Patient Preference and Adherence

Dovepress
open access to scientific and medical research

Open Access Full Text Article

ORIGINAL RESEARCH

Relationship Between Illness Uncertainty and Family Resilience Among Caregivers of Stroke Patients in Chinese Nuclear Families: The Mediating Role of Perceived Stress

Qian Li[1,2], Caifeng Luo[1], Jianqin Ye[3], Zekun Bian[1], Weiyi Sun[1], Man Zhou[4], Mingzhu Rong[4]

[1]School of Medicine, Jiangsu University, Zhenjiang, Jiangsu, People's Republic of China; [2]Department of Neurosurgery, Xiangcheng People's Hospital, Suzhou, Jiangsu, People's Republic of China; [3]Department of Nursing, Xiangcheng People's Hospital, Suzhou, Jiangsu, People's Republic of China; [4]Department of Neurology, Suzhou Municipal Hospital, Suzhou, Jiangsu, People's Republic of China

Correspondence: Caifeng Luo, School of Medicine, Jiangsu University, No. 301 Xuefu Road, Jingkou District, Zhenjiang, 212013, People's Republic of China, Email lcf0105@163.com

Purpose: Stroke is a major disease endangering the health of Chinese people, and patients need to rely on the care of family members, which brings heavy caregiving burdens and pressures to caregivers and families, thus disrupting the stable family structure. In view of this, this study was to analyse the current status of family resilience among caregivers of stroke patients in Chinese nuclear families, and to explore the correlation and mechanism of action among perceived stress, illness uncertainty and family resilience.

Patients and Methods: This study used a cross-sectional research design. A total of 350 carers of stroke patients in nuclear families from four tertiary hospitals in Suzhou City, Jiangsu Province, China were selected by convenience sampling method and assessed by using demographic questionnaires, the Chinese Perceived Stress Scale (CPSS), the Parental Perceptions of Uncertainty Scale-Family (PPUS-FM), and a short Chinese version of the Family Resilience Assessment Scale (FRAS-C). Based on the above data, structural equation model was used to test the mediating role of perceived stress between illness uncertainty and family resilience.

Results: Family resilience among caregivers of stroke patients in nuclear families was at the medium lower level, illness uncertainty was at the medium level, and perceived stress was at the relatively high level. Illness uncertainty was positively correlated with perceived stress ($P<0.01$) and negatively correlated with family resilience ($P<0.01$). Illness uncertainty directly predicted family resilience ($\beta = -0.516$, $p < 0.05$). And the pathway between illness uncertainty and family resilience was partially mediated by perceived stress (Effect= −0.091, 95% CI [−0.141, −0.055]).

Conclusion: Healthcare professionals should pay adequate attention to the level of illness uncertainty and perceived stress among carers of stroke patients, with the need to take measures to reduce carers' illness uncertainty and perceived stress in order to improve family resilience.

Keywords: nuclear family, stroke, caregivers, perceived stress, illness uncertainty, family resilience

Introduction

The number of stroke patients in China is the highest in the world.[1] According to the data, By 2019, there were 17.04 million stroke patients in people aged 40 years and above in China, and 3/4 of the patients had residual complications such as motor impairment, cognitive impairment, speech impairment, and swallowing disorders.[1] Moreover, stroke was the second most common cause of death and the third leading cause of disability worldwide.[2] How to cope better depends largely on the patient's family members.[3] The nuclear family is defined as parents with or without unmarried children, regardless of the age of the unmarried children.[4] The nuclear family is the predominant family model in modern urban and industrial societies and the first family type structure in the country.[5] Research has

Received: 8 February 2024
Accepted: 25 May 2024
Published: 4 June 2024

shown that family structure determines the way in which resources within and outside the family coalesce and interact, and is a core element of family resilience.[6]

Family resilience refers to the ability and process of the family as a whole to cope with the stressful events that it encounters, helping it to disengage from difficult situations and regain a healthy adaptation of the family.[7,8] Stroke can also disrupt stable family structures and the disease creates a greater sense of uncertainty among family members.[9,10] Perceived stress is an individual's subjective perception of internal and external stressful events.[11] In terms of unmarried children in nuclear families, some are still in their first semester of school, and with about 75% of stroke patients being left with varying degrees of disability,[12] caregivers are faced with multiple pressures such as the burden of long-term care, child rearing, and financial obligations. Stress-coping theory[13] adds positive coping and positive emotions to traditional theoretical frameworks; that is, instead of focusing solely on the negative emotions brought about by the stressor, the focus is more on managing the stressful event with positive coping styles.

Existing research suggests that disease uncertainty is negatively associated with family resilience;[14] perceived stress mediates the relationship between disease uncertainty and quality of life,[15] and family resilience is related to quality of life.[16] Therefore, this study proposes the hypothesis that perceived stress may be an important mediating variable between illness uncertainty and family resilience. The study explores how illness uncertainty in carers of stroke patients in nuclear families affects family resilience through perceived stress, with the individual's stress response to the stressor as the mediating variable. In uncovering the positive psychology of caregivers of stroke patients in small Chinese families, a theoretical basis can be provided for interventions on family resilience for caregivers of stroke patients in nuclear families.

