

Coping Styles of Primary Caregivers of Children with Acute Lymphoblastic Leukemia: Current Status and Influencing Factors

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Abstract

Background: Acute lymphoblastic leukemia is the most common childhood malignancy, placing primary caregivers under extreme physical and psychological strain. Coping styles adopted by caregivers critically influence their mental health and the child's treatment outcomes, yet comprehensive data on the determinants of coping strategies in this population remain limited. This study aimed to investigate the current status of coping styles among primary caregivers of children with ALL and to identify the key factors influencing their coping strategies based on the Capability, Opportunity, Motivation–Behavior (COM-B) model.

Methods: Using a convenience sampling method, 237 primary caregivers of children with ALL admitted to the Department of Hematology at a tertiary children's hospital in Suzhou between January and June 2026 were enrolled. Data were collected using the Simplified Coping Style Questionnaire (SCSQ), the Chinese version of the Parental Perception of Uncertainty Scale (PPUS), the Herth Hope Index (HHI), the Social Support Rating Scale (SSRS), and the Caregiver Knowledge Questionnaire for Childhood Acute Leukemia. The current status of coping styles was described. Pearson correlation analysis was performed to examine the relationships among scores on the SCSQ, PPUS, HHI, SSRS, and the Caregiver Knowledge Questionnaire. Univariate analysis and binary logistic regression were employed to identify influencing factors.

Results

A total of 243 questionnaires were distributed, and 237 valid responses were retrieved, yielding an effective response rate of 97.53%. Among the participants, 125 (52.7%) were classified as active copers, while 112 (47.3%) were classified as passive copers. Binary logistic regression analysis revealed that occupational status, monthly per capita household income, place of residence, level of illness uncertainty, hope level, social support rating, caregiving knowledge, and the presence of complications during the current treatment period were significant influencing factors of coping styles among primary caregivers of children with acute lymphoblastic leukemia (all $P < 0.05$).

Conclusion

The majority of primary caregivers of children with acute lymphoblastic leukemia tend to adopt active coping styles. In nursing practice, particular attention should be directed toward caregivers who are unemployed, have a monthly per capita household income between RMB 3,000 and 5,000, or whose children experienced complications during the current treatment period. Targeted interventions aimed at enhancing caregiving knowledge and hope levels, strengthening social support, and reducing illness uncertainty may help alleviate passive coping patterns, thereby improving caregivers' quality of life and contributing to better treatment outcomes for the children.

Introduction

Acute lymphoblastic leukemia (ALL) is a clonal and aggressive hematopoietic malignancy originating from B-lineage or T-lineage lymphoid progenitor cells in the bone marrow, accounting for approximately one-third of all childhood cancer cases worldwide. The global annual incidence of childhood leukemia is approximately 5 per 100,000, with ALL accounting for about 3 per 100,000 new cases each year; moreover, its incidence has been increasing at an annual rate of 0.7% in recent years^[1-3]. ALL can lead to bone marrow hematopoietic dysfunction, manifesting clinically as anemia, fever, hemorrhage, skin ecchymosis, and recurrent infections, and may involve multiple organ systems including the liver, lymph nodes, and meninges, thereby posing a serious threat to the life and health of affected children^[4,5].

Due to their young age and limited disease awareness and self-management capacity, children with ALL rely heavily on their primary caregivers for daily care and medical support. However, the rapid progression, clinical complexity, and prolonged disease trajectory of ALL necessitate long-term companionship and intensive caregiving. As a result, primary caregivers frequently face multifactorial stressors, including occupational disruption, financial strain, and role conflict, with the caregiving burden substantially exceeding that reported among caregivers of children with other chronic conditions^[6]. Consequently, this population often experiences a range of psychosocial difficulties, such as sleep disturbances, psychological distress, anxiety, post-traumatic stress disorder, and social isolation, which may compromise their caregiving competence and ultimately impede the child's recovery^[7].

Research^[8] has indicated that whether individuals can overcome adversity and demonstrate positive adaptation, rather than enduring severe psychological distress, largely depends on the coping strategies they adopt when facing similar adverse circumstances. Coping styles refer to the behavioral approaches individuals employ to adapt to difficult situations, encompassing both negative and positive coping styles^[9]. Active coping can alleviate stress induced by challenging events, whereas passive coping tends to exacerbate stress responses. Furthermore, coping strategies not only shape the nature, characteristics, and duration of an individual's stress reactions but also exert significant effects on both physiological and psychological outcomes^[10].

The coping strategies adopted by primary caregivers of children with ALL directly influence the child's rehabilitation outcomes and quality of life. Research^[11] has demonstrated that when confronted with the stressful event of their child's cancer diagnosis, most primary caregivers are prone to emotional dysregulation, often resorting to negative coping behaviors such as anger and avoidance. These responses may impair their rational judgment, adversely affect their decision-making capacity and the child's treatment adherence, and potentially accelerate disease progression.

Existing studies on coping strategies have predominantly focused on patients themselves, with relatively limited attention given to their primary caregivers. Research specifically examining coping styles among primary caregivers of children with ALL remains scarce both domestically and internationally. Moreover, most available studies have primarily concentrated on analyzing the correlational relationships between coping styles and single variables such as psychological resilience or illness uncertainty^[12-14], with few

systematically investigating the multifaceted influencing factors of coping styles in this population. This gap limits the ability to inform evidence-based nursing interventions in clinical practice.

