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Thyroid

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Title Page

Barriers and Facilitators to the Choice of Active Surveillance for Low-risk Papillary Thyroid Cancer in China: A Qualitative Study Examining Patient Perspectives

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Abstract

Background: Internationally, several clinical practice guidelines recommend active surveillance as a non-surgical management strategy for select patients with low-risk papillary thyroid carcinoma. However, patient's decision making when choosing active surveillance as a management approach is not well understood. Thus, our aim was to examine the barriers and facilitators to selecting active surveillance amongst patients with low-risk papillary thyroid carcinoma in China.

Methods: Thirty-nine participants diagnosed with low-risk papillary thyroid carcinoma were purposively recruited between July – Nov 2021 for semi-structured interviews; 24 of whom rejected and 15 patients chose 'active surveillance' as a management approach in our sample. Inductive content analysis illustrated emerging themes. Audit trails, member checks and thematic discussions were used to assert rigor.

Results: Barriers and facilitators were classified as patient-related, disease-related, and external factors. Patient-related factors included patient's knowledge, attitudes and emotions. Disease-related factors included the response to having cancer, the constant state of being diseased and perceived value of the thyroid gland. External factors included the residual effects of surgery, the active surveillance protocol and physicians' recommendations.

Conclusions: Patient's the acceptability of the active surveillance as a management approach are complex with many influencing factors. The public acceptance of active surveillance as a disease management approach needs to be improved, through the presentation of active surveillance as an evidence-based and optimized dynamic management strategy. Clinicians must address their patients' psychological struggles when patients choosing active surveillance and patients require more attention and supportive intervention.

Introduction

As the global burden of thyroid cancer increases (1), the incidence of differentiated thyroid cancer has increased across China, with most observed in incident low-risk papillary thyroid microcarcinoma (tumor diameter ≤1cm) (2,3). Active surveillance is a disease management approach which is hailed as a safe and economical alternative to immediate surgical resection (4-7).

A tertiary care center study in China revealed almost 45% (n=2659) of patients with nodules of ≤1cm chose surgery rather than active surveillance (8). Liu, Yan and Cheng noted that 47.9% of patients with low-risk papillary thyroid microcarcinoma in one institution could be considered potential cost saving relating to hospitalization, thyroxine supplementation and missed work time (9). In China, patients may not be given the option of active surveillance or may choose to decline it.

At present, little is known about the barriers and facilitators to choosing active surveillance as a disease management option for papillary microcarcinoma in China. The aim of this study was to explore barriers and facilitators of Chinese patients when choosing active surveillance.

Materials and Methods

Participants and setting

Participants were recruited from the outpatient departments linked to the endocrinology and the thyroid surgery wards of four tertiary care hospitals located across the Jiangsu Province. We recruited patients 18 years of age or older, Chinese speakers, diagnosed with papillary thyroid cancer with tumor diameter ≤1cm according to the American Thyroid Association criteria (10) or suspected highly for papillary thyroid cancer with tumor diameter ≤1cm by professional clinicians according to ultrasound imaging (11,12). Inclusion was also limited to those were offered treatment options of active surveillance and surgery and they had either chosen the active surveillance approach for at least six months or had decided to have surgery. Patients with a history of prior thyroid surgery, other tumors, and cervical lymph node metastasis identified before or during

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surgery were excluded. Purposive sampling enabled patients with the specific diagnosis, to meet our strict inclusion criteria for the study. Interested hospital medical staff at the respective hospitals assisted in the recruitment of study participants. Potential participants were informed of our commitment to confidentiality in any response data and we assured that their participation would, in no way, impact any care. Information was offered via a short PowerPoint presentation of the study and written information with an opportunity to speak with clinicians for further information. Data collection was undertaken July – Nov 2021. The participants provided written informed consent to participate in this study and ethics approval from the Institutional Research Ethics Committee was obtained (No. YZUHL20210095).

Data collection

Individual interviews were conducted in a private area in the outpatient lounge and ward consulting rooms under relevant Covid-19 infection prevention protocols. Two experienced and registered nursing interviewers (QZ, QW) followed a pre piloted question directed interview for each participant. Interviewees were encouraged to share any pre-existing assumptions they may hold on active surveillance to uphold veracity and rigout and ensure no a prior assumption could skew interviews. The interview questions were taken from existing literature and consultations with psychologists and experts in the field of thyroid surgery and endocrinology. We piloted the questions in a small number of patients (n=4) and further modified the interview outline (Table 1). The results of the pilot study interviews were not included in the data analysis.

Interviews duration was 45-126 minutes and data were translated verbatim within 24 hours. Unique participant identifiers were applied prior to coding to ensure anonymity.

Analysis

The study followed the item consolidated criteria for reporting qualitative research (COREQ) (13). Anonymized transcripts were summarized by QZ and then imported to NVivo 12 software (QSR international). Data were analyzed by PZ, QZ, QW, and GS using inductive content analysis to present the themes and sub-themes (14,15). Data analysis occurred in four steps, details of which are described in (Table 2 (16)). We resolved

discrepancies between coders through discussion and group consensus. Data saturation was assumed to be reached when no new analytical information about the phenomena being studied arises (17) and this was achieved at the point at which no new sub-themes or data units 'emerged' from the data at interview 36. A further three interviews were conducted to confirm that data saturation was achieved. The data we collected from all 39 participants was included.

The analysis process was conducted on the transcribed data which was in Chinese. The translation of the themes and exemplary quotes into English was checked by PZ and QZ who are fluent English speakers. All participants details were presented anonymously using participant numbers for example: participant 13 was female, aged 30 years and had surgery (F, 30, surgery). An audit trail provides documentary evidence of the sequence of activities from the beginning to the end of the study (18). Member checks were performed with interviewees (n=39) and all but three confirmed that the results resonated with their perspectives.

Results

Forty-four potential participants were approached, and ultimately 39 (88.6%) patients with low-risk papillary thyroid cancer chose to participate in the study. 24 patients had rejected the active surveillance approach and 15 patients had chosen ‘active surveillance’ as disease management strategy. Participant ages ranged from 22 to 58 years. 28 (71.8%) participants were female, 29 (74.4%) were married, and 22 (56.4%) had college degrees (Table 3 (19)).

Results of thematic analysis

Barriers to choosing active surveillance for patients

The barriers to choosing active surveillance for participants were broadly identified as patient-related, disease-related, and external factors (Table 4).

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Patient-related factors

Patient-related factors included: patient's knowledge of active surveillance; patient's attitudes and emotions relating to active surveillance.

Patient's knowledge of active surveillance

Nearly half of the participants (n=10) receiving surgical intervention expressed that lack of comprehensive knowledge about active surveillance had been a barrier for their choice (Table 4). Participant 13 (F, 30, surgery) stated, "I have no interest and energy to know it [active surveillance], when I knew it was a cancer." Participants reported they wanted professional guidance and explanation about active surveillance. Participant 3 (F, 25, surgery) described, "I read a lot about it [active surveillance] online, but still [I am] confused. I need a professional explanation about it [active surveillance]."

Patient's attitudes and emotions relating to active surveillance

The subtheme of "patient's attitudes and emotions relating to active surveillance" included predefined expectancies about the outcome of treatment; their struggles to make a choice; active surveillance and living with a tumor coupled with psychological distress and perceived responsibility to their family.

Predefined expectancies about the outcome of treatment

The most prominent barriers amongst participants who chose surgery related to concerns about the adverse disease outcomes associated with an untreated cancer under active surveillance. Participant 22 (F, 38, surgery) stated, "I am still very worried about metastasis and posing a threat to my life. This is something that my family and I, in any case, will never accept." Participant 20 (M, 34, surgery) explained that the cancer was like "a time bomb". Most participants (n=21) differentiated between management options with surgery being viewed as a definite treatment preventing disease progression, whereas active surveillance seemed to be uncertain in terms of managing disease progression (Table 4).

Struggle to make a choice

Most of the participants (n=19) who chose surgery struggled to make a choice about active surveillance (Table 4). For example, participant 16 (F, 34, surgery) explained, "I am not sure about the safety and science of active surveillance. I do not have the courage to choose it [active surveillance]." Some of the participants sought second opinions and asked for advice on treatment decisions. Participant 25 (M, 49, surgery) stated, "I saw three physicians [from different hospitals] and had pathological punctures three times, but the outcomes [the biopsy results and three physicians all suggested he could choose active surveillance] were the same."

Active surveillance and living with a tumor coupled with psychological distress

Nearly half of participants (n=11) who chose surgery expressed psychological distress and negative emotions associated with their thyroid tumor, which were barriers to choosing active surveillance (Table 4). Participant 7 (F, 28, surgery) said, "I suffered mental anguish and had to undergo surgery." In addition, Participant 22 (F, 38, surgery) stated sadly, "I cannot handle this. I cannot live with it [the tumor]."

