

# BMJ Open 'Is it painful'? A qualitative study on experiences of patients before prostate needle biopsy

Jinjiao Mao <sup>1,2</sup>, Yun Dai,<sup>1</sup> Lijuan Wang,<sup>1</sup> Shucheng Pan <sup>1</sup>, Wei Wang,<sup>1</sup> Hongwei Yu<sup>2</sup>

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## ABSTRACT

**Objective** To assess the experiences and emotional reactions of men prior to receiving a prostate needle biopsy (PNB).

**Design** This was a qualitative study involving (1) material research and filter, (2) interviewer training, (3) cognitive semistructured interviews with open-ended questions, (4) data analysis, including translation and back translation and (5) group discussions to determine common themes in the data. All interviews were digitally audio-recorded. The thematic analysis was conducted by repeatedly reading the data manuscript and engaging in group discussion.

**Setting and participants** A total of 30 participants with suspected prostate cancer (PC) who were scheduled to receive a PNB were interviewed. Eligible participants were Chinese native men aged 51–77 years, and the study was conducted in China between September and December 2020. All participants were informed about the purpose of the study and provided written informed consent.

**Results** Four main themes were identified based on the interview content: (1) fear (of pain, adverse effects and bad results), (2) impact of lower urinary tract symptoms (on emotional impact, work and sleeping), (3) inner struggles (relating to hesitation, regret and embarrassment) and (4) lifestyle change (including diet, exercise and receipt of traditional Chinese medicine).

**Conclusions** This patient cohort had a low level of knowledge about PC and PNB. Providing additional education about these topics would help to reduce patient fear and anxiety and improve experiences of the procedure.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ In-depth interviews were used to characterise patient experiences prior to receiving a prostate needle biopsy (PNB).
- ⇒ The study focused on patient feelings about a suspected prostate cancer diagnosis and PNB.
- ⇒ All study participants were from China, a non-English-speaking country, so it is possible that some nuances were missed in translation.
- ⇒ Although the data and themes were thoroughly discussed and analysed, this method of analysis is not objective because no professional text analysis was used.
- ⇒ This is a single-centre study with a small sample size. A multicenter study with a larger sample size will be needed to better understand the psychological state of this patient population prior to PNB.

and Control of China in 2015, PC had the seventh highest prevalence of all types of cancer occurring in men.<sup>6</sup> In 2017, the Global Burden of Disease study reported that 144 887 PC cases and 51 718 deaths occurred in China.<sup>2</sup> Increasing prevalence of this disease is attributed to differential gene expression in an ageing and expanding population, in addition to environmental factors, an increasingly westernised lifestyle and improved detection methods.<sup>6 7</sup>

Prostate needle biopsy (PNB) is the gold standard for PC diagnosis. This method can be used to distinguish malignant from benign tumours and determine the degree of inflammation or hyperplasia of the prostate.<sup>1</sup> PNB is performed in patients who have elevated prostate-specific antigen (PSA) screening indicators (PSA>4 ng/mL)<sup>8</sup> and those with prostate nodules detected through MRI or abnormal digital rectal examination (DRE) results suggestive of PC.<sup>9</sup> Technological advancements have greatly improved the accuracy of PC diagnosis and a multicenter survey recently reported that the rate of PC detection in China is 44%.<sup>10</sup> Scheduled biopsy

## INTRODUCTION

Prostate cancer (PC) is one of the most common malignancies of the urinary system among older men worldwide. PC morbidity and mortality continue to rise, seriously impacting patient's health and putting a significant burden on society.<sup>1</sup> PC is seventh highest among male-specific cancers in China and while the incidence is lower than in Western countries, it has increased in recent years.<sup>2–4</sup> A preliminary study by Zhu *et al* showed that ≤10 of every 100 000 individuals are diagnosed with PC in China.<sup>5</sup> In a survey by the National Office for Cancer Prevention