The Capability, Opportunity, Motivation–Behavior (COM-B) model^[15] synthesizes the factors influencing behavior into three core components: Capability, Opportunity, and Motivation. Capability refers to the individual's physical and psychological capacity to engage in behavioral change; Motivation encompasses the beliefs and reflective processes that drive and sustain such change; and Opportunity comprises the external environmental and social factors that facilitate or hinder behavior. According to the model, these three elements interact reciprocally to generate the target behavior. Xing et al.^[16] applied the COM-B theoretical framework to explore the caregiving needs of caregivers of children aged 3–6 years with dental caries, as well as the facilitators and barriers to toothbrushing behavior, thereby providing a theoretical basis for interventions aimed at improving children's oral health-related behaviors. To date, this model has been widely adopted in both domestic and international research to investigate determinants of various health behaviors, and its validity has been well established. Nevertheless, its application to the study of coping styles remains relatively uncommon among Chinese researchers. Therefore, drawing upon the COM-B model, this study aimed to investigate the current status of coping styles among primary caregivers of children with ALL and to identify its influencing factors. The findings are expected to assist clinical healthcare professionals in developing targeted interventions to mitigate negative coping patterns and promote active engagement in the child's treatment process.

Methods

1.1 Participants

Using a convenience sampling method, 237 primary caregivers of children with ALL who were hospitalized in the Department of Hematology at a tertiary children's hospital in Suzhou between January and June 2026 were recruited as participants.

Inclusion criteria for children:

- ☐ Diagnosis of ALL confirmed according to the Guidelines for the Diagnosis and Treatment of Leukemia in Children and Adolescents (2025)^[17] established by the Chinese Society of Clinical Oncology;

- ☐ Age < 18 years.

Exclusion criteria for children:

- ☐ Comorbidities involving other major physical or intellectual disorders.

Inclusion criteria for primary caregivers:

- ☐ Age ≥ 18 years;

- ☒ A relative who assumed the primary caregiving responsibility for the child, with an average daily caregiving duration of ≥ 12 hours or a weekly caregiving duration of ≥ 72 hours ^[18];
- ☒ Normal cognitive and comprehension abilities to correctly understand and complete the questionnaire;
- ☒ Informed consent voluntarily provided, with signed written consent to participate in this study.

Exclusion criteria for primary caregivers:

- ☒ Presence of major physical illnesses or psychiatric/psychological disorders;
- ☒ Exposure to other major stressful life events within the preceding six months;
- ☒ Concurrent participation in other studies.

Sample size estimation

The required sample size for this study was estimated based on the Kendall criterion, which recommends that the sample size for multivariate analysis should be 5 to 10 times the number of independent variables^[19]. In this study, the general information questionnaire comprised 25 variables, and the four scales—the Chinese version of the Parental Perception of Uncertainty Scale, the Herth Hope Index, the Social Support Rating Scale, and the Caregiver Knowledge Questionnaire for Childhood Acute Leukemia—comprised a total of 9 dimensions, yielding 34 variables in total. Accounting for a 10% rate of invalid responses, the estimated sample size ranged from 189 to 378 cases.

Ethical considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki and has received ethical approval from the Ethics Committee of Children's Hospital of Soochow University (Approval No. 2025CS392). All participants voluntarily participated in the study and provided written informed consent. The informed consent form provided detailed information about the study's objectives, procedures, confidentiality measures, and the voluntary nature of participation. Participants were informed that their decision to participate in the study would not affect their child's treatment. In addition, they were told that they could withdraw from the study at any time before submitting the questionnaire without facing any penalties.

No personally identifiable information was collected. All responses were stored anonymously on a secure server, to which only the research team had access. Throughout the study, appropriate safeguards were implemented to protect the confidentiality of the data and ensure the anonymity of the participants.

1.2 Instruments

1.2.1 General Information Questionnaire

This questionnaire was self-designed based on a comprehensive literature review, expert consultation, and the study objectives. It consists of three parts:

- ☒ Child's general demographic characteristics: sex, age, educational level, whether the child is the only child, and method of medical expense payment;
- ☒ Primary caregiver's general demographic characteristics: relationship to the child, whether the caregiver has other dependents besides the child, sex, age, educational level, marital status, occupational status, monthly per capita household income, self-rated health status, place of residence, religious belief, personality traits, and number of other co-caregivers;
- ☒ Child's disease-related characteristics: time of initial diagnosis, treatment phase, disease risk stratification, presence of complications during the current treatment period, length of current hospitalization, disease relapse, and number of hospitalizations.

1.2.2 Simplified Coping Style Questionnaire (SCSQ)

The SCSQ was originally developed by Folkman and Lazarus^[20] and subsequently simplified and adapted by Xie^[21] for the Chinese population. The scale has two dimensions: positive coping and negative coping, with a total of 20 items. Each item is rated on a 4-point Likert scale, scored from 0 to 3. The tendency toward coping style is determined using the following formula: Coping tendency = standardized score for positive coping (Z-score) – standardized score for negative coping (Z-score), where the standardized score = (actual score for positive/negative coping – sample mean) / standard deviation. A coping tendency > 0 indicates a positive coping style, whereas a coping tendency ≤ 0 indicates a negative coping style. The overall Cronbach's α coefficient of the original scale was 0.90, with subscale coefficients of 0.89 for positive coping and 0.78 for negative coping, demonstrating good reliability and validity. In the present study, the Cronbach's α coefficient for the SCSQ was 0.797.

1.2.3 Social Support Rating Scale (SSRS)

Xiao et al.^[22] created the SSRS, which comprises of three subscales (objective support, subjective support, and support utilization) with a total of ten items. The total score ranges from 11 to 66, with higher scores indicating greater levels of social support. Scores ≤ 22 are classified as low level, 23–44 as moderate level, and ≥ 45 as high level. The correlation coefficients between the three subscales and the total scale ranged from 0.724 to 0.835, indicating satisfactory content validity; the inter-subscale correlation coefficients ranged from 0.462 to 0.664, which were lower than those with the total scale, suggesting good construct validity. The Cronbach's α coefficient for the total scale was 0.896, and those for the three subscales were 0.849, 0.825, and 0.833, respectively. In the present study, the Cronbach's α coefficient for the SSRS was 0.832.

1.2.4 Caregiver Knowledge Questionnaire for Childhood Acute Leukemia

The caregiving knowledge subscale of the Caregiver Knowledge, Attitude, and Practice Questionnaire for Childhood Acute Leukemia, developed by Wang et al.^[23] in 2019, was used to assess caregivers' knowledge levels. The subscale comprises 22 items, each rated on a 5-point Likert scale, with scores ranging from 0 ("strongly disagree") to 4 ("strongly agree"). The total score ranges from 0 to 88, with higher scores indicating more adequate knowledge among caregivers. The original subscale demonstrated a Cronbach's α coefficient of 0.953, a test-retest reliability of 0.842, and a content validity index of 0.909. In the present study, the Cronbach's α coefficient for this subscale was 0.916.

1.2.5 Herth Hope Index (HHI)

The HHI was originally developed by Herth^[24] in 1992 based on the conceptual framework of hope, and was subsequently translated and culturally adapted into Chinese by Professor Zhao Haiping in 2000^[25]. The scale consists of three dimensions: positive attitude toward taking action, positive attitude toward maintaining close relationships with others, and optimistic attitude about the present and future, with a total of 12 items (4 items per dimension). Each item is rated on a 4-point Likert scale, ranging from 1 ("strongly disagree") to 4 ("strongly agree"). The total score ranges from 12 to 48, with higher scores indicating higher levels of hope. Scores ≤ 23 are classified as low hope level, 24–35 as moderate hope level, and ≥ 36 as high hope level. The original scale demonstrated a Cronbach's α coefficient of 0.97, a test-retest reliability of 0.86, and a validity coefficient of 0.89. In the present study, the Cronbach's α coefficient for the HHI was 0.881.

1.2.6 Chinese Version of the Parents' Perception of Uncertainty Scale (PPUS)

The PPUS was originally developed by Mishel^[26] in 1983 and was subsequently revised into a Chinese version for parents of children with cancer by Ye et al.^[27]. The scale is divided into two dimensions: ambiguity and lack of communication, with 14 items total. Each item is rated on a 5-point Likert scale, ranging from 5 ("strongly agree") to 1 ("strongly disagree"), with one item reverse-scored. The total score ranges from 14 to 70, with higher scores indicating greater levels of illness uncertainty among parents. The content validity indices for all items ranged from 0.83 to 1.00. The Cronbach's α coefficients for the two dimensions were 0.830 and 0.877, respectively, and the overall Cronbach's α coefficient for the total scale was 0.894. In the present study, the Cronbach's α coefficient for the PPUS was 0.904.

1.3 Data Collection and Quality Control

A paper-based questionnaire survey was conducted. A pilot test was first carried out with 20 primary caregivers of children with ALL to evaluate the validity and reliability of the questionnaire and to assess the readability and comprehensibility of the items, after which the formal survey was administered. During the formal survey, two uniformly trained researchers collected the data. After explaining the purpose of the study and obtaining informed consent from the children or their parents, questionnaires were distributed on-site, and caregivers were instructed to complete them using standardized guidance. For those unable to complete the questionnaire independently, researchers provided assistance in a

question-and-answer format. All questionnaires were retrieved and reviewed on the spot, with any ambiguities clarified immediately. Questionnaires were rigorously screened according to predefined criteria: those with a completion time of < 5 minutes, those with repetitive selection of the same option across items within the same section, and those with logical inconsistencies in reverse-scored items were all deemed invalid. Researchers also collected general demographic and disease-related data of the children through medical record reviews. All data were double-entered to ensure accuracy.

1.4 Statistical Analysis

All data were analyzed using SPSS version 27.0. Categorical variables were described as frequencies (n) and percentages (%). Continuous variables following a normal distribution were presented as mean $\pm$ standard deviation ($\bar{x} \pm s$) and compared using independent-samples *t*-tests or chi-square tests as appropriate. Pearson correlation analysis was performed to examine the relationships between coping strategies and illness uncertainty, hope level, social support, and caregiving knowledge among primary caregivers of children with ALL. Binary logistic regression analysis was employed to identify the influencing factors of coping strategies. A *P*-value < 0.05 was considered statistically significant.

Results

2.1 General Characteristics of Children with ALL and Their Primary Caregivers

A total of 243 questionnaires were distributed, and 237 valid responses were retrieved, yielding an effective response rate of 97.53%. Among the children with ALL, 140 (59.10%) were male and 97 (40.90%) were female, with the majority aged between 3 and 12 years. Regarding disease severity, the intermediate-risk group comprised the largest proportion, with 111 cases (46.80%), followed by the low-risk group with 60 cases (25.30%), and the high-risk group with 21 cases (8.90%). Among the primary caregivers, 44 (18.60%) were male and 193 (81.40%) were female, with 125 (52.70%) aged between 30 and 40 years. The majority of primary caregivers were mothers, accounting for 178 cases (75.10%), and 79 caregivers (33.30%) had an educational level of junior high school or below. Additional general characteristics are presented in Table 1.

2.2 Current Status of Coping Strategies Among Primary Caregivers of Children with ALL

Among the 237 primary caregivers, the mean score for positive coping was 20.45 ± 6.61 , and the mean score for negative coping was 9.15 ± 4.23 . Based on the coping tendency classification, 125 caregivers (52.7%) were identified as active copers, while 112 (47.3%) were classified as passive copers.

2.3 Univariate Analysis of Influencing Factors of Coping Styles Among Primary Caregivers of Children with ALL

Univariate analysis revealed statistically significant differences between the negative coping group and the positive coping group in terms of educational level, self-rated health status, occupational status, place of residence, monthly per capita household income, method of medical expense payment, and presence of complications during the current treatment period ($P < 0.05$). The results are presented in Table 1.

