

Correlation Between Illness Uncertainty in Caregivers of Patients with Liver Cancer, Their Coping Styles, and Quality of Life

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Objective: This study explores the correlation between coping style, quality of life, and illness uncertainty in the family caregivers of patients with liver cancer.

Methods: Employing convenience sampling, 210 family caregivers of patients with liver cancer who met the admission criteria were selected from a grade A infectious disease hospital in Beijing between January and December 2022. A cross-sectional survey was conducted using the Simplified Coping Style Questionnaire, Caregiver Quality of Life, and the Mishel Uncertainty in Illness Scale for Family Members. This study analysed the correlations between coping styles, quality of life, and illness uncertainty in these caregivers.

Results: The study found that family caregivers of patients with liver cancer had average scores for illness uncertainty (83.44 ± 11.86), coping style (33.19 ± 9.79 ; both positive [23.02 ± 6.81] and negative [10.17 ± 5.05]), and quality of life (169.53 ± 32.46). A negative association was observed between illness uncertainty in these caregivers and positive coping style ($r = -0.207$, $p = 0.003$), physical status ($r = -0.182$, $p = 0.008$), psychological status ($r = -0.200$, $p = 0.004$), and social adaptation ($r = -0.229$, $p = 0.001$).

Conclusion: The study concludes that illness uncertainty in family caregivers of patients with liver cancer is at a moderate level. Furthermore, there is a notable correlation between illness uncertainty, coping style, and quality of life in these caregivers.

Keywords: liver cancer, family caregivers, uncertainty in illness, coping style, quality of life

Introduction

Liver cancer poses a substantial global health challenge. As of 2019, Chinese liver cancer incidence rate stood at 14.80 per 100,000 individuals, ranking fourth among all malignant tumours. Its mortality rate was 8.44 per 100,000, placing it second in malignant tumour deaths.¹ Notably, in 2015, the 5-year survival rate for individuals with liver cancer was a mere 12.1%, underscoring the disease's severity.² Liver resection surgery, particularly for those in advanced stages or with tumour transformation, remains a key treatment option, offering a potential cure.³ However, this complex procedure, characterised by considerable trauma, prolonged duration, excessive bleeding, and high-risk factors, presents substantial challenges. Patients undergoing liver resection often have preoperative liver dysfunction, increasing the likelihood of severe postoperative complications. This elevates caregiving needs during treatment and postoperatively, emphasising the critical role of family caregivers alongside healthcare professionals.^{4,5}

Family caregivers, although not medically trained, play an integral role in the patient's treatment and care processes. Their lack of professional medical training often leads to inadequate medical knowledge, causing uncertainty about disease progression, treatment options, and appropriate care in various scenarios. This uncertainty can markedly affect caregivers' quality of life.⁶⁻⁹ The coping style of family caregivers is multifaceted, influencing their response to the

challenges they face. Their coping strategies may include problem-solving, seeking social support, positive reframing, and acceptance, among others. It is vital to understand how family caregivers employ these strategies to fully grasp their experiences and identify potential intervention areas. The quality of life of family caregivers, encompassing physical health, emotional well-being, social interactions, and overall life satisfaction, is profoundly impacted by their caregiving role. Therefore, assessing and improving their quality of life is essential for maintaining their well-being and, by extension, their ability to provide effective care. The concept of disease uncertainty, introduced by American scholar Mishel in 1988, pertains to the induction and comprehension of the meaning and components of disease-related stimuli by the patient. It includes unpredictability, information scarcity, complexity, and ambiguity. Family caregivers experiencing difficulty in establishing a cognitive framework to assess or predict relevant disease stimuli often face disease uncertainty, frequently accompanied by emotional distress, fear of the disease, and physiological decline.¹⁰

Despite the wealth of research on disease uncertainty among patients, there has been a notable lack of focus on family caregivers, especially regarding their coping strategies and how these strategies are associated with their quality of life. This study aims to address this oversight by delving into the complex relationship between disease uncertainty, coping strategies, and quality of life in family caregivers of patients with liver cancer. The insights gained from this research could be instrumental in guiding the creation of targeted interventions for family caregiving in the context of liver cancer, with the ultimate goal of enhancing the well-being of both patients and their family caregivers.