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<sup>1</sup>The First Affiliated Hospital, School of Medicine, Zhejiang University, Hangzhou, Zhejiang, China

<sup>2</sup>School of Medicine and Nursing Sciences, Huzhou University, Huzhou, Zhejiang, China

### Correspondence to

Wei Wang;  
wangw2005@zju.edu.cn



is being used more commonly to conduct active surveillance of localised PC and prevent tumour advancement in men who choose not to undergo radical treatment.<sup>11</sup> Compared with Western men, men in China appear less motivated to undergo PC screening. This may be a consequence of insufficient knowledge about the illness, the influence of traditional Chinese cultural norms, or gaps in public health management systems used in China. Patients in China tend to receive biopsies and be diagnosed at later stages of the disease when their PSA levels and Gleason scores are higher.<sup>10</sup>

Previous studies have indicated that individuals feel fear and anxiety about a suspicion or diagnosis of cancer. This anxiety may affect their biopsy results and worsen adverse reactions to the procedure.<sup>12 13</sup> Thus, it is important to better characterise and understand the reasons for patient fears and anxieties prior to PNB. A multicenter study performed in the Netherlands reported that 28% of the patients had elevated anxiety and depressive symptoms before a breast cancer screen,<sup>14</sup> and a cancer diagnosis is known to cause trauma for most patients.<sup>15</sup> While infection or prostate enlargement, as well as PC, can be a cause of elevated PSA levels<sup>16</sup> individuals often feel restless and anxious (PSA anxiety) if they learn that their levels are above normal.<sup>17</sup> PNB is also recommended for some patients with normal PSA levels who had prostate nodules observed by MRI or abnormal DRE results.

To date, studies of PNB have primarily focused on the method, position and diagnostic accuracy of the operation. Some studies have focused on complications and feelings of patients after PNB,<sup>9 11 18</sup> and others have concentrated on patient responses following a diagnosis of PC. PNB is an invasive operation associated with a risk of bleeding, infection, haematuria and dysuria that may impact patients' decisions to undergo subsequent prostate surgery.<sup>13 19</sup> The interval between clinical suspicion and a diagnosis of cancer is associated with a range of feelings, including anxiety, fear, depression and uncertainty. To the best of our knowledge, no studies on the psychology of patients, including their experiences and attitudes, prior to receiving a prostate biopsy have been conducted. Thus, this study aimed to characterise the emotional experiences of Chinese patients undergoing initial PNB to inform directions for future studies.

## METHODS

### Design

This is a qualitative study with phenomenology that used semistructured individual interviews of men with suspected PC who were scheduled to receive a PNB. Data on patient experiences were analysed and characterised into themes.

### Participants and recruitment

The study cohort included men who visited the First Affiliated Hospital at the Zhejiang University School of Medicine for a PNB between September and December

2020 based on a physician's recommendation. Participants were recruited through educational flyers that were handed out about the study. An overview of the study aim, process and potential risks was described to patients who expressed interest in participating. Patients were included if they had (1) an abnormal PSA index and/or DRE and/or MRI, (2) had suspected PC and were advised by their doctors to receive a PNB and (3) had not received a PNB previously. The sample size was determined based on the principle of information saturation. A total of 30 participants, 51–77 years of age, were recruited because the contents that they experienced were saturation and repeat.

### Patient and public involvement

Five men with a prior PC diagnosis and experience with PNB who were not participants in the study helped with data analysis and deciding on themes and subthemes. An additional two men helped to transcribe the interview responses of participants who spoke a non-Mandarin dialect. And the results of this study will be communicated to these participants by phone or WeChat.

### Process

Each participant received an in-depth, qualitative, one-on-one interview that was 20–40 min in length. The interviews were conducted in a quiet room and were digitally audio-recorded, transcribed verbatim and audio-verified. Before initiating the review, three participants were preliminarily selected for interviews, their responses analysed and the final interview questions determined following repeated discussion and revision (box 1). Open-ended questions were asked to elicit the most in-depth and insightful responses about how the patients were feeling and encourage them to share their experiences and provide their own perspectives. The researcher has been trained in qualitative research and interviewing techniques prior to conducting the research.

A questionnaire made by researchers was sent to participants for collecting demographic data. Researchers explained particular subjective items that participants had difficulty understanding. For example, for the item, 'self-care ability', a response of 'great' meant living independently without relying on others, a response

### Box 1 Interview questions

#### The interview questions

1. Could you please tell me the reason that you come to do the prostate needle biopsy (PNB)?
2. Tell me about any symptoms that you have been experience recently because of your prostate problems.
3. Please tell me your understanding of PNB.
4. What were your reactions when doctor told you the suspicion of prostate cancer?
5. Do you have any concern about the PNB and your disease? And what are these?
6. What do you think about the reason of your disease?

of ‘moderate’ meant living with some support (such as help finding treatment or conducting outdoor activities) and a response of ‘poor’ meant living only with the help of others. For the item ‘understanding of disease’, a response of ‘high’ meant having detailed knowledge about PC and PNB, including symptoms and treatment methods, a response of ‘moderate’ meant knowing about PC but having no awareness of PNB or disease symptoms, and a response of ‘low’ meant having nothing prior knowledge about PC.

### Data analysis

Group discussion was used as the primary method of data analysis because some dialect expressions may be biased by software analysis. The study team repeatedly listened to recordings of all the interviews and transcribed the contents verbatim into Chinese. The transcripts were then verified against the recordings, deidentified to ensure confidentiality and translated into English by two researchers proficient in both Chinese and English. The documents were read repeatedly to understand the content and each researcher proposed themes and subthemes that emerged from the data. The research team convened to discuss any disagreements and decide on the final set of themes and subthemes. Involvement by the public (ie, those with a prior PC diagnosis and experience with PNB) occurred at this stage.

## RESULTS

Table 1 shows the demographic data of all participants.

Four themes pertaining to patient experiences and feelings prior to undergoing PNB were determined based on data analysis and discussions: fear, impact of lower urinary tract symptoms (LUTS), inner struggle and lifestyle change. The subthemes are listed in figure 1.

### Fear

#### Pain

Patients commonly experience a fear of pain when facing an invasive operation in this sensitive and private region. Most participants in this study reported a substantial fear of pain regarding the PNB procedure.

P1: PNB sounds like a painful operation. I am a little afraid of it. This is my first time undergoing a traumatic medical operation. I don't know, I don't know whether I can hold on to it.

P2: Is it painful? The prostate is small like a chestnut, but it will be punctured with at least 10 needles. It must be painful! Maybe I will shout out in the process of getting the PNB.

Despite a fear of pain, some patients still faced the operation with an optimistic attitude.

P4: It is inevitable that there will be pain, but I think the doctor should be able to use anesthetics. In addition, if others can hold it, so can I.