Materials and Methods

Study Design and Participants

A convenience sampling method was used to recruit 350 caregivers of stroke patients who were admitted to the neurology and neurosurgery units of four tertiary hospitals in Suzhou City, Jiangsu Province, China, from January to December 2023. The participant inclusion criteria were as follows: patient and carer belonging to the same nuclear family; carers of stroke patients meeting the diagnostic criteria in the Clinical Guidelines for Neurology (2010) compiled by the Chinese Medical Association and whose diagnosis has been confirmed by CT or MRI;patients in the acute period of stroke with stable vital signs; family members with primary caring responsibilities, that is, the person who spends the most time caring for the patient and who has the most caregiving tasks during the day; aged ≥ 18 years; able to co-operate with investigators. The exclusion criteria were as follows: persons with other major traumatic events in the family; and being a paid professional escort.

Data Collection

Before the survey, the researcher was trained in matters related to administering surveys. During data collection, for subjects with reading difficulties, the researcher paraphrased the questionnaire entries and recorded the subjects' answers faithfully. The researcher explained any entries that the subjects did not understand, but did not interfere with the subjects' choice of answers. The questionnaires were distributed on-site, anonymised, filled out independently, collected on-site, and checked for completeness, with the whole survey taking approximately 20–30 minutes to complete. According to the formula $n=\mu 2\alpha/2\sigma 2/\delta 2$,[17] $\alpha=0.05$, $\mu 0.05/2=1.96$ were taken in this study. The results of the pre-survey conducted in this study among 60 stroke carers showed that the total family resilience score was (92.85 ±19.02); therefore, $\sigma=19.02$ and δ takes the absolute value of $(X-\mu)$. Based on previous literature,[18] it is known that the total family resilience score is (96.66±8.15); therefore, $n=1.962\times19.022/3.812$. The calculation was made for a sample of 96, taking into account a 20% dropout rate, estimating a total of 116. In addition, structural equation model generally recommends a median sample size of 200.[19] Including pre-survey data, a total of 365 primary carers were recruited to complete the questionnaire: 11 carers refused to participate, four questionnaires were excluded due to incomplete information, and 350 (95.9%) participants returned a complete and valid questionnaire.

Measures

Socio-Demographic Characteristics

Based on an extensive review of the literature, a self-designed questionnaire was used to collect the basic demographic characteristics of acute stroke patients and their primary caregivers within the nuclear family. The data included the patient's age, gender, marital status, type of stroke (obtained by consulting medical records), whether they were the main source of family finances before the disease, and their level of self-care ability (A score of ≤60 for moderate and severe dependence and 61–99 for mild dependence,[20] this was obtained by consulting the medical records). Information on the primary caregiver included age, sex, marital status, place of residence, daily caregiving hours, literacy level, caregiver–patient relationship, and monthly household disposable income. These data were collected mainly through medical records and caregiver self-reporting.

Shortened Chinese version of the Family Resilience Assessment Scale (FRAS-C)

The FRAS-C was translated and introduced by Li et al.[21] It consists of 32 entries in three dimensions, including family communication and problem solving, utilizing social resources, and maintaining a positive outlook. The scale is rated on a four-point Likert scale. The total score ranges from 32 to 128, with "strongly disagree" scoring 1 and "strongly agree" scoring 4. The higher the score, the higher the level of family resilience. The Cronbach's coefficient for this scale among the stroke patient caregivers in this study was 0.976.

Chinese Perceived Stress Scales (CPSS)

The CPSS was compiled and revised by the Chinese scholar Yang,[22] and is mainly used to assess the individual's perception of stressful events. The scale consists of 14 items, including two dimensions: sense of tension (7 items) and loss of control (7 items). The scale was scored on a five-point Likert scale, in which the seven entries of the sense of loss of control (4, 5, 6, 7, 9, 10, 13) were reverse-scored (4–0), with the total score ranging from 0 to 56. The scores for normal stress ranged from 0 to 28, for relatively high pressure were 29–42, and for excessive stress were 43–56. The higher the scores, the higher the perceived stress. The Cronbach's coefficient for this scale among the stroke patient caregivers in this study was 0.976.

Parents' Perception of Uncertainty Scale—Family (PPUS-FM)

The survey was conducted using the Chinese version of the Parents' Perception of Uncertainty Scale—Family (PPUS-FM), which was translated and modified by Cui.[23] The scale consists of 30 items, including four dimensions: ambiguity (13 items), complexity (8 items), inconsistency (5 items), and unpredictability (4 items). The scale is based on a five-point Likert scale. Method: 1 to 5 points from "strongly agree" to "strongly disagree", with 20 positive points and 10 negative points. Entries 6, 9, 11, 19, 23, 25, 27, 28, 30, and 31 were reverse-scored, and the total score of the scale ranged from 30 to 150 points, divided into three levels, with 30–70 points being low, 71–111 points being medium, and 112–150 points being high. The higher the score, the higher the uncertainty of the disease. The Cronbach's alpha coefficient for this scale among the stroke patient caregivers in this study was 0.968.

