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Experiences of health information-seeking behavior in preoperative lung cancer patients: 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 the health information-seeking behaviors of lung cancer patients before undergoing surgery.

Design: The study utilized a qualitative descriptive design, adhering to the COREQ guidelines. 23 participants were purposively selected for semi-structured 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 11 males and 12 females, were recruited. Eligible participants were lung cancer patients 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 personalized health information needs in their information-seeking behavior. 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

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displayed a tendency to passively receive information, thereby impeding their ability to effectively self-manage throughout the perioperative stage.

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

Strengths and Limitations of this Study:

1. Qualitative research can reveal the barriers that lung cancer patients face in their health information seeking behavior through in-depth interviews, observations, and analysis of their behavior and experiences. This approach captures the patients' true feelings and perspectives, providing rich and detailed insights.
2. 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.
3. 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..Future research efforts should prioritize multi-center studies across primary healthcare institutions to augment the applicability and robustness of these findings.

Introduction

Lung cancer has emerged as a serious public health concern, posing a serious threat to human well-being. According to recent data, it accounts for 12.4% of the global cancer incidence, with an estimated 2.48 million new cases annually, making it a leading cancer worldwide.¹ Surgery currently stands as the primary treatment method to enhance long-term survival rates among early and mid-stage non-small cell lung cancer patients.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 utilizing 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, receiving accurate and comprehensible information during the preoperative stage can bolster patients' confidence levels, thereby enhancing their readiness to engage in self-care and adapt to treatment regimens.^{6,7} In contrast, lung cancer patients with insufficient

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health knowledge in the preoperative stage are at greater risk of misunderstanding surgical procedures, potentially leading to inferior surgical outcomes.⁸

Health information-seeking behavior encompasses various aspects such as information demand, resource availability, information effectiveness and accuracy, and patient attitudes.⁹ It involves methods for acquiring health information, utilizing disease-related information for self-care, and identifying health-threatening factors.¹⁰ A scoping review indicated that in middle and low-income countries, particularly in Africa and Asia, many lung cancer patients lacked adequate knowledge about disease risk factors, warning signs, and symptoms.¹¹ A study in Taiwan revealed that lung cancer patients prioritize information about the disease itself, recovery prospects, dietary choices, and social welfare resources.¹² Variations in health information needs were evident among lung cancer patients undergoing radiation and chemotherapy in a UK study, emphasizing the importance of understanding treatment effects.¹³

Despite extensive research on the knowledge levels and information needs of lung cancer patients, there remains limited insight into their experiences and the obstacles they face during health information-seeking behavior. Addressing these gaps is crucial for effectively promoting health among preoperative lung cancer patients. Therefore, this study aimed to explore the health information-seeking behaviors of lung cancer patients before undergoing surgery and to ascertain effective strategies for healthcare providers to deliver information support to these individuals in the future.

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.¹⁴ Adherence to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines was maintained to ensure comprehensive and transparent reporting throughout the study.¹⁵

Participants and Recruitment

We employed purposive sampling to select lung cancer patients 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 (Tumor 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: (i) initial cancer diagnosis based on imaging examinations or histopathology, (ii) scheduled for surgical treatment, (iii) adults aged 18 and older capable of articulating their thoughts clearly, (iv) comprehension of their diagnosis, and (v) voluntary participation with informed consent. Exclusion criteria included: (i) critically ill patients unable to cooperate, (ii) concurrent presence of other malignancies, (iii) a history of mental illness or communication impediments.

Data Collection

The semi-structured interviews were conducted face-to-face by the J.G. and J.Z.,

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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 finalized 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?". As needed, ask exploratory questions such as "What exactly does it mean?" or "Could you please explain it again?". The interviews were conducted between February and March 2024, with each session lasting between 20 to 30 minutes. 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 demeanor was maintained during interactions with participants to facilitate open dialogue and unbiased data collection. Furthermore, after each interview, reflective journals were meticulously kept to document noteworthy findings and promptly address any potential biases. Thematic redundancy was observed by the 21st interview, prompting an additional two interviews to verify data saturation among participants.

Data Analysis

Audio recordings were transcribed verbatim within 24 hours of the interviews and double-checked by two interviewers. Inductive conventional content analysis was employed to analyze the qualitative data, allowing for the avoidance of preconceived categories often associated with a deductive approach. This method enabled the emergence of categories and their respective names to be derived directly from the data itself.^{16,17} Nvivo V.12 software was used for data coding and management in this study. Data were individually analyzed by J.G. and J.Z., 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 analyzing and reorganizing the data, marking the important meanings. The coding was then categorized based on the research objectives to establish the final themes. In each interview, the Nvivo V.12 coding comparison tool was used to evaluate ICR, 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. J.G., who has experience translating qualitative research reports, summarized the results into English. Then, she sent the translated document to J.Z. for verification. Finally, a professor who teaches nursing and English at the university reviewed and revised the translation.

Ethics

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This study has obtained ethical approval from the research institution. All participants were informed about the voluntary nature of their participation and provided their consent by completing participant information sheets and written informed consent.

Results

A total of 23 preoperative lung cancer patients 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 **Supplementary File 1**. For more detailed verbatim quotes, please refer to the coding matrix (**Supplementary File 2**). The interview participants shared their experiences regarding health information-seeking behaviors, which were categorized into four themes. These themes mainly involve varied attitudes, needs, and behaviors of participants towards health information, as well as the understanding and evaluation of information related to different types of disease.

Personalized 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, personalized 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 seem 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. 6 participants (26.09%) expressed a lack of understanding of the etiology of lung cancer, especially non-smoking participants, which had left them feeling confused at

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4 this stage. They mentioned that doctors and nurses rarely give them clear
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6 explanations. For example, 2 participants diagnosed with lung cancer within the past 3
7
8 months explained: *'I don't know why I got lung cancer because I never smoke. What*
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10 *risk factors should I avoid (P11, female, 29 years old)'*? *'I never smoke and it's*
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12 *difficult for doctors to explain the cause, but I want to know what exactly caused my*
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14 *illness so that I can avoid this factor after the surgery (P3, female, 40 years old)'.*
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16 Three participants (13.04%) found it challenging to effectively evaluate information
17
18 regarding treatment options. Even though surgery is imminent, they still worry about
19
20 the side effects of surgical treatment, exhibiting behaviors of seeking alternative
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22 solutions and seeking more information during the process of seeking health
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24 information. *'If it wasn't for my daughter insisting, I wouldn't have come for the*
25
26 *surgery and I want to seek treatment with traditional Chinese medicine...because you*
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28 *know, lung surgery involves cutting into the chest cavity, it might affect my breathing*
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30 *in the future. (P19, female, 48 years old)', 'Even though my surgery is just a few days*
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32 *away, I'm still determined to explore other treatment options. (P21, female, 42 years*
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34 *old)'.*
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46 Most participants tended to choose healthcare professionals as reliable sources of
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48 information, but most of the time, healthcare workers were always very busy and
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50 found it difficult to spend time explaining to patients. Therefore, patients always
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52 turned to the Internet or disease education manuals. 4 participants (17.39%) indicated
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54 that the difficulty in distinguishing the truthfulness of news on the internet hindered
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56 their understanding of disease-related information. *'An online article suggested*
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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)'. 3 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)'*. 2 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 optimizing pulmonary ventilation function, enhancing surgical tolerance, and mitigating postoperative complications among patients undergoing lung surgery. Our interviews showed that the majority of preoperative lung cancer patients 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*

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4 *feel physically fine with no pain or coughing. I haven't put much effort into*
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6 *preoperative exercises (P18, male, 39 years old)', 'I did start practicing at first, and*
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8 *then I found that I could blow up several balloons. I felt like my breathing was fine, so*
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10 *I just got lazy and didn't continue practicing (P15, male, 55years old)'.*

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14 Others have mentioned time pressure before surgery, citing the extensive
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16 preoperative examinations that make it difficult for them to schedule adequate time
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18 for respiratory exercises. *'Now I have to do several checks every day, I don't have*
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20 *time at all to do preoperative exercises, and I can't even remember to do exercises*
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22 *(P22, male, 44 years old)", "There are too many checks to do before the surgery, after*
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24 *the checks I just want to go back to the ward and rest (P7, female, 35 years old)',*
25
26 Some participants also mentioned, *'As long as the surgery goes smoothly, nothing else*
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28 *matters (P12, male, 57 years old)', 'I feel like it's too troublesome to do this, and I'd*
29
30 *rather just chat with my family (P12, male, 57 years old)'.*

31 32 33 34 35 36 37 38 **The Impact of Passive Information Reception on Self-care**

39
40 Some participants exhibited proactive behavior by actively seeking out relevant
41
42 information and engaging in communication with their healthcare providers. In
43
44 contrast, other participants demonstrated a more passive information seeking, relying
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46 heavily on medical advice and guidance while decreasing their attention and efforts
47
48 towards self-care. For example, Three participants expressed: *'I rarely search for*
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50 *relevant information because once I have any questions, I just go to see a doctor (P7,*
51
52 *female, 35 years old)', 'I don't think it's necessary to have the relevant information.*
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54 *Just following the doctor's advice is enough for me (P9, female, 69 years old)', 'I*
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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

The research findings indicated that participants demonstrated personalized psychological coping strategies and information needs in seeking health information behaviors, 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.

McKenna et al.¹⁸ suggested that psychological factors, such as perceived control over health management and self-efficacy, influence individuals' utilization of health knowledge. Our study expanded on this by demonstrating that the psychological state and coping strategies of preoperative lung cancer participants influenced their demand

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for perioperative health information, potentially affecting its utilization. Preoperative anxiety commonly precedes scheduled surgery and can impact postoperative pain severity and analgesic requirements.¹⁹ Our interviews revealed that some participants experiencing preoperative anxiety or other psychological distress tend to temporarily avoid disease-related information, preferring immediate and personalized 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 anesthesia, intraoperative risks, postoperative pain, and related uncertainties.²⁰ 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. Recognizing these diverse preferences, healthcare professionals are advised to cautiously and progressively provide relevant information according to patients' preferences.²¹ Moreover, offering psychological support to patients experiencing negative emotions is crucial for addressing individual needs effectively.

In the preoperative stage of lung cancer, participants encountered difficulties in grasping the information they sought. Primary challenges included a lack of comprehension regarding causative factors of lung cancer, alongside barriers in understanding or evaluating treatment protocols, surgical side effects, information

from online media, and preoperative exercise practices. Initially, participants acknowledged the significant association between smoking and lung cancer but often overlooked other risk factors, consistent with a previous study.¹¹ Our interviews indicated that limited understanding of the etiology contributed to feelings of uncertainty and lack of control over disease progression during the perioperative stage. Emerging report ²² suggested a rising incidence of lung cancer among non-smokers, particularly among women and younger individuals, underscoring the evolving epidemiology of the disease amid declining smoking rates. Addressing these complexities is crucial as understanding the etiology and nuances of lung cancer becomes increasingly imperative, necessitating tailored diagnostic and therapeutic approaches.²³ 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 specialized medical professionals can further enhance their understanding and decision-making process. Furthermore, our findings indicate that preoperative lung cancer patients often turned to online sources for guidance on diet and nutrition. 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

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4 their comprehension, assessment, and utilization of health information.^{24,25} Future
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6 studies should prioritize reliable tools to enhance information accuracy and foster the
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8 trustworthy dissemination of digital health information. In addition, our study
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10 underscored the critical role of education level as a predictor of health information
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12 literacy, aligning with existing literature finding.²⁶ Participants with lower education
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14 levels had more difficulty understanding medical information, including medical
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16 terminology and textual descriptions. This underscored the importance for healthcare
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18 providers to prioritize these populations, offering personalized, face-to-face
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20 counseling and developing patient-centric health education strategies.
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27 Lung cancer, often termed the "silent killer," is characterized by a lack of
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29 early-stage symptoms, with many cases only detected during routine medical
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31 examinations.²⁷ The interviews showed that preoperative respiratory training is the
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33 most easily overlooked, which has been rarely mentioned in previous studies. A
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35 majority of participants reported experiencing no physical discomfort prior to surgery,
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37 leading to a neglect of preoperative breathing training. This oversight may be
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39 attributed to a lack of understanding about lung cancer and a generally optimistic
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41 perception of their health status. However, preoperative respiratory training remains
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43 crucial even in the absence of apparent symptoms. Techniques such as deep breathing
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45 exercises and coughing have been demonstrated to mitigate postoperative pulmonary
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47 complications and shorten hospital stays.^{28,29} Therefore, it is recommended to enhance
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49 the communication of information concerning preoperative respiratory training during
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51 preoperative education, helping patients fully understand the benefits of it to improve
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their level of preoperative exercise and awareness. Additionally, it is necessary to supervise and record preoperative respiratory training for lung cancer patients.

Our research identified that some participants lacked self-management awareness in the preoperative stage, leading to a passive attitude towards information acquisition due to their heavy reliance on physicians. It appeared to hinder their ability to independently make health-related decisions during the perioperative stage. Additionally, 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 post-discharge.³⁰ Proactive interaction with oncologists plays a role in enhancing patients' symptom self-management abilities and their confidence in health literacy.³¹ 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 analyze health information and actively engage in treatment decisions in order to improve treatment outcomes.

Limitations

Our study has the following limitations. Firstly, 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

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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, minimizing the likelihood of such occurrences.

Conclusions

This qualitative study explored experiences and barriers within the health information-seeking behavior of preoperative lung cancer patients, offering healthcare providers effective strategies for health education. Firstly, our study identified personalized 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. Secondly, 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. Thirdly, 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 cancer patients

allows healthcare providers to enhance patients' health literacy, empower them, and ultimately improve their overall health outcomes.

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Authors' contributions Jiayi Guo: data collection; formal analysis; visualisation; writing-original draft & revising. Jie Zhu: data collection, formal analysis, writing-original draft & revising. Lihua Huang: data collection, data analysis and writing-review. Wei Li: data analysis and writing-review. Man Ye: conceptualisation, formal analysis, visualisation, writing-review & editing. All authors read and approved the final manuscript.

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Availability of data and material The dataset generated and analyzed is not available for others according to Norwegian data protection legislation. Analysis files can be made publicly available from the corresponding author on reasonable request.

Ethics approval Ethical approval was provided by the College Ethics Review Committee of Xiangya Nursing School of Central South University (Approval number: E2023129).

Ethics Accordance This study was performed in line with the principles of the

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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.

Competing interests The authors declare that there are no conflicts of interests.

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Supplementary File 1 Demographic Characteristics of Participants

Variable	Number	Frequency (%)	Mean±SD
Gender			
Male	12	52.17	
Female	11	47.83	
Age			44.18±14.26
Illness time (months)			18.01±15.34
Type			
Adenocarcinoma	16	69.57	
Squamous cell carcinoma	4	17.39	
Adenosquamous carcinoma	3	13.04	
TNM staging			
I	12	52.17	
II	7	30.43	
IIIA	4	17.39	
Habitation			
Urban	14	60.87	
Rural	9	39.13	
Education level			
Primary school	4	17.39	

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High school	6	26.09
Bachelor's degree	6	26.09
Other	7	30.43
Marriage		
married	16	69.57
unmarried	5	21.74
divorce	2	8.69
Employed		
No	7	30.43
Yes	16	69.57

Abbreviation: SD, standard deviation; TNM, Tumor Node Metastasis.