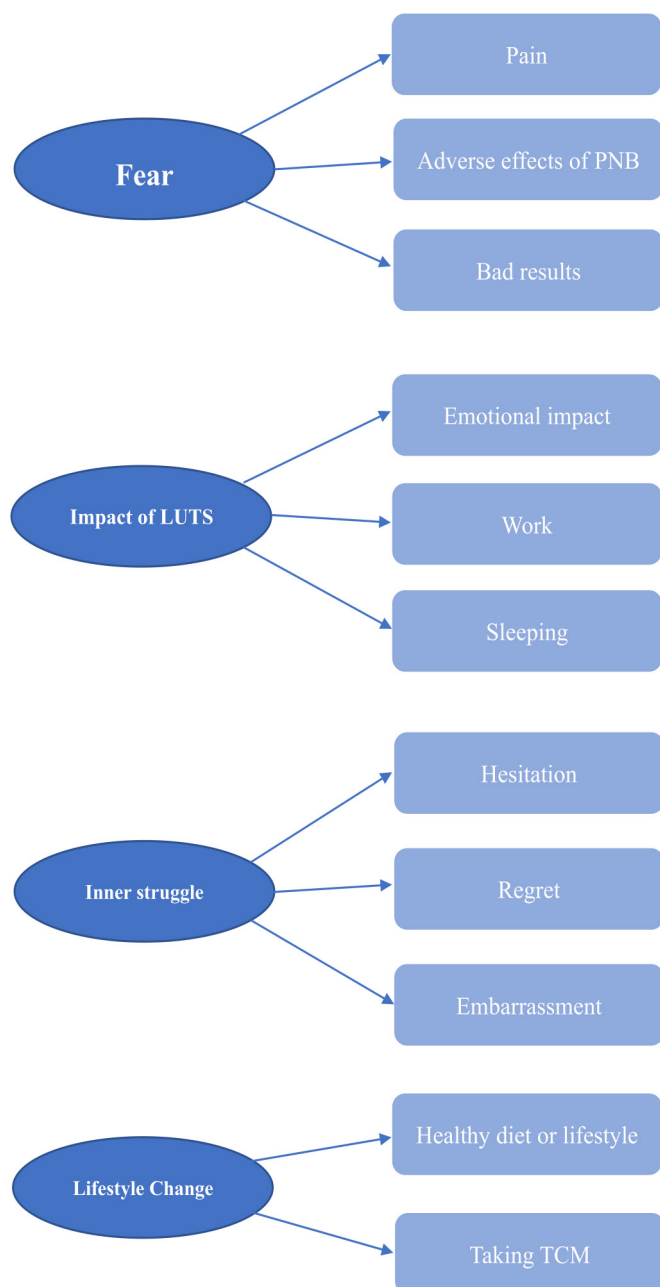
**Table 1** Demographic characteristics of participants (N=30)

	Mean	Number	Percentage (%)
Age (Year)	67.20		
BMI	23.98		
Educational level			
Elementary school and below		16	53.33%
Middle school		5	16.67%
High school		4	13.33%
Collage and above		5	16.67%
Work status			
Yes		5	16.67%
No		25	83.33%
Income monthly (¥)			
<4000		13	43.33%
4000–6000		10	33.33%
6000–8000		3	10.00%
>8000		4	13.33%
Self-care ability			
Great		20	66.67%
Moderate		7	23.33%
Poor		3	10.00%
Live place			
City		17	56.67%
Countryside		13	43.33%
Understanding of disease			
High		6	20.00%
Moderate		14	46.67%
Low		10	33.33%
Prostate-specific antigen level (ng/mL)			
<4		4	13.33%
4–10		14	46.67%
>10		12	40.00%
History of Lower urinary tract symptoms			
Frequent urination		8	26.67%
Urgency		9	30.00%
Painful urination		6	20.00%
Increased nocturia		6	20.00%

### Adverse effects of PNB

PNB is an invasive operation that carries potential risks. Almost all participants expressed concern about the adverse effects of PNB.

One participant with diabetes was worried about persistent bleeding after the puncture.



**Figure 1** Themes (dark blue) and subthemes (light blue) of this study. LUTS, lower urinary tract symptoms; PNB, prostate needle biopsy; TCM, traditional Chinese medicine.

P5: I have diabetes and my wounds are difficult to heal. The last time I fell, the wound on my arm took half a year to heal. I am afraid that my wound will not heal for a long time after the puncture and continue bleeding.

Some participants conducted internet searches, read articles or had discussions with others about the procedure. They expressed concern about the risk of intestinal leakage.

P6: I checked on the computer that a prostate puncture involves penetration through the rectum. I am

very worried about whether there will be intestinal leakage and whether I will need an enema.

Some patients also feared that the puncture could lead to tumour metastasis.

P8: If I have cancer, the prostate will be pierced during the puncture and the cancer cells will flow out and transfer to other places. I am worried that the puncture will cause tumor metastasis.