Perceived responsibility to family

For some participants (n=10), active surveillance was perceived to be an irresponsible course of action for their partners and families (Table 4). Participant 14 (F, 31, surgery) explained, "I am responsible for my child, the kid is my whole motivation to ... [having surgery]." In addition, participant 1 (F, 30, surgery) stated, "I chose it [the surgery] because I felt responsible for my future partner."

Disease-related factors

The negative response to having cancer

Almost all people (n=23) who chose surgery said they had a negative response to having cancer and their negative response to cancer was a major barrier to choosing active surveillance (Table 4). Most participants felt devastated by having a pathological diagnosis including the word "cancer". Participant 9 (F, 25, surgery) claimed, "I was young, I could

not accept the word "cancer", so I came here [for surgery] ...” Participant 10 (M, 39, surgery) described that “cancer is lethal and must get it out at first time”. Participants discussed the influence of tumor characteristics on their treatment decision. Participant 6 (F, 35, surgery) said, “I have cancer, you know...I need surgery.”

The constant state of being diseased

Some participants (n=8) who chose surgery mentioned active surveillance would keep them in a diseased state, which became was a barrier to active surveillance (Table 4). Participant 21 (F, 27, surgery) stated, “The approach made me a patient all the time, my body was flawed and defective.” In addition, Participant 2 (F, 29, surgery) recalled, “I wanted to get my surgery done quickly and got my health back.”

Uncomfortable thyroid organs

A few participants (n=6) who chose surgery mentioned uncomfortable thyroid organs using the words “bad organs” and “defective organs” (participant 20, F, 34, surgery) (Table 4). Participant 29 (F, 27, surgery) stated, “I often felt pain in my neck, I knew it [the organ] was not really hurt; it had been with me for more than twenty years, now it was wrong, it was miserable for me... [looking sad and helpless].”

External factors

Willing to accept the residual effects of surgery

A few participants (n=5) who chose surgery expressed acceptance of the side-effects of surgery. For example, participant 19 (F, 37, surgery) accepted her scar and said the scar on her neck was like “an angel's hickey with a smile”. In addition, participant 24 (F, 31, surgery) stated, “I had the habit of taking health care products, taking drugs regularly was not a trouble for me.” Participants expressed they would not choose active surveillance to avoid the side-effects or residual effects post-surgery (Table 4).

Active surveillance protocol

The disease surveillance program experienced by participants in the study varied by hospital and region, often dependent on the doctor’s medical experience and the ability to

support serial ultrasound examinations. The need for regular follow-up needed in active surveillance was a barrier for some patients (n=6) (Table 4). Participant 4 (M, 51, surgery) explained, “It was very inconvenient for me to come from a remote area in the country to this big hospital for follow-up every time, a one-time surgical removal would be better for me.”

The facilitators to choosing active surveillance for patients

The facilitators to choosing active surveillance for participants were broadly identified as patient-related, disease-related, and external influencing factors (Table 4).

Patient-related factors

Patient’s knowledge of active surveillance

Nearly half (n=7) of the participants who chose active surveillance indicated that they had a good understanding of the approach (Table 4). Participant 30 (F, 30, surveillance) stated, “I consulted a lot about the active surveillance strategy, including professional medical literature, it [active surveillance] was an advanced approach.”

A positive mental attitude linked to choosing active surveillance

Participants (n=8) expressed an optimistic attitude was a facilitator for choosing active surveillance (Table 4). Participant 15 (F, 33, surveillance) recalled, “I had maintained a relatively optimistic attitude, and active surveillance was suitable for me.” In addition, participant 17 (M, 32, surveillance) said, “It was a disease I'm coping with right now. It did not change my life much. I'm willing to live with it.”

Disease-related factors

Characteristic of having a “good cancer”

The perception of thyroid cancer as a “good cancer” (n=14) was a facilitator for choosing active surveillance (Table 4). For example, participant 31 (F, 58, surveillance) said, “It [papillary thyroid carcinoma] was not as scary as other tumors, and… I did not die...so I

was not afraid of it." Participant 23 (F, 38, surveillance) stated the main reason to choose active surveillance was the tumor was less harmful.