Statistical Analysis

The data were entered using EpiData 3.1 and were double-checked and statistically analyzed using SPSS 26.0. Bilateral $p< 0.05$ was statistically significant. Depending on whether the data obeyed a normal distribution, continuous data were described by mean ± standard deviation (SD) or median, categorical data by frequency and percentage, and Pearson correlation was used to explore the relationship between these variables. Structural equation model (SEM) was used to test the mediating effect of perceived stress, bias-corrected non-parametric percentile bootstrap analysis was used with a setting of 5000 repetitions of the sample, and confidence intervals were set to 95% to test for the significance of the mediating effect. The model fitting was carried out using the maximum likelihood ratio method. The chi-square/degrees of freedom ($\chi 2$/df), comparative fit index (CFI), Tucker–Lewis index (TLI) and incremental fit index (IFI), relative fit index (RFI), norm fit index (NFI), comparative fit index (GFI) and root-mean-square of the approximation error (RMSEA) were used to evaluate the model's goodness-of-fit. The 95% confidence intervals (CI) were used to estimate the significance of the mediation effect. The mediation effect is significant if the 95% CI does not contain 0. SEM was run in AMOS 23.0.

Results

Demographic Characteristics

Caregivers of stroke patients with acute period strokes in 350 nuclear families, 73 cases (20.9%) were aged <45 years, 227 cases (64.8%) were aged 45 to 60 years, 50 cases (14.3%) were aged >60 years. There were 279 cases (79.7%) of ischaemic stroke and 71 cases (20.3%) of haemorrhagic stroke. The demographic characteristics of the 350 nuclear families are shown in Table 1.

Table 1 Descriptive Statistics of Demographic Characteristics (n = 350)

Variables	Categories	Number of Cases (Percentage, %)
Patient's age (years)	<45	73 (20.9)
	45–60	227 (64.80)
	>60	50 (14.3)
Patient's gender	Man	197 (56.3)
	Women	153 (43.7)
Patient's marital status	Married	288 (82.3)
	Unmarried	42 (12)
	Divorcee	15 (4.3)
	Widowhood	5 (1.4)
Type of stroke	Ischemic	279 (79.7)
	Haemorrhagic	71 (20.3)
The main source of family finances before the disease	Yes	271 (77.4)
	No	79 (22.6)
Level of self-care	Moderate to heavy dependence	149 (42.6)
	Mild dependence	201 (57.4)
Age of caregivers (years)	<45	108 (30.9)
	45 to 60	218 (62.3)
	>60	24 (6.8)
Gender of caregivers	Man	139 (39.7)
	Women	211 (60.3)
Marital status of caregivers	Married	293 (83.7)
	Unmarried	52 (14.9)
	Divorcee	4 (1.1)
	Widowhood	1 (0.3)
Caregivers' place of residence	City	199 (56.9)
	Countryside	151 (43.1)
Daily care hours	≤4h/d	49 (14)
	5~8h/d	157 (44.9)
	9~12h/d	79 (22.6)
	≥13h/d	65 (18.6)
Literacy level of caregivers	Primary and below	152 (43.4)
	Middle school	134 (38.3)
	College and above	64 (18.3)
Patient-caregiver relationships	Spouse	256 (73.1)
	Parent	33 (9.4)
	Children	39 (11.1)
	Other	22 (6.4)
Monthly disposable household income(yuan)	<1000	65 (18.6)
	1000 to 3000	119 (34.0)
	3000 to 5000	116 (33.1)
	>5000	50 (14.3)

Illness Uncertainty, Perceived Stress, and Family Resilience Scores for Stroke Caregivers

The total scores of family resilience, illness uncertainty, and perceived stress of the stroke caregivers in this study were (90.55±21.29), (82.17±22.79), and (33.95±15.65), respectively. The scores for each dimension are shown in Table 2

Analysis of the Correlation Between Illness Uncertainty, Perceived Stress, and Family Resilience Among Stroke Carers

According to the results of bivariate correlation analyses, illness uncertainty was significantly positively associated with perceived stress and significantly negatively associated with family resilience; perceived stress was significantly negatively associated with family resilience; the results are shown in Table 3

Mediating Role of Perceived Stress Between Illness Uncertainty and Family Resilience

SEM for Model Testing

Structural equation model was constructed using illness uncertainty as the independent variable, family resilience as the dependent variable, and perceived stress as the mediator variable. The SEM results showed that the structural equation model fitted the data well:[24] $\chi 2/df = 1.659$, SRMR = 0.0360, GFI = 0.975, NFI = 0.976, CFI = 0.990, TLI = 0.986, RFI=0.964, IFI= 0.990, and RMSEA = 0.043.