Hearing from friends about their prior negative experiences with biopsy also increased patient anxiety.

P10: My friend underwent PNB last year and had a fever after the PNB because of infection. I also saw on the Internet that hematuria may occur after the needle biopsy, so I am a little anxious now.

#### Bad results

Patients are also worried about receiving a cancer diagnosis after the PNB. Individuals associated the diagnosis of cancer with very serious outcomes, such as death or a decline in quality of life.

P7: When I heard the doctor saying it may be PC, I was almost scared to death. I have never had cancer. How long will I live if I have PC? I have had insomnia and need to take sleeping pills to fall asleep.

The fear of a negative result impacted the emotional state of patients and their families.

P12: The doctor told me that there may be cancer in my prostate. I feel very depressed and have not slept well for several days. I told my wife what the doctor said and she is very worried about me. I saw her secretly wiping tears.

One participant reported that he hesitated to undergo the PNB because he was worried about receiving a negative result.

P15: What should I do if I have PC? I don't want to undergo PNB because I am afraid that the result will not be good. It is like a knife hanging above my head.

#### Impact of LUTS

##### Emotional impact

Half of the participants said that they currently live with LUTS and nine reported a history of benign prostatic hyperplasia (BPH).

P16: I was diagnosed with BPH 6 years ago and it has seriously affected my life. I am unwilling to go out for a long time because I will urinate every 1 hour and I can't take a bus or car for a long time either. I never drink water before I go out.

P19: Whenever I go to a place, I must first find out where the toilet is. I am very eager to solve this problem. I have been suffering from these symptoms so

much. I don't know what to do and what else I will undergo afterwards.

The problems of frequent and urgent urination have negatively affected the daily activities of some patients.

P20: I used to participate in instrumental performances with my friends. I like to play Erhu. But I have frequent urination and it has affected the entire band's rehearsal process. I gave up this hobby gradually.

P22: I like to play mahjong (a traditional entertainment in China) with other older men in our community. But now, many of them are unwilling to play with me because I always urinate. I feel isolated from them because of my disease. Now I seldom go out for mahjong.

Some participants expressed a desire to have prostate surgery because of their LUTS is so debilitating.

P25: My urinary problems affect me seriously. The medicine is of no use now. I really want surgery to eliminate my problem and get rid of this nightmarish life immediately!

P19: I can't stand them (frequent urination, urgency, and hematuria) anymore! My purpose is very clear, I want to remove my prostate regardless of the presence of cancer!

### Work

Some participants stated that their work has been affected by their urinary problems.

P23: It is a habit for me to have to urinate before I have a meeting. Even so, I still want to urinate during the meeting. My urine line is thin and it takes a while before I can urinate, which affects my speech and meeting efficiency.

P26: I am a writer. I need to focus my attention when I write but my frequent urination always disrupts my train of thought. I can't concentrate on my work.

### Sleeping

In addition to affecting daily activities and work, the increasing need to urinate at night also impacted the sleep and life of patients.

P13: I always get up 5–6 times to urinate at night. I can't sleep well. Especially in winter, it is very cold. I seldom drink water before sleep, but I always have to urinate many times.

Frequent urination has even altered the biological clock of patients.

P21: I have formed a biological clock that I must wake up to urinate every hour at night. I urinate very little each time. So that I don't have to get up every hour, I bought a bedside urinal.

### Inner struggle

#### Hesitation

The interviews revealed that a percentage of patients experienced an inner struggle after being advised to receive a PNB. Some did not wish to undergo the PNB but were also worried that their abnormal PSA levels indicated that they may have cancer.

P3: At the beginning, I did not want to undergo PNB because I did not think it was necessary for me. I re-asked the doctor and other people, and they said some patients with PC have no symptoms before diagnosis. Well, I decided to have the check for confirmation.

P11: I feel nothing bad, just a blood index (PSA) is abnormal. I think it is unlikely to be cancer. I even suspected this is an overcheck.