Materials and Methods

Participants

A convenience sampling method was used to select 210 family caregivers of patients with liver cancer who met the admission criteria at a tertiary grade A infectious disease hospital in Beijing between January and December 2022. The inclusion criteria were as follows: (1) primary responsibility for care; (2) aged 18 or above; (3) ability to read, write, think, and understand independently. The exclusion criteria were as follows: (1) family caregivers of patients with severe complications; (2) individuals with cognitive or mental disorders. In this survey, 240 questionnaires were distributed, 227 were collected, and 210 were valid (fully completed and usable), resulting in a response rate of 94.58% and an effective questionnaire rate of 92.51%. The flowchart illustrating patient enrolment is shown in Figure 1. The study was conducted with the informed consent of the participants and was approved by the hospital's ethics review committee. It was conducted in compliance with the Helsinki Declaration.

According to Kendall's sample size estimation method,¹¹ the sample size is recommended to be 5–10 times the number of variables and then increased by 20% to reduce error. The maximum number of variables in this questionnaire was 35, and a factor of 6 times the number of variables was used to calculate a sample size of 210 cases for this study. The sample size was ultimately set at 240 cases to compensate for potential inadequacies due to factors such as invalid questionnaires.

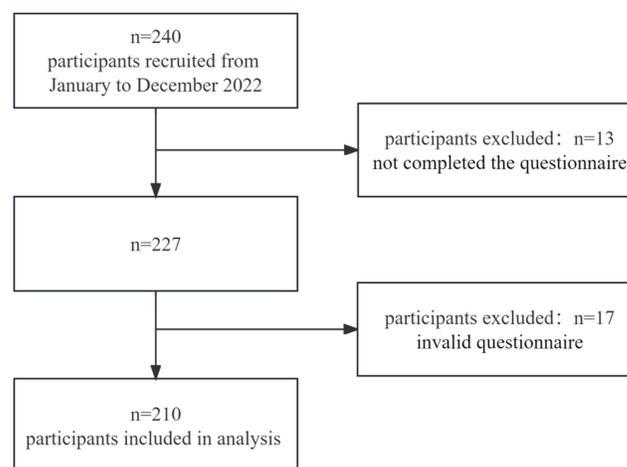


Figure 1 Flowchart of enrolled patients.

Methods

The survey employed four instruments: the Demographic Characteristics Questionnaire, the Caregiver Quality of Life Scale (CQOL), the Simplified Coping Style Questionnaire (SCSQ), and the Chinese version of the Mishel Uncertainty in Illness Scale for Family Members (MUIS-FM).

- (1) The Demographic Characteristics Questionnaire includes 11 items covering age, gender, education level, occupation, marital status, relationship to the patient, number of children, family residence, monthly household income, medical expenses payment, and cumulative caregiving time.
- (2) The MUIS-FM, in its Chinese version translated and revised by Xu et al,¹² is comprised of four dimensions: unpredictability, lack of information, complexity, and ambiguity, totalling 30 items. The scoring range is from 1 to 5 points, with the total score varying between 30 and 150, categorised into three levels: low (30–70), moderate (71–111), and high (112–150). Higher scores indicate greater perceived illness uncertainty.
- (3) The SCSQ, developed by Xie Yaning,^{13,14} encompasses two dimensions, positive coping and negative coping, comprising a total of 20 items. Each item is scored on a scale from 0 to 3 points, depending on the options selected by the respondents. Of these, 12 items assess positive coping styles, indicative of proactive coping strategies, while the remaining 8 items evaluate negative coping styles associated with less adaptive coping strategies. Higher scores in each dimension suggest a greater tendency towards the respective coping styles.
- (4) The Chinese version of the CQOL, translated and revised from Ferrell et al,¹⁵ evaluates four dimensions: physical health, psychological health, social adaptation, and spiritual well-being, through 37 items rated on a 10-point scale. Each item scores from 0 to 10, with higher scores reflecting better quality of life for family caregivers.

Quality Control

The researchers initially explained the necessity and importance of the study to the participants, followed by a preliminary survey on a small scale. The preliminary survey contains 30 participants. Subsequent to the necessary adjustments, the questionnaire was finalised. The researchers provided comprehensive explanations of the questionnaire items to the participants. If participants were unable to comprehend certain items, the researchers offered clarifications without imparting any personal opinions. Upon collection of the questionnaires, the two researchers cross-checked them for any evident logical inconsistencies. They then contacted the participants for additional clarification and revision as required.

Statistical Analysis

Statistical analyses were conducted using SPSS version 23.0. Shapiro–Wilk tests were executed to confirm the normal distribution of samples before analysis. Continuous variables were presented as mean \pm SD ($\bar{x} \pm s$). Categorical variables were expressed as frequencies (percentages). The correlation between the two variables was examined using Pearson's correlation analysis. For this study, the statistical significance threshold was set at $p < 0.05$ for two-tailed tests.

Results

Baseline Characteristics of the Study Participants

The study included 210 family caregivers of patients with liver cancer. Of these, 54.3% were women and 45.7% were men. A notable majority of the family caregivers (94.8%) had a direct relationship with the patients, such as being immediate family members or spouses. The largest group of family caregivers (61.4%) had only one child. Most families (70.5%) resided in urban areas. The predominant method for covering medical expenses was partial medical insurance, accounting for 72.9%. The highest proportion of caregivers (41.9%) reported a cumulative caregiving duration of over 6 months. The details are presented in [Table 1](#).

Table 1 Baseline Characteristics of Family Members of Liver Cancer Patients (n =210)

Variables		n (%)
Sex	Male	96 (45.7)
	Female	114 (54.3)
Age	18~	91 (43.3)
	40~	106 (50.5)
	>60	13 (6.2)
Education level	Middle school or below	35 (16.7)
	High school or vocational school	70 (33.3)
	College degree or above	105 (50.0)
Vocational	Government/Institution.	68 (32.4)
	Worker/Farmer.	50 (23.8)
	Retired/Unemployed.	31 (14.8)
	Others	61 (29.0)
Relationship with patients	Spouse.	73 (34.8)
	Parents	55 (26.2)
	Children	71 (33.8)
	Siblings	5 (2.4)
	Other relationships	6 (2.9)
Marital status	Single	18 (8.6)
	Married	188 (89.5)
	Divorced/widowed	4 (1.9)
Number of children	None	30 (14.3)
	1	129 (61.4)
	2 or more	51 (24.3)
Place of residence	Urban area	148 (70.5)
	Rural area	62 (29.5)
Average monthly household income(CNY)	≤2000	42 (20.0)
	2000~5000	71 (33.8)
	5000~10,000	68 (32.4)
	≥10,000	29 (13.8)
Medical expense payment	Fully self-pay	14 (6.7)
	Partial health insurance coverage	153 (72.9)
	Full health insurance coverage	43 (20.5)
Cumulative care time(months)	<1	45 (21.4)
	1~3	54 (25.7)
	4~6	23 (11.0)
	>6	88 (41.9)

Scores Across All Dimensions of the MUIS-FM, SCSQ, and CQOL

In the survey, the MUIS-FM scores of the 210 family caregivers of patients with liver cancer were as follows: the overall MUIS-FM score was 83.44 ± 11.86 , with the unpredictability score at 10.34 ± 2.18 , the informational deprivation score at 13.87 ± 2.22 , the complexity score at 22.84 ± 4.04 , and the uncertainty score at 36.39 ± 6.34 . The coping style score was 33.19 ± 9.79 , including a positive coping style score of 23.02 ± 6.81 and a negative coping style score of 10.17 ± 5.05 . The quality-of-life score was 172.16 ± 47.25 , with scores for physical health at 26.86 ± 7.61 , psychological health at 68.56 ± 26.03 , social adaptation at 45.54 ± 17.33 , and spiritual well-being at 31.20 ± 7.09 . These details are outlined in [Table 2](#).