Perceived value of the thyroid gland

Nearly half of participants (n=7) who chose active surveillance expressed that they were unwilling to give up a functioning organ (Table 4). Participant 30 (F, 30, surveillance) said she needed the thyroids to working normally. In addition, participant 32 (M, 38, surveillance) mentioned that no medicine could completely replace organs in his mind.

External factors

Not willing to accept the residual effects of surgery

More than half of participants (n=11) who chose active surveillance expressed the residual effects of surgery were facilitators for choosing active surveillance (Table 4). Participant 35 (F, 28, surveillance) said she was terrified of surgery and couldn't handle it. In addition, participant 33 (F, 35, surveillance) stated, "I would have to take drugs for the rest of my life, which was a big hassle for me, now I prefer active surveillance."

Active surveillance protocol

High-quality surveillance systems are conducive to early detection of disease progression, which facilitates the choice of active surveillance for some patients (n=6) (Table 4). For example, participant 27 (M, 45, surveillance) said, "I had been followed up for 1 year with the best ultra-sonographers, it gave me a lot of support."

Following physicians' recommendations

Most of participants (n=10) who chose active surveillance indicated that a professional physician recommendation was a prominent facilitator for active surveillance (Table 4). For example, participant 28 (F, 27, surveillance) said, "I was preparing for pregnancy, and the doctor advised me to get pregnant first, so I chose active surveillance." Participant 18 (M, 35, surveillance) stated, "I came here [to a provincial hospital] from a small town, and I believed the physician here would give me [good] treatment advice [in choosing active surveillance]."

Discussion

This study is the first to qualitatively investigate the barriers and facilitators to selecting active surveillance as a treatment strategy for patients with select low-risk thyroid cancer in China. For patients opting for surgery, fear of adverse disease outcomes and the negative response to having cancer were major barriers. In a systematic review, Wei *et al*. reported that the risk of cancer spread and recurrence influenced the decision making of patients with low-risk thyroid cancer and the possibility of tumor metastasis (20). Currently, more and more studies from China report on the feasibility of active surveillance as a management strategy for low-risk papillary thyroid cancer (21). In our study, the patients that chose surgical strategies were strongly influenced by the cancer diagnosis and possibly the Confucian culture. In this study, patients with low-risk thyroid cancer showed the same cancer concerns, fear of disease progression and consider papillary microcarcinoma as a potentially life-threatening disease like patients in other countries when offered options of surgery and active surveillance (22). In China, however, patients are concerned not only about cancer concerns, but also about cancer cultural taboos. In the context of Chinese culture, study showed the experience of having cancer is also thought to affect a person's likelihood of promotion at work, influence interpersonal relationships and destroy their "good luck (23). Cancer sometimes is seen as bad luck in Chinese culture. This cancer cultural taboos and cancer concerns has a big impact on patient decision-making in China. The effectiveness and scientific validity of active surveillance in China needs to be studied and reported more, to promote a change in patients' beliefs about the potential adverse consequences of active surveillance and living with cancer.

We found that a lack of knowledge about active surveillance hinders the patient choosing active surveillance. Studies have shown that information can improve the degree to which patients with cancer participate in medical decision-making (24). The primary information source for patients with cancer is medical staff (25). In this study, patients sometimes struggled to make a choice for active surveillance even when doctors recommended active surveillance to them. Studies have shown that clinicians lack confidence and experience when recommending an active surveillance strategy to

patients, which may affect the agreement of patients with an active surveillance approach (26). Therefore, it is necessary to enhance the education of clinicians and patients on active surveillance as a disease treatment strategy.

We observed that, patients with psychological distress and negative emotions pertaining to having cancer are more likely to choose surgery rather than active surveillance. A systematic review of qualitative studies showed that the process of making the decision to choose active surveillance is complex and patients experienced an array of emotions that often lead to uncertainty and anxiety (27). Another qualitative study demonstrated that emotion has a great influence on treatment decision-making in patients with low-risk thyroid cancer (28). This is consistent with our findings. However, data from Japan showed that levels of cancer worry decreased over time among patients with thyroid cancer who under active surveillance. These findings suggest that cancer concerns and negative emotions should not be viewed as prohibitive to successful active surveillance selection. Medical staff should openly discuss uncertainty and fear related to making and living with decision, establish a shared decision-making model, and use understanding, hopeful and optimistic communication methods to greatly reduce the burden of the patient's negative emotions (29).