When asked about their attitudes toward PNB, three participants said that a PNB would not be helpful for them and would involve unnecessary pain.

P14: I really don't know why I must undergo the biopsy. My symptoms are so serious and visible. Besides, I have undergone the blood test, MRI, and DRE. These were all uncomfortable for me and the results all showed that the tumor exists in my prostate. They (the doctors) can directly perform surgery on me. Why do I have to do another puncture and increase my pain?

Some participants worried that PNB may lead to the over-detection of cancer.

P17: Many elderly men were advised by doctors to do PNB, but I think it is a little over-detection and over-diagnosis. Maybe some patients who are diagnosed with PC do not actually have cancer. Who knows?

#### Regret

As a result of a lack of knowledge about PC, many men consider abnormal LUTS an 'old person's disease' (ie, a common phenomenon). Some participants expressed deep regret for not seeking advice from their doctor earlier.

P20: I always feel a little pain when I urinate but didn't pay any attention. I thought elderly men were all like this. I regret that I didn't see the doctor earlier.

P28: They (families and friends) all said it is an elderly man's disease. Many old men have these symptoms (LUTS). I didn't focus on my urination problems before and now I am so regretful.

#### Embarrassment

Some patients, particularly younger participants, felt embarrassed because of their increased PSA levels and the biopsy.

P21: It's a little embarrassing for me because I am not that old. I did not expect that I may have prostate disease at this young age. I dare not tell others about it.

P24: I feel shameful at this age to come for a PNB. Many patients who undergo this operation are older. I never talk to my friends or colleagues about it because it's too embarrassing...

### Lifestyle change

Almost half of the participants reported that they had changed their lifestyles since developing LUTS or being monitored for PC. This included increasing outdoor exercises, quitting smoking and alcohol consumption and drinking more water.

### Healthy diet or lifestyle

P9: The doctor told me it may be PC. I had already quit smoking and drinking and started eating healthy food. I don't eat spicy or fast food now.

P18: I run 5 miles every morning. I have benign prostatic hyperplasia, and I have developed good living habits now to control my disease. I am still young. I don't want cancer.

### Taking traditional Chinese medicine (TCM)

Several participants reported their experiences with taking TCM to control their disease. Many Chinese individuals trust TCM.

P24: I have seen a superior Chinese doctor who prescribed Chinese medicine for me. It is useful and I take the medicine three times a week.

One participant stated that he received suggestions from many resources, including television.

P35: I don't take Western medicine. I eat pollen. I learned from a health program on TV that it is a type of TCM and is used as a prostate medicine. It is effectively controlling my urinary disease.

## DISCUSSION

### Summary of the main study

In-depth interviews can be used to investigate the experiences, attitudes, perceptions, thoughts and feelings of patients, which may be overlooked by medical professionals. Unlike other clinical studies that have assessed the method, location and detection accuracy of PNB,<sup>20 21</sup> the present study focused on the mental health and experiences of patients prior to undergoing this procedure, providing critical insight to medical staff. Four themes were developed out of the findings: fear, impact of LUTS, inner struggle and lifestyle change. These aspects of the patient experience are important and should be considered by the clinical community because they may impact disease progression and the results of a PNB.

### Comparison with other studies

PNB is an invasive procedure involving puncture of the prostate using 10–18 needles.<sup>22</sup> Following a suspected cancer diagnosis, patients may experience shock, fear