Supplementary File 2 Example Quotations of Themes

Themes	Quotations
Personalized information needs: focusing on the present or planning for the future	<p><i>'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).'</i></p> <p><i>'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></p> <p><i>'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).'</i></p> <p><i>'I would prefer not to acquire an excess of information and simply focus on living in the present moment.(P6, male, 51 years old).'</i></p> <p><i>'I hope you can provide me with more information about the surgery, such as the risks involved and how long the recovery process will take (P1, female, 32 years old).'</i></p> <p><i>'I want to know how to recover as quickly as possible because I want to return to work as soon as possible (P13, male, 42 years old).'</i></p> <p><i>'Yes, I want to know more information, such as what should I do after surgery?(P21, female, 42 years old)' .</i></p> <p><i>'What is the prognosis of this disease and how can we avoid recurrence?(P15, male, 55years old).'</i></p>
Challenges in comprehending and evaluating desired information	<p><i>I feel like everything has happened too quickly, and I still don't know what caused my illness. I am going into surgery completely confused (P5, male, 32 years old)</i></p> <p><i>'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></p> <p><i>' 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 (P1, female, 40 years old) '.</i></p> <p><i>'I don't smoke anymore, I'm still so young, I really can't figure out why I got this disease (P20, female,</i></p>

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	<p>30 years old)'. 'So I don't even understand why I got this disease right now. I'm worried that it might recur after surgery (P21, female, 42 years old)'. I have good lifestyle habits and no family history of inheritance. I really don't understand why I still get this disease (P18, male, 39 years old)'. 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 cancer surgery involves cutting into the chest cavity, it might affect my breathing in the future. (P19, female, 42 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)'. 'I'm not even sure if my surgery was the right choice right now. I am still searching online for more effective treatment plans (P22, male, 44 years old)'. '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)'. 'There is a lot of conflicting information on social media. Some people say that you should avoid drinking milk, while others say it doesn't matter. There are also various dietary considerations. It can be confusing to know which advice to believe. (P13, male, 42 years old)'. 'It is said online that taking traditional Chinese medicine can treat early lung cancer, but I am not sure if it is true or false (P15, male, 55 years old)'. 'There are claims online that lung cancer patients should avoid eating watermelon, as it contains substances that could affect lung function. However, others argue that it is not a concern. I'm confused about whether I should eat it or not. (P18, male, 39 years old)'.</p>
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	<p><i>'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).'</i></p> <p><i>'I am illiterate and cannot understand the words written on the manual or poster (P14, female, 64 years old).'</i></p> <p><i>I can't understand some of your majors, I can only understand the pictures (P15, male, 55 years old).'</i></p> <p><i>'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).'</i></p> <p><i>'I don't understand what pursed lip breathing is, I can't understand and written descriptions, and it's difficult to do it myself (P9, female, 69 years old).'</i></p>
Inadequate awareness of the preoperative respiratory training	<p><i>'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></p> <p><i>'I didn't do preoperative exercise and it felt very troublesome (P9, female, 69 years old).'</i></p> <p><i>'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).'</i></p> <p><i>'I feel like I'm doing well now. It's not very useful to do that (P1, female, 35 years old).'</i></p> <p><i>'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).'</i></p> <p><i>"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).'</i></p> <p><i>'As long as the surgery goes smoothly, nothing else matters (P1, male, 57 years old).'</i></p> <p><i>'I feel like it's too troublesome to do this, and I'd rather just stay at home with my family (P12, male, 57 years old).'</i></p>
The Impact of Passive Information Reception on Self-care	<p><i>'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></p> <p><i>'I don't think it's necessary to have the relevant information. Just following the doctor's advice is</i></p>

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	<p><i>enough for me (P9, female, 69 years old) ’</i></p> <p><i>‘I’m too lazy to search for that information, I feel like I’m wasting time (P18, male, 39 years old) ’.</i></p> <p><i>‘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) ’.</i></p> <p><i>‘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></p> <p><i>‘Anyway, I’ll just wait for the doctor to tell me what to do (P13, male, 55years old) ’.</i></p> <p><i>‘I always wait for the doctors to remind me to get checked up, 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 (P13, male, 52 years old) ’.</i></p>
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Experiences of health information-seeking behavior in preoperative lung cancer patients: 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 behavior (HISB).

Design: The study utilized a qualitative descriptive design, adhering to the COREQ guidelines. 23 participants were purposively selected for semi-structured 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 lung cancer patients 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 personalized health information needs in their information-seeking behavior. 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

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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 lung cancer patients. Healthcare providers should adopt a patient-centered approach in health education, with a targeted effort to recognize and mitigate specific barriers in clinical practice. Further research is needed to explore effective strategies aimed at augmenting health information seeking process among lung cancer patients before surgery.

Strengths and Limitations of this Study:

1. 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.
2. 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.
3. 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 tumors 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 utilizing 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 utilize health information during the preoperative phase can improve their preoperative preparation, thereby enhancing pain management and surgical experience.⁶ In contrast, lung cancer patients with insufficient health knowledge in the preoperative stage are at greater risk of

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misunderstanding surgical procedures, potentially leading to inferior surgical outcomes.⁷

Health information-seeking behavior (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, cancer patients 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 favored information sources, followed by the internet.¹¹ The method dimension emphasizes 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 (CMIS), 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 behavior itself.⁸ A recent study in China have shown that preoperative lung cancer patients 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 lung cancer patients to reveal the underlying complexities of their behavior. 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 (COREQ) guidelines was maintained to ensure comprehensive and transparent reporting throughout the study.¹⁷

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Participants and Recruitment

We employed purposive sampling to select lung cancer patients 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 (Tumor 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: (i) initial cancer diagnosis based on imaging examinations or histopathology, (ii) scheduled for surgical treatment, (iii) adults aged 18 and older capable of articulating their thoughts clearly, (iv) comprehension of their diagnosis, and (v) voluntary participation with informed consent. Exclusion criteria included: (i) critically ill patients unable to cooperate, (ii) concurrent presence of other malignancies, (iii) a history of mental illness or communication impediments.

Data Collection

The semi-structured interviews were conducted face-to-face by the J.G. and J.Z., 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 finalized 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 to 30 minutes. 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 demeanor 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 rigor 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

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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 analyze 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 analyzed by J.G. and J.Z., 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 analyzing and reorganizing the data, marking the important meanings. The coding was then categorized based on the research objectives to establish the final themes. In each interview, the NVivo V.12 coding comparison tool was used to evaluate ICR, 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. J.G., who has experience translating qualitative research reports, summarized the results into English. Then, she sent the translated document to J.Z. for verification. Finally, a professor who teaches nursing and English at the university reviewed and revised the translation.

Ethics

This study has obtained ethical approval from the research institution. All

participants were informed about the voluntary nature of their participation and provided their consent by completing participant information sheets and written informed consent.

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 lung cancer patients 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 **Supplementary File 1**. For more detailed verbatim quotes, please refer to the coding matrix (**Supplementary File 2**). The interview participants shared their experiences regarding health information seeking process, which were categorized into four themes. These themes encompassed participants' personalized needs, types of health information sought, preferred information sources, specific behaviors and the barriers encountered during the process of health information seeking.

Personalized 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, personalized 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 seem 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. 6 participants (26.09%) expressed a lack of understanding of the etiology 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, 2 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 behaviors 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

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turned to the Internet or disease education manuals. 4 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)'*. 3 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)'*. 2 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 optimizing pulmonary ventilation function, enhancing surgical tolerance, and mitigating postoperative complications among patients undergoing lung surgery. Our interviews showed that the majority of preoperative lung cancer patients 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, 55years 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 behavior 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 personalized 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 utilization. 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 personalized 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 anesthesia, 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. Recognizing 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.

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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 behavior 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 utilization of health information.^{24,25} Future studies should prioritize 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 etiology contributed to feelings of uncertainty and lack of control over disease progression during the perioperative

stage. Recent a study have 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 etiology 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 specialized 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 prioritize these populations, offering personalized, face-to-face counseling and developing patient-centric health education strategies.

Lung cancer, often termed the "silent killer," is characterized by the fact that most early-stage cases lack obvious clinical symptoms.³⁰ Notably, information regarding pre-surgery exercises appeared to be overlooked by the participants, a finding that has