Correlation Between Illness Uncertainty, Quality of Life, and Coping Style

Pearson's correlation analysis indicated that illness uncertainty in family caregivers of patients with liver cancer was negatively correlated with positive coping style ($r = -0.207$, $p = 0.003$), physical status ($r = -0.182$, $p = 0.008$), psychological status ($r = -0.200$, $p = 0.004$), and social adaptation ($r = -0.229$, $p = 0.001$). For detailed information, please refer to [Table 3](#).

Table 2 Scores of Illness Uncertainty, Coping Styles, and Quality of Life

Variables	Min	Max	Mean \pm SD
Unpredictability	4	20	10.34 \pm 2.18
Information deficiency	7	21	13.87 \pm 2.22
Complexity	9	35	22.84 \pm 4.04
Uncertainty	18	55	36.39 \pm 6.34
Total score of illness uncertainty	47	121	83.44 \pm 11.86
Positive coping style	1	36	23.02 \pm 6.81
Negative coping style	0	24	10.17 \pm 5.05
Total score of coping style	1	59	33.19 \pm 9.79
Physical status	3	46	26.86 \pm 7.61
Psychological status	10	151	68.56 \pm 26.03
Social adaptation	6	88	45.54 \pm 17.33
Mental status	10	50	31.20 \pm 7.09
Total score of quality of life	61	329	172.16 \pm 47.25

Discussion

Liver cancer is one of the most prevalent malignant tumours in clinical practice, often associated with a poor prognosis. Currently, radical surgery remains the primary treatment modality for liver cancer.^{16,17} However, the stress of surgery can have a substantial psychological impact on both patients and their family caregivers. The lack of a comprehensive understanding of the disease and its surgical treatment often leads to uncertainty in patients and their family caregivers, potentially affecting their confidence in treatment and hindering postoperative recovery. This study investigated disease uncertainty, coping strategies, and quality of life among the family caregivers of patients with liver cancer. It was found that the family caregivers exhibited a moderate level of disease uncertainty (83.44 \pm 11.86), and there was a notable negative correlation between disease uncertainty among family caregivers and both positive coping style ($r = -0.207$) and quality of life ($r = -0.310$).

In this study, the mean score on the MUIS-FM for caregivers of patients with liver cancer was 83.44 \pm 11.86. This score, although lower than the results reported by Yao Yi,¹⁸ still falls within the moderate range. Most family caregivers, lacking professional medical knowledge, face considerable uncertainty throughout the diagnosis, treatment, and care of cancer. It has been observed that increased social support can help individuals gain more encouragement, support, and assistance, thereby improving their handling of disease uncertainty.¹² This study's findings highlighted that family caregivers of patients with liver cancer scored relatively high in terms of unpredictability, likely due to fears surrounding the cancer and a limited understanding of surgical options. The majority of family caregivers not involved in medical professions have limited knowledge about the disease and its treatment. This often leads to feelings of helplessness and powerlessness throughout the prolonged and recurring nature of the illness, resulting in heightened unpredictability. However, the lowest score was observed in the lack of information domain, possibly reflecting the effective health education provided by the hospital. This underlines the importance of clinical nursing staff offering sufficient guidance to family caregivers, providing timely updates on the patient's condition, and aiding in understanding disease progression. This approach can help reduce disease uncertainty and improve psychological well-being while caring for the patient. Therefore, nursing staff can play a crucial role in integrating vital support systems for family caregivers, such as information support, health education, and psychological care, into the overall care plan. This comprehensive and systematic approach to high-level social support can reduce caregivers' disease uncertainty and ultimately enhance the quality of patient care and prognosis.¹⁹