The perception of having a “good cancer” and an optimistic attitude were linked to choosing active surveillance. A qualitative study reported patients’ thoughts of their cancer being relatively good were quite positive, eliciting feelings of comfort, gratitude, and reassurance (30). To some extent, it has a positive effect on alleviating patients' fear of cancer and promotes the choice of active surveillance. Informed decision making refers to the selection of the best treatment for patients in consultation with medical staff (31). In a recently updated Cochrane systematic review, Stacey *et al.* (32), reported that people exposed to decision aids feel more knowledgeable, are clearer about their values, and are more likely to have a more active role in decision making and more accurate risk perceptions. Therefore, time for consultation with health care professionals and the use of decision aids for low-risk thyroid cancer patients may be helpful for patients in choosing the optimal treatment decision for them.

Limitations

Our study has limitations. In order to ensure our researchers remained external to any clinical care and treatment decision making, those patients still in the decision-making processes for active surveillance versus surgery were excluded from the study. Other investigator reported that patients' home circumstances, acceptability of care and treatments, and trust in health care providers strongly influenced patients' decisions and choices in care (33), so further studies are required to reveal factors associated with patients' decision making in care. Our participants choosing active surveillance may eventually choose surgical intervention –so long term follow-up is needed. Clinical interventions, support and guidance may vary between hospital sites, with participants receiving slightly different support and information upon which to base their decisions. Using just two interviewers mitigated this to some extent, but there is a limitation that participants may have received slightly disparate care across the four sites. Finally, the restriction of data collection to one Chinese province, thereby limiting external generalizability. Thus, more data from other Chinese provinces may be needed.

Conclusions

This in-depth qualitative study identified that the barriers and facilitators to active surveillance including patient-related, disease-related, and external influencing factors. These findings reveal that fear of adverse disease outcomes, the negative response to having cancer, lack of recognition of active surveillance, patients' own psychological problems and negative emotional reactions are major barriers for low- risk thyroid patients. Furthermore, the advice of medical staff, the support of family members and the surveillance protocol influenced the decision-making of patients on active surveillance. These findings may be used to guide development of future educational and behavioral interventions designed for patients, their families, and staff, with the ultimate goal of enhancing the adoption and the implementation of active surveillance in patients who may want it. Future interventions should aim to improve patients' knowledge of active surveillance and provide more psychosocial support.

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Authors Contributions Statement

Pingting Zhu: Conceptualization(equal); formal analysis (lead); writing – review and editing (supporting). Qianqian Zhang: Conceptualization(equal); formal analysis (supporting); Software(supporting); writing – original draft (lead); writing – review and editing (supporting). Qiwei Wu and Guanghui Shi: formal analysis (supporting); writing – review and editing (supporting). Wen Wang: Software(lead); writing – review and editing (supporting). Huiwen Xu: Methodology(lead); writing – review and editing (supporting). Li Zhang: Methodology(supporting); writing – review and editing (supporting). Meiyan Qian: Software(supporting); writing – review and editing (supporting). Josephine Hegarty: Methodology(supporting); writing – review and editing (lead).

Author Disclosure Statement

The authors hereby confirm that no part of this manuscript has been published or is under consideration for publication elsewhere. All authors of the article have no conflicts of interest to disclose.

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Table 1. Interview Outline

The questions asked for participants who chose surgery and who chose active surveillance of low-risk papillary thyroid cancer (questions were tailored to each group):
1. What do you know about the active surveillance approach? What do you think of it?
2. What experiences and feelings did you have when faced with making a decision between active surveillance and surgery?
3. What are the reasons you chose surgery and not active surveillance or chose active surveillance and not surgery?
4. Are there any barriers that may have limited the choice of active surveillance for you or any facilitators that motivated you to choose active surveillance? What is the biggest one?
5. Do you have any advice for a patient who is going through the choice of an active surveillance approach versus surgery?

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Table 2. Steps in Inductive Content Analysis

Steps	Details
1. Reading carefully and unitizing data	Researchers read the data repeatedly and gained an overall grasp and understood of the content of the interview transcripts.
2. Open coding and identification of initial categories	A word, phrase, sentence, or complete view or attitude were encoded as a data unit. These data units were reviewed and organized into category units according to their common properties and meaning. Then all data units were open coded together and developed to form the initial set of categories. No data was discarded. Each data unit could only be grouped into one category.
3. Naming and defining initial categories	Within each category, the category was named using words/phrase that best represented the category. Using constant comparison techniques the researchers sought to ensure that there was no overlap between categories (16). Each data unit was evaluated against each category to ensure that each category best fitted the data unit and all categories were mutually exclusive.
4. Identification of sub-themes	The categories were organized according to their common attributes to form a sub-theme. The sub-theme was named with the word/phrase that best represented the content of the category. Constant comparisons were made to ensure that there was no overlap between sub-themes (16).

