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Development of a self-management behavior assessment scale for liver cancer patients from ethnic minorities

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Abstract

Background Liver cancer poses significant health challenges worldwide, particularly for ethnic minority populations, who often face barriers such as cultural differences, limited health literacy, and inadequate access to healthcare, contributing to poorer self-management and treatment outcomes. Existing self-management tools do not adequately address the unique needs of ethnic minority liver cancer patients, necessitating the development of a culturally tailored assessment scale.

Methods Grounded in the Health Belief Model, this study developed a self-management behavior assessment scale specifically for ethnic minority liver cancer patients. The scale was constructed using a comprehensive literature review, semi-structured qualitative interviews with 11 ethnic minority liver cancer patients, and two rounds of expert consultation via the Delphi method. The initial item pool was refined through expert input to ensure relevance and cultural sensitivity.

Results Through literature review and semi-structured qualitative interviews with 11 ethnic minority liver cancer patients, four key dimensions were identified: health behavior management, disease perception and cognition, psychological and emotional regulation, and information acquisition and decision-making participation. These dimensions and items were further refined through two rounds of expert consultation using the Delphi method, ensuring the scale's cultural relevance and content validity. As a result, a self-management behavior assessment scale was developed, consisting of four dimensions and 31 items tailored to the specific needs of ethnic minority liver cancer patients.

Conclusion This newly developed scale provides a culturally sensitive tool to assess self-management behaviors in ethnic minority liver cancer patients. It has the potential to enhance patient care by identifying culturally specific barriers to effective self-management. Further research is needed to validate the scale's reliability and applicability in broader patient populations.

Keywords Ethnic minority, Liver neoplasms, Self-management, Assessment

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Introduction

Liver cancer is one of the leading causes of cancer-related morbidity and mortality globally. Its incidence continues to rise, particularly in developing countries [1, 2]. As indicated by data from the Global Cancer Report, liver cancer has become the third leading cause of cancer-related mortality worldwide in 2022 [3]. The majority of patients with liver cancer are diagnosed at an advanced stage, with an average life expectancy typically ranging from 6 to 12 months [4]. Even among patients who receive treatment at an early stage, the 5-year survival rate is below 50% to 70% [5]. Consequently, enhancing the quality of life and improving treatment outcomes for patients represent critical challenges in current management. Self-management is the process by which patients actively participate in the management of their health and treatment, encompassing behaviors aimed at maintaining physical health, adhering to medical advice, managing symptoms and side effects, and regulating psychological well-being. Studies have indicated that self-management behaviors play a significant role in prolonging the quality of life and increasing survival rates among patients [6, 7]. Ethnic minorities are defined in this paper as non-Han groups within China known for their distinctive cultures, languages, and traditional practices. Patient engagement in self-management is critical for recovery and long-term prognosis in liver cancer treatment [8]. However, many patients, especially those from ethnic minorities, encounter significant challenges due to cultural differences, limited awareness of effective disease management strategies, and a lack of knowledge about their condition [9, 10], which directly impacts their treatment adherence and physical and mental health [11]. These challenges are compounded by traditional beliefs about health and illness that may influence treatment decisions, leading to reduced treatment adherence and negative impacts on physical and mental health [12–15].

For instance, cultural practices pertaining to diet, traditional medicine, and health-seeking behaviors may serve as impediments to the effective self-management of health conditions. Ethnic minority patients may demonstrate a preference for traditional remedies over evidence-based treatments or may experience limitations in access to culturally appropriate health education [16], further complicating their ability to manage their illness. Such disparities are of critical importance, as they have been shown to contribute to increased incidence of complications during treatment, elevated psychological burdens, and reduced survival rates [17]. Therefore, the improvement of patient self-management capabilities represents a crucial element in the optimization of individual health outcomes and the reduction of healthcare expenditures [18].

Despite the crucial relevance of self-management in the rehabilitation of liver cancer patients, existing self-management scales, such as Self-Management Behavior Scale (SMBS) [19], Patient Activation Measure (PAM) [20], and Self-Care of Chronic Conditions Inventory II (SCCII) [21], have been widely applied in research on chronic diseases and general health behaviors. However, these scales are designed more for general assessment and lack attention to cultural sensitivity and disease-specific dimensions in self-management behaviors among liver cancer patients, especially among ethnic minority groups [22, 23]. Consequently, they fail to adequately account for the distinctive cultural and social backgrounds of ethnic minority patients. In these cases, there is a distinct absence of scales designed to systematically assess self-management behaviors. Furthermore, this may result in healthcare providers failing to take into account culturally specific factors that influence health behaviors. Accordingly, there is an urgent requirement for the development of a self-management behavior assessment scale that is tailored for ethnic minority liver cancer patients, which not only considers the distinctive health beliefs and practices of these communities, but also takes account of the psychological burdens associated with prolonged treatment [24–26]. This study aims to develop a self-management behavioral assessment scale for ethnic minority liver cancer patients (SMS-EMLC), therefore filling a critical gap in the literature and enhancing clinical nursing practice for this underserved population.

Materials and methods

Theoretical basis for the development of SMS-EMLC

In this study, the Health Belief Model (HBM) was employed as the theoretical framework for SMS-EMLC. The model was initially proposed by psychologists Rosenstock in the 1950s [27] to explain and predict the formation of individual health behaviors and the factors influencing them [28, 29]. The core dimensions of the model include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action, all of which shape an individual's decision to engage in preventive or therapeutic health behaviors. In recent years, the HBM has been widely used in health behavior research, providing theoretical guidance for self-management and health behavior interventions across various diseases [29–31]. For instance, the Health Belief Model Scale for Diabetic Patients, developed by Asiye Kartal, incorporates the dimensions of the HBM and effectively assesses patients' perceptions and behavioral choices about the disease, demonstrating strong reliability and validity [32].

This study, based on the HBM theoretical framework, combines literature review with semi-structured

interviews to extract and integrate core dimensions of self-management behaviors into four key dimensions: health behavior management, disease cognition and perception, psychological and emotional management, and information acquisition and decision-making participation, and refine scale-specific items, which are further optimized in content and sequence through subsequent Delphi method expert consultations.

Literature research methodology

A comprehensive search was conducted across six databases (CNKI, VIP, Wan Fang, PubMed, Web of Science, Embase) using a multifaceted search strategy. This approach involved utilizing both subject terms and free words, as illustrated in Table 1 with PubMed as an example. The remaining databases were tailored according to the established principles of library searches. The temporal scope of the search extended from the inception of the library to September 2024. To ensure a complete search of the literature, the search did not include qualifiers for ethnic minorities. The group engaged in repeated discussions regarding the preliminary formulation of the scale entry pool in relation to the search results. During the literature screening process, two independent researchers were used to initially screen the literature by titles and abstracts, followed by full-text screening for documents that met the criteria. Disputes over the screening of documents were resolved through discussion or by involving a third-party expert to ensure the consistency of the screening results. In the data extraction phase, the two researchers independently extracted key information from the literature and recorded it using a standardized

template to ensure the completeness and consistency of the information. Finally, all screened and extracted data were subjected to thematic analysis and synthesized into the construction of the scale items.

Qualitative research

This study employed qualitative interviews to conduct in-depth interviews with ethnic minority liver cancer patients with diverse characteristics. The objective was to gain in-depth insights into the self-management behaviors of ethnic minority liver cancer patients with diverse characteristics and the obstacles they encounter.

Inclusion criteria:

- i. Patients aged 18 years or older, diagnosed with liver cancer;
- ii. Patients from ethnic minorities;
- iii. Patients with basic Chinese communication skills;
- iv. Patients who have received or are receiving treatment;
- v. Patients who voluntarily participate in the study.

Exclusion Criteria:

- i. Patients with a combination of severe cognitive and psychiatric disorders;
- ii. Patients in an extremely critical stage of illness;
- iii. Patients who refuse to participate or withdraw.

The interview questions were designed based on the core dimensions of the HBM, covering aspects such as perceived severity, perceived susceptibility, perceived barriers and benefits, self-efficacy, and cues to action. Researchers used plain language during the interview process and confirmed the patients' understanding of the questions in real-time, ensuring that patients could respond accurately. The interviews were conducted in a quiet and private setting, and the objective and scope of the study were elucidated to the patients in advance. During the interview process, recordings are made on the principle of informed consent from the patient. Two researchers take on different roles: one focuses on communicating with the patient, ensuring that questions are asked clearly and are easy to understand; the other is responsible for recording the patient's body movements, facial expressions, and other non-verbal information to help better understand the patient's emotional responses and attitudes. The duration of the interview was limited to 30 min. Following the interview, the data was processed by the research team within 24 h using Nvivo 20. Thematic analysis was applied, and the data was coded by two independent researchers. The data was analyzed with strict adherence to the principle of data saturation

Table 1 Search strategy

| Search Strategy | PubMed |
|-----------------|--|
| #1 | (Liver Neoplasm*[MeSH Terms]) OR (Hepatic Neoplasm*[Title/Abstract]) OR (Neoplasm*, Hepatic[Title/Abstract]) OR (Neoplasm*, Liver[Title/Abstract]) OR (Cancer of Liver[Title/Abstract]) OR (Liver Cancer*[Title/Abstract]) OR (Cancer*, Liver[Title/Abstract]) OR (Hepatocellular Cancer*[Title/Abstract]) OR (Cancer*, Hepatocellular[Title/Abstract]) OR (Hepatic Cancer*[Title/Abstract]) OR (Cancer*, Hepatic[Title/Abstract]) |
| #2 | (self-management[MeSH Terms]) OR (self management[Title/Abstract]) OR (Management, Self[Title/Abstract]) OR (self-care behavior[Title/Abstract]) OR (chronic disease management[Title/Abstract]) OR (self-care[Title/Abstract]) OR (self-regulation[Title/Abstract]) OR (personal health management[Title/Abstract]) OR (individual health management[Title/Abstract]) OR (self-directed care[Title/Abstract]) |
| #3 | #1 AND #2 |

to ensure that the information from the interviews is representative of self-management for the majority of ethnic minority liver cancer patients [33].

Expert Delphi method

The preliminary draft of the SMS-EMLC outlines the structure of the expert correspondence questionnaire. It comprises five sections: (a) An introductory section, which provides a description of the purpose and significance of the study. (b) A section on the background of the experts who responded to the questionnaire. This includes their names, genders, ages, academic qualifications, titles, years of experience, and fields of work. (c) The main of the questionnaire comprises the dimensions of the questionnaire, the specific items, the importance of the items, the inclusion indicators, the modifications of the items and the additional items. The importance of the items is rated on a 5-point Likert scale, with 'no' being scored 1, 'rarely' scored 2, 'sometimes' scored 3, 'often' scored 4 and 'always' scored 5. (d) Questionnaire on experts' familiarity with entries and basis for judgement. The Delphi method was conducted via email, and the information provided by experts is kept strictly confidential.

Criteria for inclusion of experts:

- i. Professional background in the field of liver cancer diagnosis and treatment, nursing, psychology or health management;
- ii. Minority background or at least 5 years working with minorities;
- iii. Bachelor degree or above;
- iv. Voluntary and able to actively co-operate in completing 2 rounds of correspondence.

Technology roadmap

The detailed flowchart is shown in Fig. 1.

Statistical analyses

The statistical analysis was conducted using SPSS 26 and Excel 2022. Descriptive statistics, including frequencies and percentages, were used to summarize the characteristics of interview subjects and experts. Four indicators were used to evaluate the entries, namely the degree of expert positivity, the degree of expert authority, the degree of expert opinion concentration, and the degree of expert opinion coordination. The screening criteria for scale entries were as follows: mean score > 4, coefficient of variation < 0.25, percentage of experts choosing 4 or 5 points > 80% [34], and exclusion of items with lower

scores or significant disagreement based on statistical analysis.

Results

Qualitative study

General information about the interviewees

In this study, semi-structured interviews were conducted with ethnic minority liver cancer inpatients at a tertiary cancer hospital in Chengdu between August and September 2024, and data saturation was reached after 11 interviews. The demographic characteristics of these 11 patients are shown in Table 2.

Qualitative research: the collation and analysis of results

Following the analysis of the interview data, four key dimensions were identified and refined: health behavior management, disease perception and cognition, psychological and emotional management and information acquisition and decision-making participation. Qualitative interviews revealed many specific needs of ethnic minority patients, such as the impact of traditional dietary habits on health management, the role of ethnic traditional activities in emotional regulation, and the contradiction between traditional medical beliefs and modern treatment advice. These findings were integrated into the scale items, making them more culturally adaptable and specific. These details are further elaborated in Table 3.

The Delphi method of expert enquiry

General information on experts

Two rounds of expert correspondence were conducted in this study, and 13 experts participated, met the standard [35, 36]. The demographic information of the experts is provided in Table 4.

Level of expert engagement

The return rate of questionnaires and the rate of expert input were used to assess expert engagement. In the first round of correspondence, 14 questionnaires were distributed, with 13 returned, resulting in a response rate of 92.8%. Nine experts provided feedback, giving an input rate of 69.2%. In the second round, 13 questionnaires were distributed, with 12 returned, yielding a response rate of 92.3%. Seven experts provided feedback, leading to an input rate of 58.3%. These figures indicate a relatively high level of expert engagement [37].

Level of expert authority

The coefficient of expert authority was used to indicate the degree of expert authority. The coefficient of familiarity of the experts in the first round of expert correspondence was 0.846, the coefficient of the basis of