Mediating Role of Perceived Stress Between Illness Uncertainty and Family Resilience

As presented in Figure 1, the standardized coefficient of illness uncertainty on perceived stress was $\beta=0.339$, $p<0.001$, of perceived stress on family resilience was $\beta=-0.269$, $p< 0.001$, and of illness uncertainty on family resilience was $\beta=-0.516$, $p<0.001$, with significant levels of individual path coefficients for the model. A bias-corrected non-parametric percentile bootstrap analysis with 5000 replicate samples was set, and the confidence interval was set at 95% to test for the significance of the mediating effect. The results showed that the direct effect of illness uncertainty on family resilience was −0.516, the indirect effect of caregiver illness uncertainty → perceived stress → family resilience was −0.091, and the total effect of illness uncertainty on family resilience was −0.607, with a 95% CI excluding 0; thus, the mediating effect was established.

The above model was further tested using the bootstrap bias-corrected self-help method; the results are shown in Table 4.

Table 2 Illness Uncertainty, Perceived Stress, and Family Resilience Scores for Stroke Caregivers (n=350)

Variables	Scale Score (M±SD)	Item Score (M±SD)
Illness uncertainty	82.17±22.79	2.74±0.76
Ambiguity	35.29±11.77	2.71±0.91
Complexity	22.02±7.69	2.75±0.96
Inconsistency	13.42±4.4	2.68±0.88
Unpredictability	11.43±3.38	2.86±0.84
Perceived stress	33.95±15.65	2.43±1.12
Sense of tension	17.19±8.05	2.46±1.15
Sense of loss of control	16.76±8.64	2.39±1.23
Family Resilience	90.55±21.29	2.83±0.67
Family Communication and Problem Solving	65.79±15.72	2.86±0.68
Use of social resources	8.07±2.51	2.69±0.84
Hold a Positive View	16.70±4.63	2.78±0.77

Abbreviations: M, mean; SD, standard deviation.

Table 3 Correlation Analysis Between Illness Uncertainty, Perceived Stress, and Family Resilience Among Stroke Caregivers

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1 Ambiguity	1											
2 Complexity	0.588**	1										
3 Inconsistency	0.478**	0.575**	1									
4 Unpredictability	0.541**	0.737**	0.500**	1								
5 Illness uncertainty	0.887**	0.861**	0.708**	0.773**	1							
6 Sense of tension	0.170**	0.218**	0.211**	0.210**	0.233**	1						
7 loss of control	0.197**	0.293**	0.239**	0.251**	0.284**	0.759**	1					
8 Perceived Stress	0.196**	0.274**	0.241**	0.246**	0.277**	0.933**	0.942**	1				
9 FCPS	−0.320**	−0.528**	−0.338**	−0.569**	−0.493**	−0.374**	−0.400**	−0.413**	1			
10 USR	−0.193**	−0.356**	−0.199**	−0.378**	−0.314**	−0.303**	−0.318**	−0.331**	0.721**	1		
11 MPO	−0.212**	−0.427**	−0.248**	−0.447**	−0.368**	−0.330**	−0.324**	−0.349**	0.750**	0.536**	1	
12 Family Resilience	−0.305**	−0.525**	−0.327**	−0.562**	−0.481**	−0.384**	−0.403**	−0.420**	0.986**	0.767**	0.835**	1

Note: **p<0.01, two-tailed tests.

Abbreviations: FCPS, Family Communication and Problem Solving; USR, Utilizing Social Resources; MPO, Maintaining a Positive Outlook.

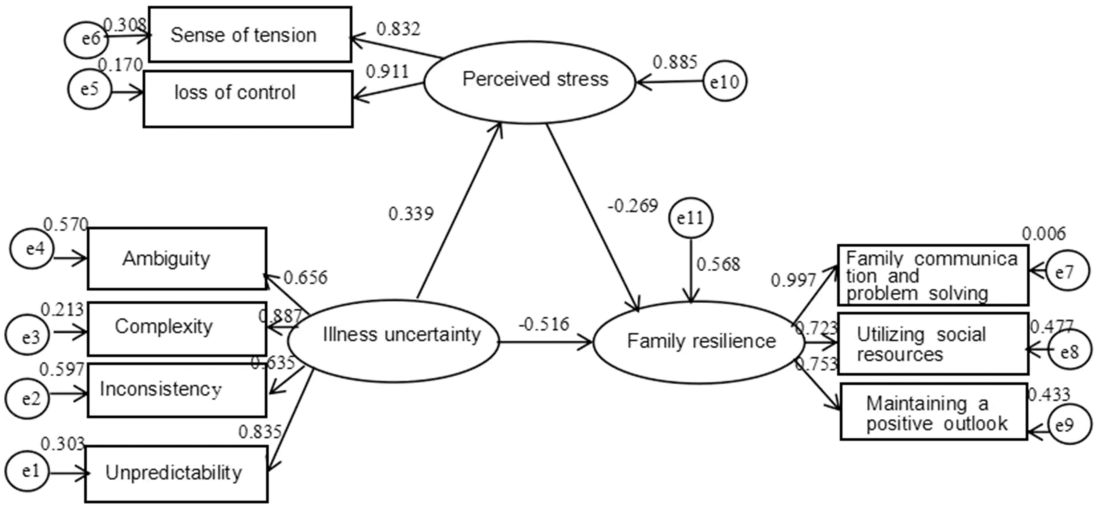

Figure 1 Fitted Model of The Mediating Role of Caregiver Perceived Stress With Illness Uncertainty and Family Resilience.