Table 1
Univariate Analysis of Factors Influencing Coping Styles Among Primary Caregivers of Children with ALL
(N = 237)

Items	Groups	Negative coping group (n = 112)	Positive coping group (n = 125)	χ^2	P value
Children					
Gender	Male	61(54.46)	79(63.20)	1.865	0.172
	Female	51(45.54)	46(36.80)		
Age	< 3 years	7(6.30)	15(12.00)	3.280	0.350
	3 ~ < 6 years	27(24.10)	31(24.80)		
	6 ~ < 12 years	47(42.00)	53(42.40)		
	12 ~ 18 years	31(27.70)	26(20.80)		
Educational level	Not enrolled	22(19.64)	30(24.00)	1.207	0.877
	Kindergarten	21(18.75)	26(20.80)		
	Primary school	47(41.96)	48(38.40)		
	Junior high school	18(16.07)	18(14.40)		
	Senior high school	4(3.57)	3(2.40)		
Only child or not	Yes	48(42.86)	53(42.40)	0.005	0.943
	No	64(57.14)	72(57.60)		
Time since diagnosis	< 1 month	27(24.11)	29(23.20)	2.386	0.496
	1 ~ < 6 months	26(23.21)	30(24.00)		
	6 ~ < 12 months	14(12.50)	24(19.20)		
	≥ 12 months	45(40.18)	42(33.60)		
Treatment phase	Window phase	15(13.39)	15(12.00)	1.742	0.783
	Induction remission phase	23(20.54)	23(18.40)		
	Consolidation treatment phase	17(15.18)	25(20.00)		
Notes:					

Items	Groups	Negative coping group (n = 112)	Positive coping group (n = 125)	χ^2	P value
Children					
	Re-induction treatment phase	11(9.82)	16(12.80)		
	Maintenance treatment phase	46(41.07)	46(36.80)		
Disease risk stratification	Not stratified temporarily	22(19.64)	23(18.40)	6.008	0.111
	Low risk	22(19.64)	38(30.40)		
	Intermediate risk	54(48.21)	57(45.60)		
	High risk	14(12.50)	7(5.60)		
Length of current hospitalization	< 10 days	53(47.32)	75(60.00)	4.947	0.084
	10 ~ 20 days	17(15.18)	10(8.00)		
	> 20 days	42(37.50)	40(32.00)		
Number of hospitalizations	1 ~ 3	38(33.93)	39(31.20)	2.062	0.357
	4 ~ 6	6(5.36)	13(10.40)		
	≥ 7	68(60.71)	73(58.40)		
Presence of complications during current treatment	Yes	80(71.43)	35(28.00)	44.604	<0.001
	No	32(28.57)	90(72.00)		
Disease relapse	Yes	7(6.25)	6(4.80)	0.240	0.625
	No	105(93.75)	119(95.20)		
Primary caregiver of the child					
Relationship with the child	Father	18(16.07)	21(16.80)	3.964	0.411
	Mother	82(73.21)	96(76.80)		
Notes:					

Items	Groups	Negative coping group (n = 112)	Positive coping group (n = 125)	χ^2	P value
Children					
	Paternal/maternal grandfather	3(2.68)	1(0.80)		
	Paternal/maternal grandmother	8(7.14)	4(3.20)		
	Other relatives	1(0.89)	3(2.40)		
Care for others besides the child	Yes	53(47.32)	53(42.40)	0.579	0.447
	No	59(52.68)	72(57.60)		
Gender	Male	21(18.75)	23(18.40)	0.005	0.945
	Female	91(81.25)	102(81.60)		
Age	18~<30 years	7(6.25)	12(9.60)	2.230	0.328
	30~<40 years	56(50.00)	69(55.20)		
	≥ 40 years	49(43.75)	44(35.20)		
Availability of co-caregivers at present	Yes	101(90.18)	117(93.60)	0.938	0.333
	No	11(9.82)	8(6.40)		
Educational level	Junior high school and below	51(45.54)	28(22.40)	17.745	<0.001
	Senior high school or technical secondary school	26(23.21)	28(22.40)		
	College	19(16.96)	32(25.60)		
	Bachelor's degree and above	16(14.29)	37(29.60)		
Marital status	Married	103(91.96)	113(90.40)	0.179	0.672
	Unmarried	9(8.04)	12(9.60)		
Self-reported health status	Poor ^a	7(6.35)	2(1.60)	8.533	0.014
Notes:					

Items	Groups	Negative coping group (n = 112)	Positive coping group (n = 125)	χ^2	P value
Children					
	Fair ^b	42(37.50)	32(25.60)		
	Good ^c	63(56.25)	91(72.80)		
Employment status	Employed	17(15.18)	50(40.00)	17.948	<0.001
	Unemployed	95(84.82)	75(60.00)		
Personality traits	Sociable ^d	47(41.96)	65(52.00)	2.387	0.122
	Unsociable ^e	65(58.04)	60(48.00)		
Residential area	Rural area	75(66.96)	59(47.20)	9.434	0.009
	Township	21(18.75)	36(28.80)		
	Urban area	16(14.29)	30(24.00)		
Religious belief	Yes	18(16.07)	10(8.00)	3.694	0.055
	No	94(83.93)	115(92.00)		
Monthly per capita household income	<3000 RMB	46(28.00)	35(41.10)	12.340	0.002
	3000 ~ 5000 RMB	38(30.40)	43(38.40)		
	>5000 RMB	52(41.60)	23(20.50)		
Medical expense payment method	Medical insurance	106(94.64)	109(87.20)	3.886	0.049
	Self-paid	6(5.36)	16(12.80)		
Notes:					

a: Poor: chronically troubled by certain chronic diseases.

b: Fair: frequently suffer from colds or other discomforts.

c: Good: physically fit and energetic, only occasionally experiencing mild illnesses.

d: Sociable: extroverted, optimistic, and good at cooperating with others.

e: Unsociable: introverted, poor at communication, and prefer being alone.

