*Sexual Medicine*, 2024, **12**, qfae019
https://doi.org/10.1093/sexmed/qfae019
**Original Research**

# Sexual experiences and information needs among patients with prostate cancer: a qualitative study

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## Abstract

**Background:** Less is known about the sexual life and information seeking of Chinese patients with prostate cancer (PCa) after androgen deprivation therapy (ADT) treatment.
**Aim:** To identify the experiences of sex and information needs among Chinese patients with PCa after ADT treatment.
**Methods:** This qualitative study included 15 Chinese patients with PCa in urology inpatient wards, selected via a purposive sampling method. Semistructured interviews were conducted face-to-face or by telephone regarding sexual experiences and information needs after ADT treatment.
**Outcomes:** