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Experiences of health information-seeking behaviour in preoperative patients with lung cancer: a qualitative study in China

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ABSTRACT

Objective Surgery represents the primary therapeutic modality for lung cancer, typically administered promptly following diagnosis. Accessing pertinent information and making well-informed decisions are imperative to navigate this challenging stage. This study aimed to explore preoperative lung cancer patients' experiences related to health information-seeking process, based on the information and methodological characteristics of health information-seeking behaviour (HISB).

Design The study used a qualitative descriptive design, adhering to the Consolidated Criteria for Reporting Qualitative Research guidelines. 23 participants were purposively selected for semistructured interviews. Data analysis was conducted using inductive conventional content analysis.

Setting The study was conducted in the thoracic surgery ward of a tertiary hospital located in China.

Participants A total of 23 participants, consisting of 12 males and 11 females, were recruited. Eligible participants were patients with lung cancer aged 18 and above, capable of articulate expression, informed about their diagnosis, preparing for surgical intervention and willing to engage voluntarily in the study.

Results Four main categories were identified. Participants exhibited different psychological coping strategies and personalised health information needs in their information-seeking behaviour. Challenges emerged in comprehending and assessing factors related to lung cancer, treatment alternatives, surgical complications, online media resources and preoperative exercise protocols. The importance of preoperative respiratory training was often underestimated. Additionally, some participants displayed a tendency to passively receive information, thereby impeding their ability to effectively self-manage throughout the perioperative stage.

Conclusions Understanding the experiences in HISB is crucial for improving the health outcomes of patients with lung cancer. Healthcare providers should adopt a patient-centred approach to health education, with a targeted effort to recognise and mitigate specific barriers in clinical practice. Further research is needed to explore effective strategies aimed at augmenting health information-seeking process among patients with lung cancer before surgery.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Qualitative research captures participants' genuine experiences and perspectives on their health information-seeking process before lung cancer surgery through in-depth interviews, providing rich and detailed insights.
⇒ By understanding the specific issues and concerns faced by patients, the qualitative research design can guide the development of targeted educational interventions and supportive strategies in clinical practice.
⇒ As this study was conducted solely within a thoracic surgery ward at a tertiary hospital in China, its findings may lack generalizability to broader contexts or diverse populations.

INTRODUCTION

Lung cancer has emerged as a serious public health concern, posing a serious threat to human well-being. According to recent data, lung cancer ranks first in both the number of new cases and deaths among malignant tumours in China.[1] Radical surgical resection is the recommended preferred local treatment for early non-small cell lung cancer.[2] Patients with lung cancer typically undergo surgery shortly after their diagnosis, during which they and their families face substantial psychological, social, economic and emotional burdens.[3] In this stage, patients often encounter negative emotions such as anxiety and tension due to lack of understanding about lung cancer and the surgical procedure, potentially impacting treatment compliance. Therefore, the preoperative stage represents a pivotal juncture in the continuum of lung cancer treatment. Accessing pertinent information and making well-informed decisions are crucial prerequisites for navigating this challenging stage.

Understanding and using relevant health information plays a pivotal role in influencing disease progression, mitigating

treatment expenses and alleviating associated psychological and emotional burdens.[4] Sufficient health knowledge is crucial for patients to comprehend the surgical procedures, make informed decisions regarding consent and adhere to postoperative care protocols.[5] Furthermore, enhancing patients' ability to obtain and use health information during the preoperative phase can improve their preoperative preparation, thereby enhancing pain management and surgical experience.[6] In contrast, patients with lung cancer with insufficient health knowledge in the preoperative stage are at greater risk of misunderstanding surgical procedures, potentially leading to inferior surgical outcomes.[7]

Health information-seeking behaviour (HISB) refers to purposeful actions taken by individuals to satisfy their health information needs, and its characteristics can be divided into information dimension and method dimension.[8] The information dimension focuses on the characteristics of the sought information, primarily including the type of information and the preferred sources. For instance, patients with cancer often seek health-related information to address specific information needs arising from their condition, such as understanding the basics of the disease, treatments and health promotion strategies.[9 10] Among diverse cancer survivors, attending physicians and nurses were the most favoured information sources, followed by the internet.[11] The method dimension emphasises the specific actions individuals take to obtain health information. Many studies highlight the ability of individuals to search for health information online as a fundamental aspect, with challenges including the understanding of medical terminology, locating relevant information and assessing the credibility of sources.[9 12]

Xu *et al*[13] investigated the influencing factors of HISB among patients with periodontal disease using the comprehensive model of information seeking, revealing that lower HISB levels were closely related to higher age and lower information comprehensibility and satisfaction levels. Similarly, most studies treated HISB as a preconceived and implicitly understood activity, primarily describing its factors or predictors based on some information-seeking models, without delving into the characteristics of the behaviour itself.[8] A recent study in China has shown that preoperative patients with lung cancer have high information needs.[14] However, most patients were dissatisfied with the information they receive, and there were discrepancies in how patients and healthcare providers perceive the importance of preoperative information, such as pain management, preoperative tests and preoperative fasting.[15] Therefore, it is necessary to study the HISB characteristics of preoperative patients with lung cancer to reveal the underlying complexities of their behaviour. This will help improve the effectiveness of intervention measures and promote the development of relevant theories.

The goal of our study is to explore preoperative lung cancer patients' experiences regarding health information-seeking process, based on the information and methodological characteristics of HISB. This involves evaluate their information needs and types, their preferred sources of information, the actions they take and the obstacles or challenges they face.

METHODS

Research design

This study employed a qualitative, descriptive research design, chosen for its efficacy in directly describing a phenomenon and identifying key aspects such as the participants involved, the events occurring and their contextual details.[16] Adherence to the Consolidated Criteria for Reporting Qualitative Research guidelines was maintained to ensure comprehensive and transparent reporting throughout the study.[17]

Participants and recruitment

We employed purposive sampling to select patients with lung cancer undergoing surgical preparation at the thoracic surgery ward of a tertiary hospital in Changsha, Hunan Province. During recruitment, efforts were made to ensure diversity among participants in terms of age, gender, education level, TNM (tumour node metastasis) staging and other factors, aiming for maximum variability sampling to provide a comprehensive range of experiences and perspectives for analysis. Inclusion criteria for participants stipulated: (1) initial cancer diagnosis based on imaging examinations or histopathology, (2) scheduled for surgical treatment, (3) adults aged 18 and older capable of articulating their thoughts clearly, (4) comprehension of their diagnosis and (5) voluntary participation with informed consent. Exclusion criteria included: (1) critically ill patients unable to cooperate, (2) concurrent presence of other malignancies and (3) a history of mental illness or communication impediments.

Data collection

The semistructured interviews were conducted face to face by JG and JZ, both of whom possessed training and experience in conducting qualitative interviews. As part of their thoracic surgery internships, they established rapport with the patients before commencing the interviews. Importantly, participants were assured that declining to participate would not impact their treatment plans, thereby fostering a relaxed atmosphere conducive to candid responses. The formal interview guide was finalised after pilot interviews with two patients, adjusting the wording of some questions to make them more accessible and understandable to patients. Interviews began with an open-ended question: 'What did you do before preparing for surgery?' This transitioned into more specific inquiries such as, 'What information did you search for?', 'what information is of interest to you?', 'What are your thoughts on the health information provided by doctors or nurses before surgery?' and 'What difficulties have you encountered during this process?'. Depending on

the context, it may be necessary to pose an exploratory question, such as 'What does that specifically mean?' or 'Could you please explain that again?'. The interviews were conducted between February and March 2024, with each session lasting between 20 and 30 min. The interviews were held in a separate and quiet room within the thoracic surgery ward, ensuring a relaxed and confidential atmosphere. During this stage, a neutral demeanour was maintained during interactions with participants to facilitate open dialogue and unbiased data collection. Thematic redundancy was observed by the 21st interview, prompting an additional two interviews to verify data saturation among participants.

To ensure the rigour and transparency of our qualitative research, we promptly wrote reflexive diaries after each interview to document significant findings from participants and our subjective perspectives. We reflected on our professional and cultural backgrounds, as well as our health beliefs, which may have influenced our interactions with participants and our interpretations of their narratives. By holding group meetings with the research team, we openly discussed these factors and addressed any potential biases in a timely manner.

Data analysis

Audio recordings were transcribed verbatim within 24 hours of the interviews and double-checked by two interviewers. In addition, we presented the transcripts to the participants for comment or correction. Inductive conventional content analysis was employed to analyse the qualitative data, allowing for the avoidance of preconceived categories often associated with a deductive approach. This method involves discovering patterns from the data.[18] NVivo V.12 software was used for data coding and management in this study. Data were individually analysed by JG and JZ, following the specific steps outlined below: Researchers repeatedly read the original data to gain immersion. They identified participants' meaningful statements about common ideas or concepts and conducted open coding by analysing and reorganising the data, marking the important meanings. The coding was then categorised based on the research objectives to establish the final themes. In each interview, the NVivo V.12 coding comparison tool was used to evaluate inter-coder reliability, including kappa coefficient and coding consistency percentage. Any coding discrepancies between the two coders were resolved through open discussions. The entire analysis process was iterative, with the team holding regular meetings to discuss the appearance of codes or themes in the data. JG, who has experience translating qualitative research reports, summarised the results in English. Then, she sent the translated document to JZ for verification. Finally, a professor who teaches nursing and English at the university reviewed and revised the translation.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

RESULTS

A total of 23 preoperative patients with lung cancer met the inclusion criteria and consented to participate in this study, including 12 males and 11 females. Their ages ranged from 29 to 69 years old, with 12 participants in TNM stage I and 11 participants in stage II or higher. The demographic characteristics of the participants are presented in online supplemental file 1. For more detailed verbatim quotes, please refer to the coding matrix (online supplemental file 2). The interview participants shared their experiences regarding health information-seeking process, which were categorised into four themes. These themes encompassed participants' personalised needs, types of health information sought, preferred information sources, specific behaviours and the barriers encountered during the process of health information seeking.

Personalised information needs: focusing on the present or planning for the future

There were varied psychological coping strategies and information needs observed among preoperative lung cancer participants. Some individuals experiencing more preoperative psychological distress demonstrated a preference for immediate, personalised health information to address their pressing concerns and needs, potentially stemming from a desire to alleviate anxiety and uncertainty. *'I just want to know what I should pay attention to before the surgery, I don't want to think about anything else right now (P2, male, 51 years old)', 'Please don't tell me about how the surgery will be done or the post-operative instructions right now. Just the thought of possible pain after the surgery makes me shudder [Frown, pinch fingers] (P4, female, 62 years old)', 'I don't want to know too much information right now, the more I know, the more anxious I become. I will try my best not to think about these things [Showing impatience] (P7, female, 35 years old)'.*

However, others exhibited a more proactive coping styles, they seemed to have an optimistic outlook and were inclined towards seeking a deeper understanding of their condition, including information related to disease recovery and detailed aspects, in order to make informed decisions and plan for the future effectively. *'For me, what is inevitable cannot be avoided, and it is crucial to face it with a positive attitude. I hope you can provide me with more information about the surgery, such as the risks involved and the expected duration of the recovery process, so that I can have a better understanding of my condition (P1, female, 32 years old)', 'I don't have much pressure now and I hope to learn more about the disease. Since I can't change the past, I will change the present and the future (P13, male, 42 years old)'.*

Challenges in comprehending and evaluating desired information

During the preoperative stage of lung cancer, participants reported various types of comprehension and evaluation

barriers regarding disease-related information. Six participants (26.09%) expressed a lack of understanding of the aetiology of lung cancer, especially non-smoking participants, which had left them feeling confused at this stage. They mentioned that doctors and nurses rarely give them clear explanations. For example, two participants diagnosed with lung cancer within the past 3 months explained: *'I don't know why I got lung cancer because I never smoke. What risk factors should I avoid (P11, female, 29 years old)'? 'I never smoke and it's difficult for doctors to explain the cause, but I want to know what exactly caused my illness so that I can avoid this factor after the surgery (P3, female, 40 years old)'*. Three participants (13.04%) found it challenging to effectively evaluate information regarding treatment options. Even though surgery is imminent, they still worry about the side effects of surgical treatment, exhibiting behaviours of seeking alternative solutions and seeking more information during the process of seeking health information. *'If it wasn't for my daughter insisting, I wouldn't have come for the surgery and I want to seek treatment with traditional Chinese medicine…because you know, lung surgery involves cutting into the chest cavity, it might affect my breathing in the future. (P19, female, 48 years old)', 'Even though my surgery is just a few days away, I'm still determined to explore other treatment options. (P21, female, 42 years old)'*.

Most participants tended to choose healthcare professionals as reliable sources of information, but most of the time, healthcare workers were always very busy and found it difficult to spend time explaining to patients. Therefore, patients always turned to the internet or disease education manuals. Four participants (17.39%) indicated that the difficulty in distinguishing the truthfulness of news on the internet hindered their understanding of disease-related information. *'An online article suggested increasing nutrition and consuming dietary supplements before surgery, while another article warned against taking dietary supplements. I'm confused and unsure how to make a judgment (P6, male, 51 years old)'*. Three participants (13.04%) reported that professional medical terminology in the promotional brochure hindered their further understanding of preoperative knowledge. *'I don't understand the term 'perioperative' written on the poster. I have a lower educational level and have trouble comprehending such terms (P9, female, 69 years old)'*. Two participants (8.70%) stated that they needed demonstration from healthcare professionals in order to understand and learn preoperative respiratory function exercises. *'I don't understand the steps for doing breathing exercises written in the manual, I'm not sure how to do those lip pursing exercises for breathing (P23, female, 62 years old)'*.

Inadequate awareness of the preoperative respiratory training

Preoperative respiratory training plays a pivotal role in optimising pulmonary ventilation function, enhancing surgical tolerance and mitigating postoperative complications among patients undergoing lung surgery. Our interviews showed that the majority of preoperative patients with lung cancer lacked preoperative respiratory training and faced challenges in maintaining a regular regimen, which included fundamental exercises like balloon blowing, pursed lip breathing and effective coughing. There appeared to be a notable lack of awareness or insufficient emphasis on strategies aimed at preventing postoperative complications.

Some participants felt well and thought they did not need to undergo respiratory training because they did not experience any discomfort prior to surgery. *'Currently, I feel physically fine with no pain or coughing. I haven't put much effort into preoperative exercises (P18, male, 39 years old)', 'I did start practicing at first, and then I found that I could blow up several balloons. I felt like my breathing was fine, so I just got lazy and didn't continue practicing (P15, male, 55 years old)'*.

Others have mentioned time pressure before surgery, citing the extensive preoperative examinations that make it difficult for them to schedule adequate time for respiratory exercises. *'Now I have to do several checks every day, I don't have time at all to do preoperative exercises, and I can't even remember to do exercises (P22, male, 44 years old)', 'There are too many checks to do before the surgery, after the checks I just want to go back to the ward and rest (P7, female, 35 years old)',* Some participants also mentioned, *'As long as the surgery goes smoothly, nothing else matters (P12, male, 57 years old)', 'I feel like it's too troublesome to do this, and I'd rather just chat with my family (P12, male, 57 years old)'*.

The impact of passive information reception on self-care

Some participants exhibited proactive behaviour by actively seeking out relevant information and engaging in communication with their healthcare providers. In contrast, other participants demonstrated a more passive information seeking, relying heavily on medical advice and guidance while decreasing their attention and efforts towards self-care. For example, three participants expressed: *'I rarely search for relevant information because once I have any questions, I just go to see a doctor (P7, female, 35 years old)', 'I don't think it's necessary to have the relevant information. Just following the doctor's advice is enough for me (P9, female, 69 years old)', 'I never look up information about health on my own because I think doctors will tell me everything I need to know. I have full trust in their judgement (P13, male, 42 years old)'*.

This passive information reception approach resulted in participants having inadequate knowledge about their health condition, as well as neglecting the importance of self-management. *'To be honest, it never crossed my mind what I would do if the doctors weren't around after the surgery (P13, male, 42 years old)', 'I always wait for the doctors to remind me to get check-ups, and I never actively monitor my health data. I have no idea about the changes in my blood sugar, cholesterol, and other indicators, leading to delays in the optimal timing for surgical treatment (P8, male, 52 years old)'*.

DISCUSSION

Based on the information and methodological characteristics of the HISB, our research findings indicated that participants demonstrated personalised psychological

coping strategies and information needs during the process of seeking health information, encountered challenges in understanding and evaluating disease-related information, underestimated the significance of preoperative respiratory training and the passive reception of information before surgery had the potential detrimental impact on self-management throughout the perioperative stage.

A systematic review indicated that emotional responses play a significant role in how individuals seek and process health information.[19] Our study expanded on this by demonstrating that the psychological state and coping strategies of preoperative lung cancer participants influenced their demand for perioperative health information, potentially affecting its utilisation. Preoperative anxiety commonly precedes scheduled surgery and can impact postoperative pain severity and analgesic requirements.[20] Our interviews revealed that some participants experiencing preoperative anxiety or other psychological distress tend to temporarily avoid disease-related information, preferring immediate and personalised health information. They showed reluctance towards detailed information on surgical precautions, aiming to balance between seeking information and averting anxiety. These preferences may be stemmed from concerns about surgical anaesthesia, intraoperative risks, postoperative pain and related uncertainties.[21] Such individuals may exhibit reduced confidence or motivation in addressing health matters, engrossed in negative emotions that hinder their acquisition and application of health information. In contrast, other participants maintained an optimistic outlook on illness treatment prospects. They expressed a preference for comprehensive perioperative information to enhance their health management and future planning. Recognising these diverse preferences, healthcare professionals are advised to cautiously and progressively provide relevant information according to patients' preferences.[22] Moreover, offering psychological support to patients experiencing negative emotions is crucial for addressing individual needs effectively.

Regarding information sources, the interview results indicated that participants accessed information through multiple channels. While healthcare providers were the preferred source, the internet and disease education manuals emerged as important alternatives due to their superior timeliness and accessibility. Participants often turned to online sources for guidance on diet and nutrition. According to Wilson's information behaviour model, this proactive search for information from various resources is referred to as 'active search.'[23] However, the proliferation of conflicting advice complicates their ability to discern the credibility of such information. Consistent with prior research, distinguishing between accurate and misleading health information posed a significant challenge for participants, impeding their comprehension, assessment and utilisation of health information.[24 25] Future studies should prioritise reliable tools to enhance information accuracy and foster the trustworthy dissemination of digital health information.

In the preoperative stage of lung cancer, participants encountered difficulties in grasping the information they sought. During the health information-seeking process, participants searched for various types of information. They most frequently searched for and had questions about the causes and triggers of lung cancer, how to choose the best treatment plan and the side effects of surgery Initially, participants acknowledged the significant association between smoking and lung cancer but often overlooked other risk factors, consistent with a previous study.[26] Our interviews indicated that limited understanding of the aetiology contributed to feelings of uncertainty and lack of control over disease progression during the perioperative stage. A recent study has shown that the incidence of lung cancer is relatively higher among non-smokers in northern China, with this trend increasing among women and younger individuals.[27] This underscores the evolving epidemiology of the disease as smoking rates decline. Addressing these complexities is crucial as understanding the aetiology and nuances of lung cancer becomes increasingly imperative, necessitating tailored diagnostic and therapeutic approaches.[28] Additionally, our study highlighted challenges participants faced in assessing the efficacy and side effects of pulmonary surgery, hindering their ability to formulate appropriate medical plans. Therefore, it is important to educate the patients on the treatment plans, including the rationale for early surgery and other interventions, along with expected outcomes and associated risks. Encouraging patients to engage in comprehensive discussions with specialised medical professionals can further enhance their understanding and decision-making process. In addition, our study underscored the critical role of education level as a predictor of health information literacy, aligning with existing literature finding.[29] Participants with lower education levels had more difficulty understanding medical information, including medical terminology and textual descriptions. This underscored the importance for healthcare providers to prioritise these populations, offering personalised, face-to-face counselling and developing patient-centric health education strategies.

Lung cancer, often termed the 'silent killer,' is characterised by the fact that most early-stage cases lack obvious clinical symptoms.[30] Notably, information regarding presurgery exercises appeared to be overlooked by the participants, a finding that has been rarely addressed in previous studies. A majority of participants reported experiencing no physical discomfort prior to surgery, leading to a neglect of preoperative breathing training. This oversight may be attributed to a lack of understanding about lung cancer and a generally optimistic perception of their health status. However, preoperative respiratory training remains crucial even in the absence of apparent symptoms. Techniques such as deep breathing exercises and coughing have been demonstrated to mitigate

postoperative pulmonary complications and shorten hospital stays.[31 32] Therefore, it is recommended to enhance the communication of information concerning preoperative respiratory training during preoperative education, helping patients fully understand the benefits of it to improve their level of preoperative exercise and awareness. Additionally, it is necessary to supervise and record preoperative respiratory training for patients with lung cancer.

Our study also observed that some participants exhibited 'passive search' behaviour.[23] During the presurgery phase, these participants lacked self-management awareness and were heavily reliant on doctors, resulting in a passive attitude towards information acquisition. This dependence appears to hinder their ability to make health-related decisions independently during the perioperative period. Influenced by traditional Chinese beliefs in predestined outcomes, some participants entrusted their health fate entirely to their physicians, perceiving them as best positioned to make decisions on their behalf. However, as indicated by a study, passive information reception may lead to patients lacking active engagement in their illness and treatment, thereby affecting their ability to self-manage postdischarge.[33] Proactive interaction with oncologists plays a role in enhancing patients' symptom self-management abilities and their confidence in health literacy.[34] Considering that patient involvement in clinical decision-making is beneficial for reducing information asymmetry and empowering patients' autonomy, it is advisable to encourage patients to critically analyse health information and actively engage in treatment decisions in order to improve treatment outcomes.

Limitations

Our study has the following limitations. First, it was conducted in a large tertiary hospital, where most participants had relatively easy access to medical information. Consequently, patients in primary healthcare facilities may encounter more obstacles. Future research should, therefore, aim to include participants from various levels of healthcare institutions to ensure a more comprehensive understanding and representation. In qualitative studies reliant on interview data, discrepancies between reported and actual experiences may arise due to participant biases, such as concerns about anonymity or values. However, the trustworthiness of our study is bolstered by the rich data gathered from numerous participants, minimising the likelihood of such occurrences.

CONCLUSIONS

This qualitative study explored the experience of preoperative patients with lung cancer seeking health information based on the information and methodological features of HISB. These findings provide healthcare providers with effective strategies for health education. First, our study identified personalised psychological coping strategies and specific health information needs among preoperative lung cancer participants. Some individuals faced challenges balancing their quest for information with anxiety avoidance. Second, difficulties in obtaining desired information stemmed from a lack of understanding cancer causes and obstacles in comprehending or evaluating treatment options, surgical side effects, online media sources and preoperative exercise practices. Third, most participants believed they experienced no preoperative physical discomfort, leading them to overlook the importance of preoperative respiratory training. Finally, some lacked self-management awareness and heavily relied on physicians, resulting in a passive approach to information acquisition that seemed to hinder their ability to independently make health-related decisions during the perioperative stage.

Addressing these unique needs and barriers faced by preoperative patients with cancer allows healthcare providers to enhance patients' health literacy, empower them and ultimately improve their overall health outcomes.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and ethical approval was provided by the College Ethics Review Committee of Xiangya Nursing School of Central South University (Approval number: E2023129). Participants gave informed consent to participate in the study before taking part. This study was performed in line with the principles of the Declaration of Helsinki. All patients were informed of the purpose of the study, the data collection process, the benefits and risks of participation, personal protection information, confidentiality, use of data for research purposes only, and the ability to withdraw from the study at any time.

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