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4 been rarely addressed in previous studies. A majority of participants reported
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6 experiencing no physical discomfort prior to surgery, leading to a neglect of
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8 preoperative breathing training. This oversight may be attributed to a lack of
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10 understanding about lung cancer and a generally optimistic perception of their health
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12 status. However, preoperative respiratory training remains crucial even in the absence
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14 of apparent symptoms. Techniques such as deep breathing exercises and coughing
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16 have been demonstrated to mitigate postoperative pulmonary complications and
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18 shorten hospital stays.^{31,32} Therefore, it is recommended to enhance the
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20 communication of information concerning preoperative respiratory training during
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22 preoperative education, helping patients fully understand the benefits of it to improve
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24 their level of preoperative exercise and awareness. Additionally, it is necessary to
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26 supervise and record preoperative respiratory training for lung cancer patients.
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35 Our study also observed that some participants exhibited "passive search"
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37 behavior.²³ During the pre-surgery phase, these participants lacked self-management
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39 awareness and were heavily reliant on doctors, resulting in a passive attitude toward
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41 information acquisition. This dependence appears to hinder their ability to make
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43 health-related decisions independently during the perioperative period. Influenced by
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45 traditional Chinese beliefs in predestined outcomes, some participants entrusted their
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47 health fate entirely to their physicians, perceiving them as best positioned to make
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49 decisions on their behalf. However, as indicated by a study, passive information
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51 reception may lead to patients lacking active engagement in their illness and
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53 treatment, thereby affecting their ability to self-manage post-discharge.³³ Proactive
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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 analyze health information and actively engage in treatment decisions in order to improve treatment outcomes.

Limitations

Our study has the following limitations. Firstly, 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, minimizing the likelihood of such occurrences.

Conclusions

This qualitative study explored the experience of preoperative lung cancer patients seeking health information based on the information and methodological features of HISB. These findings provide healthcare providers with effective strategies for health education. Firstly, our study identified personalized psychological

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1 coping strategies and specific health information needs among preoperative lung
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4 cancer participants. Some individuals faced challenges balancing their quest for
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7 information with anxiety avoidance. Secondly, difficulties in obtaining desired
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10 information stemmed from a lack of understanding cancer causes and obstacles in
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13 comprehending or evaluating treatment options, surgical side effects, online media
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16 sources, and preoperative exercise practices. Thirdly, most participants believed they
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19 experienced no preoperative physical discomfort, leading them to overlook the
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22 importance of preoperative respiratory training. Finally, some lacked
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25 self-management awareness and heavily relied on physicians, resulting in a passive
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28 approach to information acquisition that seemed to hinder their ability to
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31 independently make health-related decisions during the perioperative stage.

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

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46 experiences.

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49
50
51 writing-original draft & revising. Jie Zhu: data collection, formal analysis,
52
53
54 writing-original draft & revising. Lihua Huang: data collection, data analysis and
55
56
57 writing-review. Wei Li: data analysis and writing-review. Man Ye: conceptualisation,
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60 formal analysis, visualisation, writing-review & editing. All authors read and

approved the final manuscript. The corresponding author, Man Ye, is the guarantor for this study.

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Availability of data and material The dataset generated and analyzed is not available for others according to Norwegian data protection legislation. Analysis files can be made publicly available from the corresponding author on reasonable request.

Ethics approval Ethical approval was provided by the College Ethics Review Committee of Xiangya Nursing School of Central South University (Approval number: E2023129).

Ethics Accordance 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.

Competing interests The authors declare that there are no conflicts of interests.

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

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Supplementary File 1 Demographic Characteristics of Participants

Variable	Number	Frequency (%)	Mean±SD
Gender			
Male	12	52.17	
Female	11	47.83	
Age			44.18±14.26
Illness time (months)			18.01±15.34
Type			
Adenocarcinoma	16	69.57	
Squamous cell carcinoma	4	17.39	
Adenosquamous carcinoma	3	13.04	
TNM staging			
I	12	52.17	
II	7	30.43	
IIIA	4	17.39	
Habitation			
Urban	14	60.87	
Rural	9	39.13	
Education level			
Primary school	4	17.39	

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High school	6	26.09
Bachelor's degree	6	26.09
Other	7	30.43
Marriage		
married	16	69.57
unmarried	5	21.74
divorce	2	8.69
Employed		
No	7	30.43
Yes	16	69.57

Abbreviation: SD, standard deviation; TNM, Tumor Node Metastasis.