Discussion

Family Resilience Among Caregivers of Stroke Patients Was at the Medium Lower Level

The results showed that the total family resilience score for the caregivers of stroke patients was (90.55±21.29) and the mean score of the entries was (2.83±0.67). These findings are lower than those of Chang[25]. On the one hand, this may be related to the fact that 256 (73.1%) patients in this study were cared for by their spouses, at which point the close parent–child relationship in the longitudinal axis within the nuclear family constitutes a good cohesion within the family, which provides a coping synergy for positive coping with risk adversity. However, as some children in nuclear families are still in their first semester of school and rely on their parents to support them with food, clothing, shelter, and transport, caregivers need to take care of their sick spouses as well as raise their children, and their coping capacity is weakened.[26] This leads to lower levels of psychological resilience[27] and, consequently, lower levels of family resilience.[28] On the other hand, nearly half of the patients in this study were heavily dependent on others for self-care, and in cross-sectional surveys of breast cancer patients[29] and dementia patients,[30] longitudinal studies of families of cancer patients,[31] and qualitative studies of families of patients with schizophrenia[32] and dementia patients,[33] scholars have found that the more severe the degree of illness of the patient, the lower the level of family resilience. In this study, 60.3% of the caregivers were female, bound by the traditional female family role of caregiving, female caregivers tend to overextend themselves to care for their spouses out of instinct, resulting in a deep sense of "overwhelm". The longer the caregiving time, the greater the caregiver's commitment to the patient, the greater his or her own consumption, and the companionship of the patient will change his or her own habits of living, socializing, resting, and exercising. This makes the caregiver more prone to adverse emotions, forcing adverse changes to the harmonious and stable family relationship and affecting family cohesion, which is not conducive to the generation of family resilience.[34] It is suggested that medical professionals and

Table 4 Mediating Model Examination by Bootstrap

Effect	Effect Size	SE	Bootstrap 95% CI	
			Lower	Upper
Indirect effect (Illness uncertainty→perceived stress→family resilience)	−0.091	0.021	−0.141	−0.055
Direct effect (Illness uncertainty→family resilience)	−0.516	0.068	−0.647	−0.379
Total effect	−0.607	0.060	−0.719	−0.482

Abbreviations: SE, standard error; CI, confidence interval.

the community should mobilize family, institutional, or social organizational forces to provide respite services, emotional support, etc, for carers in order to promote proper family functioning.

Moderate Levels of Illness Uncertainty Among Caregivers of Stroke Patients

The results showed that the total illness uncertainty score of caregivers of hospitalized stroke patients was (82.17±22.79), which was in line with the findings of Liu et al,[35] with the highest mean uncertainty score (2.80±1.08) and the highest score among the uncertainty entries being "It is difficult to know if the treatments/medications are helping" scored the highest. The reason for this is that in our study, the caregivers in the nuclear family were the parents of the patients in 33 cases (9.4%), and such caregivers were relatively older, coupled with the fact that the patients were mostly without spouses, lacked the ability to obtain information about the disease from their other half, and had a higher level of fear of the disease.[36] On the other hand, approximately 81.7% of the carers had an educational level below secondary school, making it difficult for them to properly understand disease-related information, and they had more questions about rehabilitation training, disease management, life care, and other aspects, and inevitably had doubts about the efficacy of stroke treatments. It is suggested that medical staff increase disease knowledge guidance and education for carers of patients with relatively low literacy and who have no spouse, which can be carried out in the form of face-to-face explanations, knowledge brochures, ward-unified mission, etc., to increase the frequency of doctor–patient exchanges to improve carers' degree of knowledge regarding the disease and reduce their level of uncertainty.

Perceived Stress Among Caregivers of Stroke Patients Was at the Relatively High Levels

The results showed that the total score for perceived stress was (33.95±15.65), which was higher than the findings of Guo et al.[12] One reason is that nearly two-thirds of the patients in our study were aged between 45 and 60 years old, and the survey showed that the incidence of stroke in young and middle-aged people in China is 66.6%.[37] Because most of this age group is in the most important stage of social participation, in 271 cases (77.4%), the stroke patient had been the main source of family income before the disease and shouldered multiple financial obligations such as the mortgage, car loan, and raising and nurturing the children. Due to the small size of the nuclear family, there is a lack of replaceable caregivers. They are unable to fully devote themselves to their work and the family income is often not enough to make ends meet; caregivers face the double pressure of illness and finances. On the other hand, in this study, there were 39 cases (11.1%) in which the caregivers were the children of the patients, and most of these nuclear families consisted of one parent and their unmarried children; However, parents love their children and will plan far ahead for them, especially after a parent's illness, and worry that their children will have nothing to rely on in the future. However, due to the stigma associated with the disease[38] and the impact of modern marriage concepts and high marriage costs,[39] this type of nuclear family, which is unable to afford to marry, often attracts a different perspective,[40] resulting in tremendous mental stress for both patients and caregivers. High levels of perceived stress can easily lead to various problems such as cortisol rhythm disorders, non-compliance with healthcare system behaviors, and damage to one's own health.[41] Therefore, medical staff need to help carers of stroke patients to face their problems rationally, encourage patients to accept reality and to face the later stage of rehabilitation and treatment with a positive attitude. At the governmental level, the reimbursement rate of medical insurance for stroke treatment and rehabilitation should be increased to alleviate the financial pressure on core family members.