2.4 Correlation Analysis of Coping Strategies with Illness Uncertainty, Hope Level,

Social Support, and Caregiving Knowledge Among Primary Caregivers of

Children with ALL

Pearson correlation analysis revealed that illness uncertainty was negatively correlated with positive coping strategies ($r=-0.464, P < 0.05$) and positively correlated with negative coping strategies ($r = 0.316, P < 0.05$). Hope level was positively correlated with positive coping strategies ($r = 0.479, P < 0.01$) and negatively correlated with negative coping strategies ($r=-0.269, P < 0.01$). Social support was positively correlated with positive coping strategies ($r = 0.439, P < 0.01$) and negatively correlated with negative coping strategies ($r=-0.140, P < 0.01$). Caregiving knowledge was positively correlated with positive coping strategies ($r = 0.456, P < 0.01$) and negatively correlated with negative coping strategies ($r=-0.286, P < 0.01$).

Detailed results are presented in Table 2.

Table 2
Correlation analysis among illness uncertainty, hope level, social support, caregiving knowledge and coping styles (N = 237)

Positive coping style	Positive coping style	Negative coping style	Illness uncertainty	Hope level	Social support	Caregiving knowledge
	1					
Negative coping style	0.137*	1				
Illness uncertainty	-0.464*	0.316*	1			
Hope level	0.479**	-0.269**	-0.654**	1		
Social support	0.439**	-0.140**	-0.424**	0.379**	1	
Caregiving knowledge	0.456**	-0.286**	-0.630**	0.521**	0.324**	1
Notes: *: $P < 0.05$; **: $P < 0.01$.						

2.5 Binary Logistic Regression Analysis of Influencing Factors of Coping Styles Among Primary Caregivers of Children with ALL

Variables that were statistically significant in the univariate analysis and correlation analysis were entered into a collinearity diagnostic test. The variance inflation factor (VIF) values for all variables were < 5 , indicating no significant multicollinearity among the independent variables. Binary logistic regression analysis was performed with coping strategies of primary caregivers of children with ALL as the dependent variable (negative coping = 1, positive coping = 0), and the 11 variables that were statistically significant in the univariate analysis were entered as independent variables. The specific variable assignments are presented in Table 3. The binary logistic regression results revealed that occupational status, monthly per capita household income, place of residence, illness uncertainty, hope level, social support, caregiving knowledge, and the presence of complications during the current treatment period were significant influencing factors of coping strategies. Detailed results are presented in Table 4.

Table 3
Assignment of independent variables

Variables	Assignment
Medical expense payment method	Medical insurance = 0, Self-paid = 1
Presence of complications during current treatment	No = 0, Yes = 1
Employment status	Employed = 0, Unemployed = 1
Self-reported health status	Poor (reference group)
	Fair = 1, Good = 0
	Fair = 0, Good = 1
Residential area	Rural area (reference group)
	Township = 1, Urban area = 0
	Township = 0, Urban area = 1
Educational level	Junior high school and below (reference group)
	Senior high school or technical secondary school = 1, College = 0, Bachelor's degree and above = 0
	Senior high school or technical secondary school = 0, College = 1, Bachelor's degree and above = 0
	Senior high school or technical secondary school = 0, College = 0, Bachelor's degree and above = 1
Monthly per capita household income (RMB)	<3000 (reference group)
	3000 ~ 5000 = 1, >5000 = 0
	3000 ~ 5000 = 0, >5000 = 1
Illness uncertainty score	Raw score
Hope level score	Raw score
Social support score	Raw score
Caregiving knowledge score	Raw score

Table 4

Binary Logistic regression analysis of influencing factors of coping styles among primary caregivers of children with ALL (N = 237)

Factors	<i>B</i>	<i>SE</i>	<i>Wald</i> χ^2	<i>P</i>	<i>OR</i>	<i>95% CI</i>
Presence of complications	1.921	0.412	21.771	<0.001	6.849	3.049 ~ 15.385
Employment status	1.199	0.503	5.685	0.017	3.318	1.238 ~ 8.893
Monthly per capita household income	1.305	0.499	6.852	0.009	3.689	1.388 ~ 9.805
Residential area	-1.432	0.500	8.185	0.004	0.239	0.090 ~ 0.637
Illness uncertainty	0.082	0.034	5.762	0.016	1.085	1.015 ~ 1.160
Hope level	-0.148	0.064	5.245	0.022	0.863	0.760 ~ 0.979
Social support	-0.075	0.031	5.661	0.017	0.928	0.872 ~ 0.987
Caregiving knowledge	-0.070	0.030	5.314	0.021	0.932	0.880 ~ 0.990

Discussion

3.1 Current Status of Coping Styles Among Primary Caregivers of Children with ALL

The results of this study showed that 125 caregivers (52.74%) adopted positive coping strategies, while 112 (47.26%) adopted negative coping strategies. The mean score for positive coping among primary caregivers of children with ALL was 20.45 ± 6.61 , which was significantly lower than the normative mean score of 30.22 ± 8.72 reported for parents of healthy children in China. This finding is consistent with the study by Chen et al. [28]. Although the majority of primary caregivers of children with ALL tended to adopt positive coping styles, nearly half still exhibited a propensity toward negative coping styles. According to Lazarus's stress-and-coping theory [20], individuals confronted with sustained stressors adapt through cognitive appraisal and coping mechanisms. Primary caregivers of children with ALL face a treatment trajectory lasting 2–3 years, along with multi-phase, high-intensity caregiving demands, placing them in a state of chronic overload that predisposes them to physiological exhaustion and psychological distress. To balance multiple responsibilities, including disease care, family life, and parenting, primary caregivers must use cognitive restructuring and problem-solving strategies to reduce stress and promote positive coping [29]. Nevertheless, nearly half of the primary caregivers struggle to withstand the cumulative stress from multiple sources, gradually becoming emotionally depleted and resorting to negative coping patterns such as self-comfort and passive waiting. The item "trying to see the positive side of things" within the positive coping dimension received the highest score, which may be attributed to the fact that health education provided by healthcare professionals, along with accumulated caregiving experience,