Supplementary File 2 Example Quotations of Themes

Themes	Quotations
Personalized information needs: focusing on the present or planning for the future	<p><i>'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).'</i></p> <p><i>'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></p> <p><i>'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).'</i></p> <p><i>'I would prefer not to acquire an excess of information and simply focus on living in the present moment.(P6, male, 51 years old).'</i></p> <p><i>'I hope you can provide me with more information about the surgery, such as the risks involved and how long the recovery process will take (P1, female, 32 years old).'</i></p> <p><i>'I want to know how to recover as quickly as possible because I want to return to work as soon as possible (P13, male, 42 years old).'</i></p> <p><i>'Yes, I want to know more information, such as what should I do after surgery?(P21, female, 42 years old)' .</i></p> <p><i>'What is the prognosis of this disease and how can we avoid recurrence?(P15, male, 55years old).'</i></p>
Challenges in comprehending and evaluating desired information	<p><i>I feel like everything has happened too quickly, and I still don't know what caused my illness. I am going into surgery completely confused (P5, male, 32 years old)</i></p> <p><i>'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></p> <p><i>' 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 (P1, female, 40 years old) '.</i></p> <p><i>'I don't smoke anymore, I'm still so young, I really can't figure out why I got this disease (P20, female,</i></p>

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	<p>30 years old)'. 'So I don't even understand why I got this disease right now. I'm worried that it might recur after surgery (P21, female, 42 years old)'. I have good lifestyle habits and no family history of inheritance. I really don't understand why I still get this disease (P18, male, 39 years old)'. 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 cancer surgery involves cutting into the chest cavity, it might affect my breathing in the future. (P19, female, 42 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)'. 'I'm not even sure if my surgery was the right choice right now. I am still searching online for more effective treatment plans (P22, male, 44 years old)'. '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)'. 'There is a lot of conflicting information on social media. Some people say that you should avoid drinking milk, while others say it doesn't matter. There are also various dietary considerations. It can be confusing to know which advice to believe. (P13, male, 42 years old)'. 'It is said online that taking traditional Chinese medicine can treat early lung cancer, but I am not sure if it is true or false (P15, male, 55 years old)'. 'There are claims online that lung cancer patients should avoid eating watermelon, as it contains substances that could affect lung function. However, others argue that it is not a concern. I'm confused about whether I should eat it or not. (P18, male, 39 years old)'.</p>
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	<p><i>'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).'</i></p> <p><i>'I am illiterate and cannot understand the words written on the manual or poster (P14, female, 64years old).'</i></p> <p><i>I can't understand some of your majors, I can only understand the pictures (P15, male, 55years old).'</i></p> <p><i>'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).'</i></p> <p><i>'I don't understand what pursed lip breathing is, I can't understand and written descriptions, and it's difficult to do it myself (P9, female, 69 years old).'</i></p>
Inadequate awareness of the preoperative respiratory training	<p><i>'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></p> <p><i>'I didn't do preoperative exercise and it felt very troublesome (P9, female, 69 years old).'</i></p> <p><i>'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, 55years old).'</i></p> <p><i>'I feel like I'm doing well now. It's not very useful to do that (P1, female, 35 years old).'</i></p> <p><i>'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).'</i></p> <p><i>"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).'</i></p> <p><i>'As long as the surgery goes smoothly, nothing else matters (P1, male, 57 years old).'</i></p> <p><i>'I feel like it's too troublesome to do this, and I'd rather just stay at home with my family (P12, male, 57 years old).'</i></p>
The Impact of Passive Information Reception on Self-care	<p><i>'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></p> <p><i>'I don't think it's necessary to have the relevant information. Just following the doctor's advice is</i></p>

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	<p><i>enough for me (P9, female, 69 years old) ’</i></p> <p><i>‘I’m too lazy to search for that information, I feel like I’m wasting time (P18, male, 39 years old) ’.</i></p> <p><i>‘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) ’.</i></p> <p><i>‘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></p> <p><i>‘Anyway, I’ll just wait for the doctor to tell me what to do (P13, male, 55years old) ’.</i></p> <p><i>‘I always wait for the doctors to remind me to get checked up, 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 (P13, male, 52 years old) ’.</i></p>
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