Family Resilience in Relation to Illness Uncertainty and Perceived Stress

The results of the study showed that the family resilience among caregivers of stroke patients was negatively correlated with disease uncertainty ($r = -0.481$, $P < 0.01$). When the caregiver has knowledge of the disease risk factors, causes, treatment programmers, rehabilitation plans, etc., their level of uncertainty about the disease will be reduced, which reduces the level of anxiety and depression,[42] thus increasing individual resilience.[43] At this point, if the core family members can share the responsibility and actively utilize the internal resources of the family, they will successfully withstand the crisis, restore the stability of the family, and improve family resilience.

The results of the study also showed that the family resilience of caregivers of stroke patients was negatively correlated with perceived stress ($r = -0.420$, $P < 0.01$). Consistent with Tao's[44] findings, the higher the perceived stress, the lower the family's confidence in coping with the crisis and the weaker the buffering capacity against stress, resulting in a lower level of family resilience. However, it is precisely because of the simple structure of the nuclear family and the small number of members that when one person is sick, the stable and close family relationship in the nuclear family encourages the formation of the idea of "sharing the same burden" among members. This good family relationship is the core of the family's homeostatic mechanism, which is the key to the success of family resilience. It is suggested that medical personnel should encourage the frequency of interaction and communication among nuclear family members to enhance family cohesion and thereby improve family resilience.

Perceived Stress Mediates the Relationship Between Illness Uncertainty and Family Resilience

This study was validated by structural equation model using AMOS 23.0, which showed that there was a direct effect between illness uncertainty and family resilience in caregivers of stroke patients ($\beta = -0.516$, $P < 0.05$), a direct effect between illness uncertainty and perceived stress ($\beta = 0.339$, $P < 0.05$), and a direct effect between perceived stress and family resilience ($\beta = -0.269$, $P < 0.05$). Illness uncertainty can indirectly affect family resilience through perceived stress, with an indirect effect of −0.091 and a total effect of −0.607. Perceived stress partially mediates the relationship between caregivers' illness uncertainty and family resilience in stroke patients; ie, caregivers' mastery of high levels of the illness can indirectly affect the level of family resilience by decreasing perceived stress. The reason for this is that the stroke caregivers in nuclear families reduce the level of illness uncertainty while relying on the disease knowledge imparted by healthcare professionals to reduce the level of perceived stress, and lower perceived stress brings caregivers positive and active emotions, which enables them to recognize their own importance to the patient and the family, have higher levels of hope,[45] feel more caring and supportive,[46] and more easily grow and improve their family resilience.

Strengths and Weaknesses of the Study

Our study innovatively analyzed the current status of illness uncertainty, perceived stress and family resilience among caregivers of stroke patients within the Chinese nuclear family from the perspective of family structure, and explored the relationship between them using structural equation model. The pathway relationships revealed by our study could provide new insights and references for interventions on family resilience for caregivers of stroke patients. However, this study is only a cross-sectional survey. Using a structural equation model can only test the correlation between variables, not prove causality between them and the mediating role of perceived stress should be verified longitudinally. Moreover, our research was conducted in just one city, the findings had limits on extrapolation.

Conclusions

Perceived stress mediates the relationship between illness uncertainty and family resilience among caregivers of stroke patients in nuclear families. This result provides a new practical perspective to explore the mechanisms influencing the relationship between illness uncertainty and family resilience. In the future, healthcare professionals should proactively educate caregivers about the disease and caregiving to enhance caregivers' sense of control over their care and to reduce illness uncertainty; Meanwhile, a variety of interventions should be implemented to help caregivers reduce perceived stress and ultimately improve family resilience.

Data Sharing Statement

Data are available on reasonable request. Data from the study are available on reasonable request to the corresponding author.

Ethics Statement

This research programme followed the guidelines detailed in the Declaration of Helsinki and was reviewed by the Medical Ethics Committee of Jiangsu University with approve number "JSDX20221229001". All participants volunteered to take part in the study and signed an informed consent form.

Consent for Publication

Written informed consent for publication was obtained from all patients and their caregivers included in the study.

Acknowledgments

We are especially grateful for the cooperation of all stroke patients and healthcare staff in the multi-center investigate.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This research received grants from Chinese Medical Association 2022–2023 (No. CMAPH-NRG2022028) and the Graduate Research and Innovation Projects of Jiangsu Province (No. SJCX23-2097).