helps primary caregivers gradually develop a rational understanding of the disease, thereby alleviating anxiety, reinforcing treatment confidence, and enabling active coping. In contrast, the item "comforting oneself" within the negative coping dimension scored the highest. This may be related to traditional social attitudes, as childhood malignancy often generates a sense of stigma within the family. Many primary caregivers are reluctant to disclose their child's illness or family difficulties to relatives, friends, or colleagues, fearing discrimination or excessive attention. Moreover, the heavy caregiving burden leaves them with insufficient energy to seek external support, leaving self-comfort as the only available coping strategy. Clinical healthcare professionals can implement systematic educational interventions based on the family empowerment model—covering disease knowledge, treatment protocols, and daily caregiving skills—while integrating empathetic communication techniques such as open-ended dialogue and emotional feedback to facilitate the release of negative emotions among caregivers. These approaches can help caregivers reframe caregiving challenges as manageable tasks rather than uncontrollable threats, thereby fostering positive cognitive appraisals^[30]. Additionally, it is recommended that hospital departments organize monthly peer support groups, inviting experienced primary caregivers to serve as "peer mentors" to share practical experiences and address concerns. Encouraging caregivers to actively seek support from relatives, friends, healthcare professionals, and fellow caregivers may help break the cycle of self-isolation and promote more adaptive coping behaviors.

3.2 Influencing Factors of Positive Coping Styles Among Primary Caregivers of Children with ALL

3.2.1 Place of Residence

In this study, primary caregivers of children with ALL residing in towns or urban areas were more likely to adopt positive coping styles ($P < 0.05$), which is consistent with the findings of Hamad et al.^[31]. Compared with those in rural areas, caregivers in towns and urban areas had significantly greater advantages in terms of transportation accessibility, information acquisition, and availability of healthcare resources.

Research^[32] has indicated that family caregivers of children with cancer from rural areas face relatively limited healthcare resources, with insufficient availability of pediatric oncology specialists and diagnostic equipment at primary care facilities. In contrast, towns and urban areas have more well-established social networks, facilitating greater interaction among relatives, friends, and fellow caregivers. Social resources such as peer support groups and charitable foundations are also more abundant in these areas, enabling caregivers to access disease-related information, professional caregiving guidance, and other medical services more conveniently, while receiving more effective psychological support and practical assistance. Consequently, caregivers in urban and town settings are more likely to adopt positive coping strategies and face disease-related challenges with greater composure.

Therefore, nurses should pay particular attention to the needs of primary caregivers of children with ALL in rural areas. Using internet-based platforms to deliver health education and psychological support, and establishing remote nursing collaboration platforms staffed by pediatric oncology nurses from tertiary hospitals, could provide rural caregivers with remote guidance on post-chemotherapy complication recognition, peripherally inserted central catheter (PICC) maintenance, and oral mucositis care. Such interventions may help alleviate the challenges faced by rural families, including difficulties in accessing healthcare services, limited disease-related information, and insufficient specialized medical resources.

3.2.2 Hope Level

The results of this study showed that primary caregivers of children with ALL with higher levels of hope were more likely to adopt positive coping strategies ($P < 0.05$). According to Snyder's hope theory, hope, as a goal-directed positive intrinsic motivation, helps individuals maintain psychological resilience under sustained stressful conditions^[33]. Wu et al.^[34] demonstrated that hope serves as a critical psychological resource for caregivers following a child's cancer diagnosis. Throughout the course of fighting ALL, hope empowers primary caregivers with the strength and courage to confront reality, enabling them to maintain a positive mindset toward clinical treatment and nursing care, actively regulate negative emotions, and proactively acquire caregiving skills. Hope continuously guides their awareness and behaviors toward a more positive direction, thereby facilitating the adoption of positive coping styles. Caregivers with higher hope levels possess stronger intrinsic motivation and maintain greater expectations regarding their child's treatment outcomes and future life. They are better able to face the illness with rationality and a constructive mindset, and are more willing to actively explore various approaches to resolving caregiving and daily life challenges. Thus, hope serves as a significant driving force that promotes the selection of positive coping styles^[35]. In clinical practice, interventions such as mindfulness-based guidance, positive reinforcement, and sharing of successful cases can be employed to instruct primary caregivers of children with ALL in using strategies such as emotional expression, attentional shifting, emotional anchoring, and self-suggestion to facilitate positive coping. Additionally, techniques such as downward social comparison and life re-planning^[36] may help enhance caregivers' hope levels and strengthen their intrinsic motivation toward active coping.

3.2.3 Social Support Level

In this study, primary caregivers of children with ALL who reported higher levels of social support were more likely to adopt positive coping strategies ($P < 0.05$), which is consistent with the findings of Quan et al.^[12]. Social support, derived from the instrumental, emotional, and informational assistance provided by an individual's social network, represents a critical opportunity resource for adopting positive coping strategies^[11]. The diagnosis of ALL and its complex treatment process impose substantial financial and psychological burdens on families, with primary caregivers experiencing tremendous psychological stress and anxiety.