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Table 3. Participants' Demographic Data and Disease Characteristics

Characteristic	*Choose surgery* *n =24*	*Choose AS* *n=15*
Age(years), average (range)	33（22-51）	35（24-58）
Gender, *n* (*%*)		
Women	18(75)	10(67)
Men	6(25)	5(33)
Highest level of education, *n* (*%*)		
Technical school	2(8)	2(13)
Junior college	9(38)	4(27)
Undergraduate or Masters degree	13(54)	9(60)
Recruitment Site [a], *n* (*%*)		
Hospital 1	9(38)	6(40)
Hospital 2	7(28)	4(27)
Hospital 3	4(17)	3(20)
Hospital 4	4(17)	2(13)
Size of nodule (mm) [b], average (range)	6.8(2-10)	4.6(3-10)
Marital status		
Single	6(25)	3(20)

Married	17(71)	12(80)
divorced	1(4)	0(0)
Number of children, *n* (*%*)		
0	7(29)	6(40)
1	16(67)	7(47)
2	1(4)	2(13)
Model of initial detection [c]		
Physical exam finding	1(4)	1(7)
Image finding	22(92)	14(93)
Case finding at screening	1(4)	0
Type of management chosen, *n*=31		
AS	-	24(62)
Surgery	15(38)	-
Length of patients stayed on *AS* (months), average (range)	-	13(6-20)

a Hospital 1: the First Affiliated Hospital with Nanjing Medical University; Hospital 2: Northern Jiangsu People's Hospital; Hospital 3: Affiliated Hospital of Yangzhou University; Hospital 4: Affiliated Hospital of Xuzhou Medical University

b Ultrasound examination report

c How the patient was diagnosed with PMC from information discussed during the interview based on Singh-Ospina's definition of mechanism detection (19)

AS= active surveillance; *n*=number, *%*=percentage

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Table 4. Domains and Examples of Patient Expression of Barriers and Facilitators to Selecting Active Surveillance

Domains	*Description and exemplary quotes*
	Patient-related barriers: patient's knowledge
Knowledge	"I do not know much about active surveillance now. I did not know anything about it before I got thyroid cancer." participant 5 (F, 22, surgery) "Could you tell me more about active surveillance? I would like to know more about it. It seems to be more popular abroad, does not it? I want to ask the doctor about it, but they are really busy." Participant 11 (F, 32, surgery)
	Patient-related barriers: patient's attitudes and emotions
Predefined expectancy	"I am most worried about the metastasis of the tumor. I do not care about other things. Although people around me say it does not metastasize easily, while this tumor is in my body." participant 21 (F, 27, surgery) "I was terrified that the tumor would metastasize and endanger my life. I am afraid to be alone now. I think a lot of bad things about tumors. I cannot control my thoughts." Participant 26 (F, 40, surgery)
Struggle to make a choice	"When the doctor told me that I could choose surgery or observe the tumor regularly for a period of time, he soon talked about the risks of both surgery and active surveillance. he gave me a short time to think and make a choice. I felt confused and did not know how to make a choice." Participant 29 (F, 27, surgery)

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	"I had a physical examination and found this disease, and I have been feeling upset and uncertain ever since. I was particularly torn about my choice of treatment: surgery or active surveillance? I regret going to the medical examination, because it broke my normal life." participant 34 (M, 37, surgery)
Psychological distress	"When I had thyroid cancer, I had a hard time falling asleep. I didn't have the mood to do anything else. My whole mind was on the disease." Participant 38 (M, 36, surgery) "In the past few years, I was busy with my work and my body was in a state of high stress for a long time. I completely neglected my health, and that's why it has this problem. I feel so sorry for my body." (Her voice choked and cried) Participant 24 (F, 31, surgery)
Responsibility to family	"I am in lactation, and my baby is 8 months, in order to give her the longest company, I must live well." Participant 14 (F, 31, surgery) "I have two children, and my husband is very busy with his work. Now I stay at home full-time and take care of their food and clothing. I cannot have any problems with my body. They all need me." participant 13 (F, 30, surgery)
Patient-related facilitators: patient's knowledge and mental attitude	
Knowledge	I consulted with several thyroid experts, and I listened attentively to what they said about the risks of active surveillance and what to pay attention to during surveillance. I think I am fully aware of the advice they are giving me and the risks I am taking." Participant 12 (F, 35, surveillance)