Disclosure

The authors declare no conflicts of interest.

References

1. Wang L, Peng B, Zhang H, et al. Brief report on stroke prevention and treatment in China, 2020. *Chin J Cerebrovasc Dis*. 2022;19(02):136–144.
2. Feigin VL, Stark BA, Johnson CO, et al. Global, regional, and national burden of stroke and its risk factors, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol*. 2021;20(10):795–820. doi:10.1016/S1474-4422(21)00252-0
3. Zhou Y, Hua B, Shi X, et al. Exercise intention and its associated factors among persons post-stroke: a cross-sectional study. *Patient Prefer Adherence*. 2023;17:2535–2544. doi:10.2147/PPA.S424595
4. Zhang M. *A Study on the Resilience of Different Family Structures of Disabled Elderly People in Minority Areas Based on Family Life Cycle*. Shihezi University; 2022.
5. Wang L. The changes of china family structure and its policy implications—Thoughts on the"Modernization of a Huge Population". *J Popul Develop*. 2023;29(01):118–122.
6. Wang L. Analysis of family resilience status and related factors of school-age children with lobar pneumonia. *Qilu Nurs J*. 2022;28(17):101–104.
7. Cui P, Shi J, Li S, et al. Family resilience and its influencing factors among advanced cancer patients and their family caregivers: a multilevel modeling analysis. *BMC Cancer*. 2023;23(1):623. doi:10.1186/s12885-023-11101-z
8. Walsh F. Applying a family resilience framework in training, practice, and research: mastering the art of the possible. *Fam Process*. 2016;55 (04):616–632. doi:10.1111/famp.12260
9. Wang J, Cui J, Tu S, et al. Resilience and caregiving ability among caregivers of people with stroke: the mediating role of uncertainty in illness. *Front Psychiatr*. 2022;13:788737. doi:10.3389/fpsyt.2022.788737
10. Guan T, Chapman MV, de Saxe ZL, et al. Correlates of illness uncertainty in cancer survivors and family caregivers: a systematic review and meta-analysis. *Support Care Cancer*. 2023;31(4):242. doi:10.1007/s00520-023-07705-7
11. Guo LN, Liu YJ, McCallum J, et al. Perceived stress and depression amongst older stroke patients: sense of coherence as a mediator? *Arch Gerontol Geriatr*. 2018;79:164–170. doi:10.1016/j.archger.2018.08.010
12. Guo L, Zauszniewski JA, Liu Y, et al. Is resourcefulness as a mediator between perceived stress and depression among old Chinese stroke patients? *J Affect Disord*. 2019;253:44–50. doi:10.1016/j.jad.2019.04.083
13. Folkman S. Positive psychological states and coping with severe stress. *Soc Sci Med*. 1997;45(8):1207–1221. doi:10.1016/S0277-9536(97)00040-3
14. Mo X, Zhang Y. Correlation between parental resilience and uncertainty in illness in children with leukemia. *J Clin Pathol Res*. 2018;38 (11):2488–2493.
15. Yan A, Zhang Y, Wang L, et al. The relationship between uncertainty in illness and quality of life in patients with heart failure: multiple mediating effects of perceived stress and coping strategies. *J Cardiovasc Nurs*. 2021;37(3):257–265.
16. Ke J, Lin J, Lin X, et al. Dyadic effects of family resilience on quality of life in patients with lung cancer and spousal caregivers: the mediating role of dyadic coping. *Eur J Oncol Nurs*. 2023;66:102400. doi:10.1016/j.ejon.2023.102400
17. Li Z, Liu Y. *Nursing Research Methods*. People's Health Publishing House; 2018.