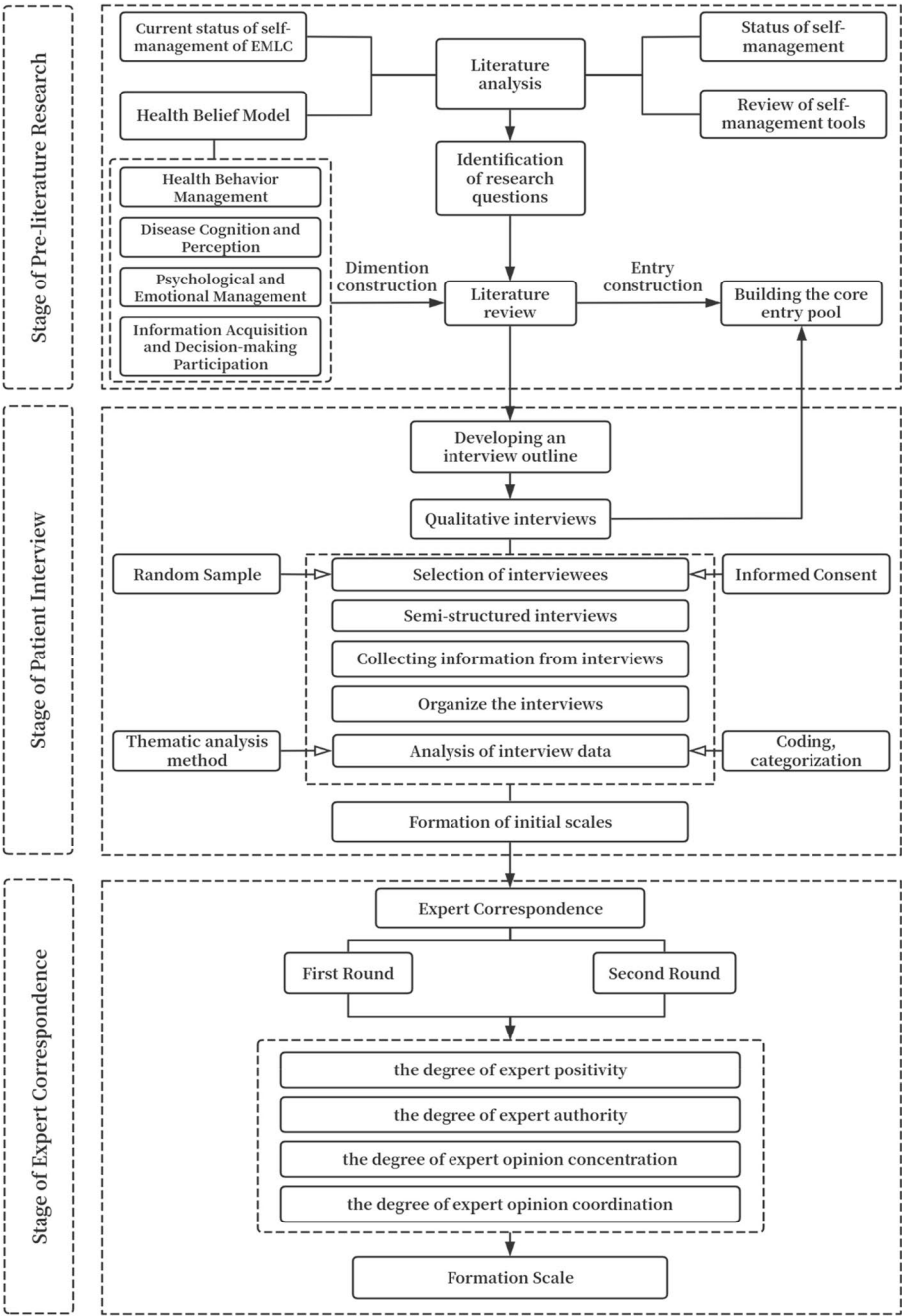


Fig. 1 The detailed flowchart

judgement was 0.976, the academic level was 0.876, and the coefficient of expert authority was 0.900. The coefficient of familiarity of the experts in the second round of expert correspondence was 0.867, the coefficient of the basis of judgement was 0.983, the academic level was 0.858 and the coefficient of expert authority was 0.903, which was a high level of expert authority [38].

Expert opinion consensus

The mean importance scores and ratios of 4 and 5 were used to measure the consensus of expert opinions. In Round 1, the mean importance scores for the scale dimensions ranged from 4.53 to 5.00, with 100% of scores between 4 and 5. For the scale items, mean importance scores ranged from 2.07 to 5.00, with 8% to

Table 2 General information about the interviewees ($n = 11$)

| Items | Category | Number | Component ratio (%) |
|-------------------|---------------------|--------|---------------------|
| Age | ≥ 50 | 10 | 91.0 |
| | < 50 | 1 | 9.0 |
| Marriage | Unmarried | 1 | 9.0 |
| | Married | 10 | 91.0 |
| | Divorce | 0 | 0.0 |
| | Widowhood | 0 | 0.0 |
| Ethnic | Yi | 6 | 54.5 |
| | Tibetan | 4 | 36.3 |
| | Qiang | 1 | 9.0 |
| Length of illness | Six months and less | 4 | 36.3 |
| | 6 months~1 year | 2 | 25.0 |
| | 1 year~3 year | 4 | 18.1 |
| | More than 3 years | 1 | 9.0 |
| Disease Stage | Stage I | 2 | 18.1 |
| | Stage II | 3 | 27.2 |
| | Stage III | 2 | 18.1 |
| | Stage IV | 0 | 0.0 |
| | Unclear | 4 | 36.3 |
| Surgery | Yes | 5 | 45.4 |
| | No | 6 | 54.5 |
| Intervention | Yes | 7 | 63.6 |
| | No | 4 | 36.3 |
| Radiotherapy | Yes | 1 | 9.0 |
| | No | 10 | 91.0 |
| Chemotherapy | Yes | 4 | 36.3 |
| | No | 7 | 63.6 |