and anxiety, which affect their response to treatment and quality of life.<sup>23 24</sup> Fear was the most common feeling reported in this study. Almost all participants expressed a fear of pain, bleeding, infection and negative results. Discomfort during DRE, false-positive test results, unnecessary biopsies and/or adverse effects from potentially unnecessary treatment are common causes of anxiety among patients.<sup>25</sup> Patients also experienced an inner struggle with the idea of undergoing a PNB. While many patients were hesitant about the procedure because of a fear of pain and adverse effects, they were disturbed by their abnormal PSA index and the possibility that they may have PC. Research conducted in Japan revealed that the psychological state of patients may be influenced by fluctuations and elevations in PSA levels that they experience while waiting to have a prostate biopsy.<sup>26</sup> Embarrassment is another factor that influences patient willingness to receive a PNB,<sup>27</sup> particularly among younger patients. Some participants in this study thought that it was not necessary to receive a PNB because they did not have symptoms and had previously received an MRI and DRE. Previous research has shown that most patients visit the hospital for medical care for different urologic symptoms.<sup>9</sup> Half the participants in this study discussed how their abnormal urinary problems had markedly affected their daily life, work and sleep. LUTS are common clinical manifestations in patients with BPH and impact quality of life,<sup>28</sup> a finding also common for patients with PC or prostatitis and urinary infection.<sup>29</sup> However, because of a lack of understanding about prostate disease, including PC, BPH and prostatitis, some patients assume that urinary symptoms are the symptoms of an 'older men's disease'. This misconception may reduce patient willingness to seek medical attention, potentially causing them to miss the optimal stage for treatment.

### Insights and suggestions

It is common for individuals to feel disturbed and frightened when facing an unknown medical procedure. Insufficient information about the procedure and the invasive nature of biopsy may increase fear and anxiety, while ignorance and misconceptions can compromise timely medical management. The present study found that participants with a higher level of knowledge about PNB had lower levels of fear or anxiety prior to biopsy. This could be explained by increased medical knowledge, as well as familiarity with and trust in medical technology. These emotions can increase the feeling of pain and negatively impact the PNB procedure.<sup>11</sup> Thus, it is important to take measures to reduce patient anxiety and fear. Evidence from other studies indicates that appropriately educating patients may influence their decision about whether to take a PSA test or undergo a biopsy.<sup>30</sup> It is necessary to provide details, including the impacts, potential risks and limitations of PNB to patients prior to the procedure. In general, patients are in need of reliable information about disease.<sup>31</sup> Most participants in this study indicated that they were less nervous after receiving

education about PNB from their nurses. These findings suggest that health authorities should provide more information about prostate disease and symptoms for the general public, particularly older men. Medical professionals should support the dissemination of medical information and encourage individuals to face the disease positively, participate in cancer screening examinations and perform a self-assessment of symptoms. The public should be encouraged to maintain a healthy lifestyle and promptly seek medical advice to prevent and effectively treat disease, respectively. Furthermore, we assumed that if there have a technique like patients said: 'why can't I do the surgery directly without PNB because there had PSA, DRE and MRI?' The use of artificial intelligence in medicine has greatly expanded.<sup>32</sup> Indeed, more exploration into methods for reaching precise diagnoses without a PNB will help to relieve patient anxiety and suffering.

### Strengths and limitations of this study

This study focused on the feelings of patients with suspected PC prior to receiving a PNB. In-depth interviews were used to explore patient perspectives and experiences. All participants in this study were Chinese men. China is a non-English-speaking country and although an experienced translator was employed to translate the interview responses, there were some languages or meaning nuances that may have been missed. In addition, participants were only recruited from one hospital. Hospitals may have varied methods and preparation procedures that lead to different patient experiences. In addition, while the data and themes were repeatedly read and discussed, this method of data analysis was not objective because no professional text analysis was used. A multicenter study with a larger sample size is warranted to further investigate the psychological state of patients before undergoing PNB. Moreover, quantitative analysis should be conducted to reliably assess the psychology and emotional state of patients.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by the by the First Affiliated Hospital, School of Medicine, Zhejiang University (approved no. 2018-7077) ethics committee and certify that the study was performed in

accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** No data are available. No additional data are available.

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### ORCID iDs

Jinjiao Mao <http://orcid.org/0000-0001-7836-2974>

Shucheng Pan <http://orcid.org/0000-0002-4386-3768>

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