Fam Nurs* 2018;24:8–28.

37 Kirkevold M. The unfolding illness trajectory of stroke. *Disabil Rehabil* 2002;24:887–88.

38 Cohen J. Statistical power analysis. *Curr Dir Psychol Sci* 1992;1:98–101.

39 Kritikos TK, Stiles-Shields C, Shapiro JB, et al. Benefit-finding among young adults with spina bifida. *J Health Psychol* 2022;27:1176–86.

40 Sanjuelan P, Garcia-Zamora C, Ruiz M Ángeles, et al. Benefit finding in cardiac patients: relationships with emotional well-being and resources after controlling for physical functional impairment. *Span J Psychol* 2016;19:E50.

41 Wen K-Y, Ma XS, Fang C, et al. Psychosocial correlates of benefit finding in breast cancer survivors in China. *J Health Psychol* 2017;22:1731–44.

42 Jones SMW, Ziebell R, Walker R, et al. Psychometric investigation of benefit finding among long-term cancer survivors using the medical expenditure panel survey. *Eur J Oncol Nurs* 2016;20:31–5.

43 Zimmermann LA, Deng M, Handorf E, et al. Understanding benefit finding among patients with colorectal cancer: a longitudinal study. *Support Care Cancer* 2021;29:2355–62.

44 Liu Z, Zhang L, Cao Y, et al. The relationship between coping styles and benefit finding of Chinese cancer patients: the mediating role of distress. *Eur J Oncol Nurs* 2018;34:15–20.

45 Cavell S, Broadbent E, Donkin L, et al. Observations of benefit finding in head and neck cancer patients. *Eur Arch Otorhinolaryngol* 2016;273:479–85.

46 Llewellyn CD, Horney DJ, McGurk M, et al. Assessing the psychological predictors of benefit finding in patients with head and neck cancer. *Psychooncology* 2013;22:97–105.

47 Thornton AA, Owen JE, Kernstine K, et al. Predictors of benefit finding after lung cancer diagnosis. *Psychooncology* 2012;21:365–73.

48 Levesque JV, Maybery DJ. Predictors of benefit finding in the adult children of patients with cancer. *J Psychosoc Oncol* 2014;32:535–54.

49 Mei Y-X, Lin B-L, Zhang W-H, et al. Creating a caregiver benefit finding scale of family caregivers of stroke survivors: development and psychometric evaluation. *J Clin Epidemiol* 2020;117:794–802.

50 Gardner MH, Mrug S, Schwabeg DC, et al. Benefit finding and quality of life in caregivers of childhood cancer survivors: the Moderating roles of demographic and psychosocial factors. *Cancer Nurs* 2017;40:E28–37.

51 Pakenham KL, Cox S. Development of the benefit finding in multiple sclerosis (MS) caregiving scale: a longitudinal study of relations between benefit finding and adjustment. *Br J Health Psychol* 2008;13:583–602.

52 Pakenham KL, Sofronoff K, Samios C. Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding. *Res Dev Disabil* 2004;25:245–64.

53 Cassidy T. Benefit finding through caring: the cancer caregiver experience. *Psychol Health* 2013;28:250–66.

54 Brand C, Barry L, Gallagher S. Social support mediates the association between benefit finding and quality of life in caregivers. *J Health Psychol* 2016;21:1126–36.

55 Lum HD, Lo D, Hooker S, et al. Caregiving in heart failure: relationship quality is associated with caregiver benefit finding and caregiver burden. *Heart Lung* 2014;43:306–10.

56 Mavandadi S, Dobkin R, Mamikonyan E, et al. Benefit finding and relationship quality in Parkinson’s disease: a pilot dyadic analysis of husbands and wives. *J Fam Psychol* 2014;28:728–34.

57 Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel index for stroke rehabilitation. *J Clin Epidemiol* 2010;63:668–73.

58 Liu Z, Zhang L, Lisa G. Cross-Cultural adaptation of cancer patient benefit scale. *Chinese Journal of Nursing* 2015;50:561–6.

59 Yang T-zhong, Huang H-teng. [An epidemiological study on stress among urban residents in social transition period], *Zhonghua Liu Xing Bing Xue Za Zhi* 2003;24:760–4.

60 Xie Y. Preliminary study on reliability and validity of simplified coping style scale. *Chinese Journal of Clinical Psychology* 1998;2:114–5.

61 Archbold PG, Stewart BJ, Greenlick MR, et al. Mutuality and preparedness as predictors of caregiver role strain. *Res Nurs Health* 2016;39:1375–84.

62 Shyu Y-L, Yang C-T, Huang C-C, et al. Influences of mutuality, preparedness, and balance on caregivers of patients with dementia. *J Nurs Res* 2010;18:155–63.

63 Hassel E, Boyce GWR. Ideas: general introduction to pure phenomenology. London: George Allen & Unwin, 1967.

64 Colaizzi P. Psychological research as the phenomenologist views it. *Existential–phenomenological alter-natives for psychology*. New York, NY: Oxford University Press, 1978.

65 Crespo Á, Millán D, Lipstein E. Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. *BMC Res Notes* 2016;9:136.

66 Fetter MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res* 2018;53:4134–56.

67 Helgeson VS, Zajdel M. Adjusting to chronic health conditions. *Annu Rev Psychol* 2017;68:545–71.

68 Li H. On the cultural adaptability of family therapy in China — the application of family therapy in China from the perspective of the transformation of traditional family culture. *Educational science* 2004;20:57–60.

69 Qiao Q. Comparative study of husband-wife relationship patterns in traditional Chinese minority families. *Guizhou Ethnic Studies* 2002;22:35–41.