100% of scores between 4 and 5. In Round 2, the mean importance scores for the scale dimensions ranged from 4.58 to 5.00, with 100% of scores between 4 and 5, while the mean scores for the scale items ranged from 3.25 to 5.00, with 17% to 100% of scores between 4 and 5.

Level of expert opinion coordination

Kendall's Coefficient of Concordance (Kendall's W) and the coefficient of variation were used to assess the coordination of expert opinions. In Round 1, the coefficient of variation for the scale dimensions ranged from 0.00 to 0.11, with a Kendall's W value of 0.401 ($P < 0.001$). For the scale items, the coefficient of variation ranged from 0.00 to 0.11, with a Kendall's W value of 0.478 ($P < 0.001$). In Round 2, the coefficient of variation for the scale dimensions ranged from 0.00 to 0.11, with a Kendall's W value of 0.354 ($P < 0.005$). For the scale items, the coefficient of variation ranged from 0.00 to 0.19, with a Kendall's W value of 0.492 ($P < 0.001$).

Results of the first round of expert consultation

Based on the results from the first round of expert correspondence, the preliminary scale entries were adjusted and optimized. By combining the coefficient of variation and the expert selection rate, items with a mean score greater than 4 and a coefficient of variation less than 0.25 were selected for the second round of correspondence. Check supplementary material (Supplementary Table 1) for specific changes.

Discussion

The development of a self-management behavior scale specifically for ethnic minority liver cancer patients addresses a significant gap in both clinical practice and research. This study not only highlights the unique challenges faced by ethnic minority populations in managing liver cancer but also provides a culturally tailored tool to assess and enhance self-management behaviors. The scale's integration of culturally specific elements, such as traditional health beliefs, national dietary practices, and decision-making dynamics, ensures its relevance and utility in improving healthcare delivery for underserved populations.

Implications for clinical practice and remote healthcare settings

In remote regions where ethnic minority populations often reside, access to comprehensive healthcare services is constrained by a number of factors, including geographical isolation, socioeconomic circumstances and healthcare resource limitations [39, 40]. The SMS-EMLC can be utilized as a valuable instrument by healthcare professionals to ascertain patients' particular requirements, even in the absence of substantial in-person interaction. The utilization of this scale permits local healthcare workers and community volunteers to conduct assessments during home visits or through telemedicine platforms [41–43], thereby facilitating continuous monitoring and support for liver cancer patients.

The feasibility of telehealth interventions is growing in remote regions as mobile network coverage expands [44]. The integration of the SMS-EMLC into telehealth platforms would facilitate patient and caregiver self-reporting of behaviors such as symptom management, adherence to dietary recommendations and emotional regulation. Remote healthcare providers enable to use this data to provide timely advice and interventions, thereby overcoming the limitations imposed by distance and limited healthcare infrastructure [45]. This approach not only empowers patients, but also facilitates improved

Table 3 Thematic extraction table of interview results for ethnic minority liver cancer patients ($n = 11$)

| Theme | Sub-theme | Patient Words |
|---|-----------------------------------|---|
| Health Behavior Management | Cessation of smoking and drinking | T2 "I gave up alcohol when I got sick and thought it would help my health. We minorities have some traditions and feel that we need to keep fit." |
| | Changes in diet | T4 "I'm eating a light diet at the moment, trying to eat more vegetables and less greasy food. We're used to eating yak meat in all sorts of ways, but now we have to control some of it." T7 "I'm eating just the average amount of food now, reduced, but there's nothing I can do about it, I still have to eat." |
| | Exercise | T2 "I walk for an hour a day and feel better. We have some traditional dances that we also do occasionally and feel happy." T9 "Exercise less because I'm too weak, but still insist on taking a walk." |
| | Work | T1 "I did physical work before, but now my body is failing me and my doctor says I can't do strenuous activities anymore, so I don't do it anymore" |
| Disease perception and cognition | Disease discovery | T1 "I was just feeling a little pain in my heart and my son suggested going for a check up to find out. We don't have too many doctors on our part, so it's up to you to pay more attention." T2 "It was discovered during a community check-up." |
| | Disease management | T1 "I came in and had surgery and am now recovering. We actually have some traditional methods on our side, but the doctor's advice first." T2 "Had two surgeries and then now it's back." |
| | Symptom management | T3 "I can usually feel the pain in this lump, usually listen to the hospital to take painkillers" T9 "When the pain gets bad, I lie down and rest, take some painkillers and watch my diet. I've heard of some folk remedies passed down from my ancestors, but my doctor said to be cautious." |
| Psychological and emotional management | Mood management | T1 "It still has an impact, but I know how to self-regulate." T11 "When I'm unhappy, I talk to my family and I feel better. We have parties sometimes, dancing and singing, and it's a lot more fun." |
| | Positive attitude | T2 "It's stressful at times, but I try to look on the bright side. We Tibetans still look on the bright side." |
| Information acquisition and decision-making participation | Medical recommendation | T1 "The doctor told me what to do and I followed his advice." T9 "I mainly listen to the doctors over here, but we have fewer doctors over there." |
| | Knowledge acquisition | T4 "The information on the internet is so scary and it feels like a lot of untruths. We occasionally hear things from relatives." T3 "I took two books from you guys and learnt a little bit." |
| | Patient communication | T9 "I spoke to fellow patients and we would get together and share what we were all going through and they gave lots of advice and encouragement." |

access to personalized healthcare that is culturally and practically relevant to their lives.

Cultural sensitivity and tailored interventions

One of the most significant attributes of the SMS-EMLC is its cultural sensitivity [46], which acknowledges and addresses the distinctive health beliefs, customary practices, and social dynamics of ethnic minority liver cancer patients. For many ethnic minority groups, cultural beliefs regarding illness, traditional healing methods and dietary customs exert a considerable influence on their approach to disease management [47]. Without a culturally sensitive approach, healthcare interventions may fail

to resonate with these patients, leading to lower adherence to treatment plans and poorer health outcomes.

By incorporating these culturally distinctive elements, the scale enables healthcare professionals to develop interventions that resonate with the patient's worldview, thereby enhancing the relevance and acceptability of care. This is of particular significance for ethnic minorities, for whom traditional medicine and culturally informed practices are often a primary focus, superseding conventional medical advice [16]. For instance, patients diagnosed with liver cancer from specific ethnic groups may opt for herbal remedies or adhere to particular dietary traditions that are thought to facilitate recovery. The scale enables

Table 4 General information about the experts ($n = 13$)

| Item | Category | Number | Component ratio (%) |
|-----------------|---------------------------|--------|---------------------|
| Age | 30~44 | 7 | 53.8 |
| | 45~54 | 5 | 38.4 |
| | ≥ 55 | 1 | 7.6 |
| Qualification | Bachelor | 4 | 30.7 |
| | Master | 5 | 38.4 |
| | PhD | 4 | 30.7 |
| Title | Mid-level | 4 | 30.7 |
| | Deputy senior | 5 | 38.4 |
| | High level | 4 | 30.7 |
| Work experience | 5~14 | 3 | 23.0 |
| | 15~24 | 6 | 46.1 |
| | ≥ 25 | 4 | 30.7 |
| Work area | Clinical Oncology Nursing | 8 | 61.5 |
| | Clinical Oncology | 2 | 15.3 |
| | Psychology | 2 | 15.3 |
| | Analytics | 1 | 7.6 |

healthcare professionals to identify such practices and collaborate with patients to achieve a balance between traditional beliefs and modern medical treatments, thereby enhancing adherence and improving outcomes.