Positive mental attitude	"I have a friend who also suffers from this disease. He is living in a good condition now. This disease is not terrible. I have almost no psychological pressure on this problem." Participant 27 (M, 45, surveillance)
	Disease-related barriers
The negative response to having cancer	"I just told my colleagues I needed to take some time off. I did not tell them I had thyroid cancer because the cancer was such a harsh word, and I did not want them to know I had it." Participant 19 (F, 37, surgery) "When I saw the puncture pathology report with the word "cancer" on it, I did not know how to accept it. I wished it could be replaced with the word "nodules" or something." Participant 29 (F, 27, surgery)
The constant state of being diseased	"I want to get surgery and accept my life without thyroid. I want to quickly adjust and adapt to this state after the operation." Participant 7 (F, 28, surgery) "I have to admit that I am a patient, I am so young, and I do not want my family and friends to look at me as a patient all the time. The good news is that I am now ready to undergo surgery." Participant 3 (F, 25 surgery)
Uncomfortable thyroid organs	"My thyroid is a bad organ, and there is no reason for this defective organ to continue working in my body." Participant 25 (M, 49, surgery)
	Disease-related facilitators
Characteristic of having a	"The prognosis of this tumor is very good, and some of my friends who have thyroid disease have very normal lives, it seems that the disease doesn't affect them very much."

"good cancer"	Participant 17 (M, 32, surveillance) "They say if you have to have one type of cancer, get thyroid cancer. It doesn't have a high recurrence rate. I'm not scared." Participant 37 (F, 27, surveillance)
Perceived value of the thyroid gland	"I have been following up for more than one year, and the thyroid function is normal, and the examination results are also good. I am satisfied with the current disease management." participant 23 (F, 38, surveillance) "I have a thyroid gland, so my body can have normal thyroid hormone, and the level of the hormone is stable, which drugs can't replace." Participant 33 (F, 35, surveillance)
External barriers	
The residual effects of surgery	"I have high blood pressure and need to take blood pressure medication for a long time. I feel that even if I take medication for life, I should have thyroid surgery, because there is no other way, I choose to accept it." Participant 4 (M, 51, surgery) "A pregnant women can take the hormone replacement drugs. I am reassured about the safety of the drugs." Participant 34 (M, 37, surgery)
Active surveillance protocol	"The doctor told me that the follow-up process did not guarantee that there was no possibility of metastasis. He coldly told me some risks, and I hoped that he could give me some professional guidance and psychological support. I hope he can help me to make a decision, rather than coldly giving me the right to make a decision." Participant 7 (F, 28, surgery)
External facilitators	

The residual effects of surgery	"I was worried that the operation would fail. I had heard that anesthesia was also a risk and that I would not wake up. I'm afraid to go through this." Participant 30 (F, 30, surveillance) "After the operation, I have to take medicine for a long time. The medicine has side effects, and I am worried that it will damage my body." Participant 36 (F, 24, surveillance)
Active surveillance protocol	"I have been following up with the same doctor for a long time. He knows my thyroid condition very well. If there is any change in my condition, I believe he can find the problem at the first time." Participant 23 (F, 38, surveillance)
Physician's recommenda-tions	"The doctor said that I could follow up first and not be in a hurry to undergo surgery. He suggested that I would consider the operation after I found a job." Participant 35 (F, 28, surveillance) "After the doctor saw me, he assessed my weight in detail. He advised me to lose weight and control my weight first, and my thyroid gland could be followed up temporarily." Participant 8 (M,40, surveillance)

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Participants' inclusion and exclusion criteria

Inclusion criteria
(a) Patients older than 18 years.
(b) Patients could communicate in Chinese.
(c) Patients were diagnosed with papillary thyroid cancer with tumor diameter ≤1cm according to the American Thyroid Association criteria or suspected highly for papillary thyroid cancer with tumor diameter ≤1cm by professional clinicians according to ultrasound imaging.
(d) Patients were offered treatment options of active surveillance and surgery and they had either chosen the active surveillance approach for at least six months or had decided to have surgery.
Exclusion criteria
Patients with a history of prior thyroid surgery, other tumors, and cervical lymph node metastasis identified before or during surgery were excluded.

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