Coping styles are personal behavioural strategies employed in managing stressful situations.²⁰ Research has shown that family caregivers who adopt a negative coping style tend to experience greater illness uncertainty,²¹ a finding echoed in this study. This suggests that enhancing positive coping styles in family caregivers can reduce their experience of illness uncertainty. Thus, it is advisable for nursing staff to increase the level of positive coping styles among family

Table 3 Correlation Analysis Between Illness Uncertainty, Quality of Life, and Coping Styles

Variables	Unpredictability				Information Deficiency				Complexity			Uncertainty				
	r	p	95% CI		r	p	95% CI		r	p	95% CI		r	p	95% CI	
Positive coping style	-0.209**	0.002	-0.365	-0.042	-0.221**	0.001	-0.353	-0.077	-0.218**	0.001	-0.360	-0.050	-0.207**	0.003	-0.255	0.070
Negative coping style	0.003	0.966	-0.178	0.163	0.178**	0.010	0.036	0.312	0.062	0.373	-0.210	0.088	0.038	0.586	-0.111	0.182
Physical status	-0.071	0.308	-0.227	0.089	-0.265**	0.000	-0.381	-0.141	-0.189**	0.006	-0.318	-0.058	-0.182**	0.008	-0.310	-0.052
Psychological status	0.088	0.206	-0.042	0.215	-0.349**	0.000	-0.464	-0.22	-0.300**	0.000	-0.435	-0.148	-0.200**	0.004	-0.333	-0.056
Social adaptation	0.036	0.604	-0.099	0.159	-0.334**	<0.001	-0.452	-0.204	-0.283**	0.000	-0.406	-0.159	-0.229**	0.001	-0.353	-0.103
Mental status	-0.251**	0.000	-0.412	-0.088	-0.313**	0.000	-0.452	-0.171	-0.142*	0.039	-0.327	0.050	-0.095	0.171	-0.275	0.091

Note: **P<0.01; *P<0.05.

caregivers of patients with liver cancer through various approaches such as dyadic interventions, transitional care models, mobile healthcare, and cognitive-behavioural interventions.

The influence of illness uncertainty on the quality of life of family caregivers is a well-established concept in domestic research.²² It has been observed that illness uncertainty can lead to a decline in the quality of life for family caregivers of patients with liver cancer, mediated by its impact on individuals' adaptation abilities and perceived stress.^{4,23} Accordingly, it is recommended that clinicians assess and manage the illness uncertainty of family caregivers in a timely and scientific manner. Tailored and targeted interventions should be provided at different stages of the disease, including personalised and professional guidance on disease-related knowledge and effective health education models. These interventions should cater to various needs such as information, emotional support, psychological care, and coping styles and should aim to promptly address their concerns. By reducing illness uncertainty, enhancing adaptive capacity, and maintaining a positive emotional state, the quality of life for family caregivers can be substantially improved.

This study has several limitations. First, it was conducted in a single hospital, and the sample size was relatively small, potentially leading to selection bias and affecting the strength of the correlation. Second, the analysis was solely from the perspective of patients' family caregivers, but the severity of the patients' illness is another major influencing factor. Therefore, future studies should consider multicentre research with larger sample sizes to explore additional relevant factors, providing a theoretical foundation for developing intervention programmes aimed at reducing illness uncertainty.

Conclusion

In summary, the current level of illness uncertainty among family caregivers of patients is moderate. Family caregivers adopting a more negative coping style tend to experience higher levels of illness uncertainty and a lower quality of life. Therefore, interventions aimed at reducing illness uncertainty among family caregivers of liver cancer patients should focus on enhancing positive coping styles. Implementing targeted interventions could lower illness uncertainty, thereby enabling family caregivers to fulfil their caregiving roles more effectively.

Data Sharing Statement

The original contributions presented in this study are included in the article, further inquiries can be directed to the corresponding author/s.

Ethics Statement

The studies involving human participants were reviewed and approved by the Beijing Youan Hospital of China Capital Medical University. The Ethics Committee archive number is LL-2021-168-K. The patients/participants provided their written informed consent to participate in this study.

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Disclosure

The authors declare no competing interests in this work.

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