Furthermore, developing a self-management scale specifically for this population is critical, as generalized scales often overlook the nuances of cultural differences. Ethnic minorities encounter specific obstacles to healthcare, including linguistic challenges, skepticism towards healthcare institutions, and a shortage of culturally sensitive care. A scale tailored to their specific needs ensures that these barriers are identified and addressed in a structured manner, facilitating more effective self-management strategies that resonate with their cultural context.

Improving patient engagement and self-efficacy

The empowerment of patients to assume an active role in their healthcare is a crucial element in the management of chronic diseases such as liver cancer. The scale emphasizes psychological and emotional management, focuses on decision-making participation, and has the potential to enhance patients' confidence and self-efficacy. For ethnic minority patients, who may already encounter numerous obstacles to accessing healthcare, fostering a sense of control over their own health is of particular importance. Such empowerment can help to mitigate feelings of helplessness or mistrust in the healthcare system, which are common among underserved populations [48].

Moreover, the scale's use in clinical practice can inform the development of health education programs that

address the specific barriers to self-management faced by ethnic minority populations [49]. These programs can be designed to accommodate cultural preferences and literacy levels, ensuring that health information is accessible and actionable. In remote regions, this can make a significant difference in reducing healthcare disparities and improving patient outcomes [50, 51].

By identifying specific areas where patients lack confidence, such as managing symptoms, adhering to dietary recommendations, or balancing traditional and modern treatment methods, healthcare providers can offer targeted support. This not only enhances adherence but also furnishes patients with the competencies they require to assume control of their health in culturally congruent manners. Furthermore, insights derived from the scale can inform the development of health education programs that are tailored to the specific needs of ethnic minority patients [52], thereby ensuring that health information is both accessible and relevant to their cultural context.

Limitations and future research

A notable limitation of this study is that the newly developed SMS-EMLC has yet to undergo comprehensive reliability and validity testing. Although the scale was developed through qualitative research and expert consultations, it has yet to be empirically tested with larger or more diverse populations to establish its psychometric properties. Accordingly, further studies are required to assess the scale's internal consistency, test-retest reliability, and construct validity. Furthermore, it is recommended that future studies examine the scale's applicability to other populations. As this scale was developed with a specific focus on ethnic minority groups in China, it is essential to evaluate its suitability for application to liver cancer patients from other ethnic and racial backgrounds.

Conclusion

This study utilized the Health Belief Model to guide the development of a self-management behavior scale for liver cancer patients. Through a combination of literature review, qualitative interviews, and expert consultations, a four-dimension, 31-item scale specifically designed for ethnic minority liver cancer patients was constructed. While the scale demonstrates scientific rigor, reliability, and clinical applicability, further testing is required to refine its reliability and validity.

Abbreviations

| | |
|----------|---|
| SMS-EMLC | Self-management behavioral assessment scale for ethnic minority liver cancer patients |
| HBM | Health Belief Model |
| SMBS | Self-Management Behavior Scale |
| PAM | Patient Activation Measure |

SCCII Self-Care of Chronic Conditions Inventory II

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-025-12272-0>.

Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

Supplementary Material 4.

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Authors' contributions

BL and JC: Conceptualization, data collation, study design and manuscript writing. XZ, YL and QG: Literature review and data extraction. BH, LF and YZ: Semi-structured interviews and collation of qualitative research findings. AY, ML and LZ: Collation of expert correspondence and overall quality control (QC). XT and GH: Manuscript writing, overall QC and reviewing.

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Data availability

The datasets used during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study has been approved by the Institutional Review Board of Sichuan Cancer Hospital (Ethical Approval Number: SCCHEC-02–2024-217). The study complied with local legal and institutional requirements. All patients signed an informed consent form when they participated in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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