Research^[37] has shown that adequate social support can provide families with financial assistance and social security, as well as offer caregivers disease-related information, caregiving skills training, and

access to various available social resources, thereby helping to alleviate anxiety and fear. Throughout the long-term caregiving process for children with ALL, multifaceted social support from family members, relatives, friends, healthcare professionals, and peer caregiver groups can effectively relieve the physical and psychological stress of primary caregivers, reduce their tension and unease, and simultaneously broaden their avenues for help-seeking. This facilitates active expression of negative emotions and problem-solving efforts, ultimately promoting more positive coping styles. Therefore, healthcare professionals should pay close attention to the level of social support available to primary caregivers of children with ALL. Encouraging caregivers to actively utilize social resources such as peer support groups and charitable organizations, while fully leveraging diverse resources from community networks, government agencies, social organizations, and volunteers, can help establish a comprehensive support system. Such a network can provide caregivers with essential medical information and emotional support, thereby facilitating the adoption of positive coping styles.

3.2.4 Caregiving Knowledge Level

The results of this study demonstrated that a higher level of caregiving knowledge was a protective factor for positive coping styles among primary caregivers of children with ALL ($P < 0.05$). Research^[38] has indicated that following the child's diagnosis of ALL, primary caregivers, as key participants in medical decision-making, are required to repeatedly weigh and select treatment options throughout the care process. To make informed decisions, caregivers actively seek out various types of caregiving knowledge and disease-related information, and generally express a strong desire for comprehensive understanding of disease progression, treatment protocols, and the child's physical and psychological status, in order to better cooperate with treatment. Systematic and comprehensive caregiving knowledge enables caregivers to proficiently manage chemotherapy-related adverse effects, daily care, and disease monitoring, thereby reducing the risk of errors and fear during the caregiving process. Caregivers of children with ALL who possess higher levels of caregiving knowledge have a clearer understanding of disease fluctuations, medication management, complication prevention, and nutritional support. This allows them to perform caregiving tasks proactively and in accordance with clinical standards, thereby fostering a sense of control and accomplishment, which in turn promotes positive coping styles. Clinicians and nurses should adopt diversified approaches to health education, including stratified health teaching, one-on-one caregiving skills instruction, and online course delivery, combined with systematic training methods such as oral explanations, illustrated manuals, video demonstrations, and bedside demonstrations, to enhance the caregiving knowledge level of primary caregivers of children with ALL.

3.3 Influencing Factors of Negative Coping Styles Among Primary Caregivers of Children with ALL

3.3.1 Presence of Complications During the Current Treatment Period

In this study, the occurrence of complications during the child's current treatment period was identified as a risk factor for negative coping strategies among primary caregivers of children with ALL ($P < 0.05$), which is consistent with the findings of Kanchanaudom et al. ^[39]. During treatment, children with ALL are at high risk of complications such as infections, hemorrhage, and organ dysfunction, which not only prolong hospitalization and increase medical costs but also directly intensify the complexity and risks of caregiving ^[40]. Faced with recurrent disease fluctuations and the threat of severe complications, caregivers are prone to emotional states of anxiety, helplessness, and panic. Under prolonged high-stress conditions, caregivers find it difficult to maintain emotional stability, making them more susceptible to adopting negative coping styles such as passive acceptance. Therefore, nurses should strengthen early identification and prevention of complications in children with ALL, while simultaneously paying close attention to the psychological status of their caregivers. Proactive education on complication prevention and control, along with emergency care skills training, should be provided in advance to help reduce caregivers' fear of the unknown regarding complications. Timely emotional support and counseling should also be offered to mitigate the tendency toward negative coping.

3.3.2 Unemployment Status

This study found that being unemployed was a risk factor for negative coping styles among primary caregivers of children with ALL ($P < 0.05$), which is consistent with the findings of Jiang et al. ^[41]. During the treatment process for children with ALL, the prolonged duration of therapeutic protocols, combined with the need for continuous close monitoring, the child's immunocompromised state, and significant disease fluctuations, present enormous challenges to primary caregivers in terms of caregiving energy, physical health, and psychological well-being. Most caregivers are compelled to interrupt their professional careers in order to devote themselves fully to the child's care. Research ^[42, 43] has shown that 34.7% of mothers chose to give up paid employment at the time of their child's cancer diagnosis, and 28.7% reduced their working hours. Family caregivers of children with cancer spend an average of 141.5 hours per week on caregiving. The prolonged and intensive caregiving demands make it extremely difficult for caregivers to maintain employment, with caring for the child becoming their top priority in life. Unemployed caregivers, who are typically engaged in full-time caregiving, devote all their time and energy to caring for the child, which severely restricts their personal life, employment opportunities, and social activities, with their daily routines confined largely to the home and hospital settings. This prolonged and monotonous caregiving lifestyle tends to keep them in a state of mental tension and social disconnection, leaving them continuously immersed in the child's disease fluctuations, treatment risks, and family stress. Lacking effective channels for emotional expression and information access, these caregivers are more prone to negative emotions such as anxiety and helplessness, thereby increasing their inclination toward negative coping styles ^[44]. This suggests that healthcare professionals should prioritize the assessment of employment status among primary caregivers of children with ALL, with particular attention to the need for social role reconstruction among unemployed caregivers. Caregivers should be encouraged to appropriately engage in offline activities during caregiving breaks, or

to expand social connections through online communication platforms, in order to alleviate feelings of loneliness and anxiety. Additionally, proactive linkage with community resources, in collaboration with community workers, should be established to provide psychological counseling and caregiving support, thereby reducing negative coping behaviors.

3.3.3 Monthly Per Capita Household Income

This study revealed that a monthly per capita household income of RMB 3,000–5,000 was a risk factor for negative coping styles among primary caregivers of children with ALL. This finding is somewhat inconsistent with the results reported by Jiang et al. ^[12]. The entire treatment course for leukemia spans 2 to 3 years, and financial concerns remain one of the most prominent issues for primary caregivers of children with ALL ^[45]. Yang et al. ^[46] demonstrated that, in addition to direct treatment costs, most families of children with ALL incur additional expenses such as transportation and accommodation for hospital visits, further exacerbating the family's financial burden. In the present study, the primary caregivers of children with ALL were predominantly the child's parents. Prolonged caregiving resulted in the loss of the family's primary income earners, leading to reduced household income and intensifying financial strain.

According to resilience theory ^[47], moderate exposure to adversity can help individuals develop more adaptive coping styles. However, when sustained high-intensity stress exceeds an individual's tolerable range, a sensitization effect may occur, which can paradoxically impair their adaptive behaviors. In this study, the sustained financial pressure experienced by families with a monthly per capita household income of RMB 3,000–5,000 may have exceeded the tolerable threshold of "moderate adversity." This group, unlike families with a monthly per capita income of < RMB 3,000, has not developed stable adaptive mechanisms to chronic financial hardship over time, and thus may not benefit from the psychological protective effects associated with such adaptation. At the same time, they lack the sufficient financial reserves of families with an income > RMB 5,000 to buffer the impact of prolonged medical expenditures. As a result, the long-term economic burden becomes a persistent stressor, leading caregivers to excessively worry about subsequent treatment costs and the potential consequences of insufficient funds on treatment outcomes. This undermines their confidence in the child's therapy and predisposes them to adopting negative coping styles. This suggests that clinical healthcare professionals should comprehensively consider the actual circumstances of primary caregivers with a monthly per capita household income of RMB 3,000–5,000 and provide targeted support. Such support may include providing information on financial assistance programs, assisting with applications for relief funds, and facilitating access to child leukemia treatment grants through social channels. At the same time, efforts should be made to develop reasonable treatment plans that minimize unnecessary examinations, thereby reducing the medical financial burden. Additionally, actively listening to caregivers' concerns and distress may help promote the adoption of positive coping styles.

3.3.4 Illness Uncertainty

This study found that a higher score on illness uncertainty was a risk factor for negative coping strategies among primary caregivers of children with ALL ($P < 0.05$). Illness uncertainty refers to the subjective experience of being unable to accurately predict, comprehend, or control the trajectory, fluctuations, and outcomes of the disease^[14]. Liu et al.^[48] found that the complexity of ALL, the variability of treatment protocols, and the individual differences in prognosis often leave caregivers facing insufficient information and unpredictable disease trajectories during the caregiving process, making them highly susceptible to illness uncertainty.

High levels of illness uncertainty make it difficult for primary caregivers of children with ALL to anticipate the child's disease trajectory or to identify various treatment-related adverse reactions. In the absence of reliable disease-related information, the ambiguous and unknown disease status continuously intensifies caregivers' sense of loss of control, triggering profound feelings of helplessness and persistent worry. Prolonged exposure to negative emotions predisposes caregivers to subjectively exaggerate treatment risks, question the effectiveness of current treatment protocols and the child's long-term prognosis, and resist standardized treatment. This directly diminishes their treatment adherence and cooperation with nursing care, undermines their intrinsic motivation to actively seek information and engage in positive coping, and ultimately increases their tendency toward negative coping styles.

In clinical practice, interventions such as distributing illustrated educational booklets covering the disease process, treatment, caregiving, and nutritional needs of ALL, combined with multimedia presentations to reinforce educational outcomes, can be implemented. Additionally, providing information support, hope therapy, mindfulness-based interventions, and organizing peer support groups for primary caregivers of children with ALL^[49] may help reduce their level of illness uncertainty.

Conclusion

The findings of this study indicate that while the majority of primary caregivers of children with ALL tend to adopt positive coping styles, nearly half still exhibit a propensity for negative coping styles. The coping styles of these caregivers are influenced by multiple factors, including occupational status, monthly per capita household income, place of residence, illness uncertainty, hope level, social support, caregiving knowledge, and the presence of complications during the current treatment period. This highlights the need for healthcare professionals to prioritize the assessment of coping styles among primary caregivers of children with ALL. Targeted, stratified, and individualized interventions can be implemented through disease-related health education, regular organization of peer support group meetings, and training programs focused on complication prevention.

Limitations and future directions

This study was conducted at a single tertiary children's hospital in Suzhou, and the sample predominantly consisted of mothers, which to some extent limits the generalizability of the findings.

Future research should consider multi-center studies with increased representation of fathers, grandparents, and other types of caregivers, and incorporate qualitative approaches to further explore the influencing factors of coping styles among primary caregivers of children with ALL.

Abbreviations

ALL

Acute Lymphoblastic Leukemia

COM-B

Capability, Opportunity, Motivation–Behavior

SCSQ

Simplified Coping Style Questionnaire

PPUS

Parental Perception of Uncertainty Scale

HHI

Herth Hope Index

SSRS

Social Support Rating Scale

SPSS

Statistical Package for the Social Sciences

VIF

Variance Inflation Factor

OR

Odds Ratio

CI

Confidence Interval

PICC

Peripherally Inserted Central Catheter

Declarations

Ethics approval and consent to participate

This study has received ethical approval from the Ethics Committee of the Children's Hospital of Soochow University (Approval No: 2025CS392). All participants voluntarily enrolled in this study and signed a written informed consent form. The informed consent form provided detailed explanations of the study's objectives, procedures, confidentiality measures, and the voluntary nature of participation. All methods and procedures used in this study comply with relevant guidelines and the provisions of the Declaration of Helsinki.

Consent for publication

Not Applicable.

Availability of data and materials

The datasets used and analyzed in this study are available from the corresponding author upon reasonable request.

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Authors' Contributions

R.W. and A.X. conceived and designed the study. R.W. and Y.Z. performed the literature review and developed the theoretical framework. R.W., Y.Z., and H.Y. conducted the questionnaire survey and collected the data. Y.F. and X.Y. performed the statistical analysis and interpreted the data. R.W. wrote

the main manuscript text and prepared all tables. A.X. supervised the study, provided critical revisions, and acted as the corresponding author. All authors reviewed and approved the final manuscript.

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