18. Jiang S, Ma L, Miao X. Current status of family resilience of family members of patients with postoperative intracerebral hemorrhage and its influencing factors. *J Nurs*. 2023;30(2):7–11.
19. Kline RB. *Principles and Practice of Structural Equation Modeling New York*. Guilford Press; 2011.
20. Mahoney FI, Barthel DW. Functional evaluation the Barthel Index. *Maryland Med J*. 1965;14:61–65.
21. Li Y, Zhao Y, Zhang J, et al. Psychometric properties of the shortened Chinese version of the family resilience assessment scale. *J Child Family Stud*. 2016;25(9):2710–2717. doi:10.1007/s10826-016-0432-7
22. Yang T, Hang H. An Epidemiological studies study on stress among urban residents in social transition period. *Chin J Epidemiol*. 2003;24 (9):760–764.
23. Cui H. *The Relationship Among Uncertainty in Illness Social Support and Coping Style About Family Members of Patients with Chronic Disease*. Yanbian University; 2010.
24. Li-tze H, Bentler Peter M. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equa Model*. 1999;6(1):1–55. doi:10.1080/10705519909540118
25. Chang L, Zhang S, Yan Z, et al. Symptom burden, family resilience, and functional exercise adherence among postoperative breast cancer patients. *Asia Pac J Oncol Nurs*. 2022;9(11):100129. doi:10.1016/j.apjon.2022.100129
26. Lee SM, Sung KM. The effects of violence coping program based on middle-range theory of resilience on emergency room nurses' resilience, violence coping, nursing competency and burnout. *J Korean Acad Nurs*. 2017;47(3):332–344. doi:10.4040/jkan.2017.47.3.332
27. Zhang L, Jiang M, Wang L, et al. The mediating effect of perceived social support and medical coping modes between psychological resilience and meaning in life in COVID-19 patients. *Patient Prefer Adherence*. 2023;17:571–582. doi:10.2147/PPA.S391014
28. Qiu Y, Huang Y, Wang Y, et al. The role of socioeconomic status, family resilience, and social support in predicting psychological resilience among Chinese maintenance hemodialysis patients. *Front Psychiatry*. 2021;12:723344. doi:10.3389/fpsyt.2021.723344
29. Li Y, Qiao Y, Luan X, et al. Family resilience and psychological well-being among Chinese breast cancer survivors and their caregivers. *Eur J Cancer Care*. 2019;28(2):e12984. doi:10.1111/ecc.12984
30. Kim GM, Lim JY, Kim EJ, et al. A model of adaptation for families of elderly patients with dementia: focusing on family resilience. *Aging Mental Health*. 2018;22(10):1295–1303. doi:10.1080/13607863.2017.1354972
31. Chen CM, Du BF, Ho CL, et al. Perceived stress, parent-adolescent/young adult communication, and family resilience among adolescents/young adults who have a parent with cancer in Taiwan: a longitudinal study. *Cancer Nurs*. 2018;41(2):100–108. doi:10.1097/NCC.0000000000000488
32. Fitryasari R, Yusuf A, Tristiana RD, Nihayati HE. Family members' perspective of family Resilience's risk factors in taking care of schizophrenia patients. *Int J Nurs Sci*. 2018;5(3):255–261. doi:10.1016/j.ijnss.2018.06.002
33. Deist M, Greeff AP. Living with a parent with dementia: a family resilience study. *Dementia*. 2017;16(1):126–141. doi:10.1177/1471301215621853
34. Daniels AD, Bryan J, Liles S, et al. The family system amidst complex trauma: a driving force to enhance resilience and reduce depression in young adults. *Family J*. 2022;30(4):531–541. doi:10.1177/10664807221104115
35. Liu J, Liu Q, Huang Y, et al. Effects of personal characteristics, disease uncertainty and knowledge on family caregivers' preparedness of stroke survivors: a cross-sectional study. *Nurs Health Sci*. 2020;22(4):892–902. doi:10.1111/nhs.12743
36. Jiao J, Liao G, Zhou Z, et al. Analysis of disease fear status and influencing factors in 182 patients with ischemic stroke. *Med Forum*. 2022;26 (11):1–3.
37. Wang L, Peng B, Zhang H, et al. Brief report on stroke prevention and treatment in China 2019. *Chin J Cerebrovasc Dis*. 2020;17(5):272–281.
38. Hu R, Wang X, Liu Z, et al. Stigma, depression, and post-traumatic growth among Chinese stroke survivors: a longitudinal study examining patterns and correlations. *Top Stroke Rehabil*. 2022;29(1):16–29. doi:10.1080/10749357.2020.1864965
39. Jin X, Duan Z. A perspective on the "Overpriced Bride Price": status, causes and governance. *J Shandong Womens Univ*. 2023;1(1):37–49.
40. Xu M. *A Study of the "Leftover Woman" phenomenon in Contemporary China from the Perspective of Marxism*. Southwest Jiaotong University; 2017.
41. Fleshner M, Kennedy SL, Johnson JD, et al. *Exercise and Stress Resistance: Neural-Immune Mechanisms*. Boston, MA: Springer US; 2009:87–107.
42. Wang T, Sun J, Gu D, et al. Dyadic effects of social support, illness uncertainty on anxiety and depression among lung cancer patients and their caregivers: a cross-sectional study. *Support Care Cancer*. 2023;31(7):402. doi:10.1007/s00520-023-07876-3
43. Zhang X, Zhang H, Zhang Z, et al. The mediating effect of resilience on the relationship between symptom burden and anxiety/depression among Chinese patients with primary liver cancer after liver resection. *Patient Prefer Adherence*. 2023;17:3033–3043. doi:10.2147/PPA.S430790
44. Tao L, Zhong T, Hu X, et al. Higher family and individual resilience and lower perceived stress alleviate psychological distress in female breast cancer survivors with fertility intention: a cross-sectional study. *Support Care Cancer*. 2023;31(7):408. doi:10.1007/s00520-023-07853-w
45. Wepf H, Joseph S, Leu A. Benefit finding moderates the relationship between young carer experiences and mental well-being. *Psychol Health*. 2022;37(10):1270–1286. doi:10.1080/08870446.2021.1941961
46. Mei Y, Xiang D, Zhang Z, et al. Family function, self-efficacy, care hours per day, closeness and benefit finding among stroke caregivers in China: a moderated mediation model. *J Clin Nurs*. 2023;32(3–4):506–516. doi:10.1111/jocn.16290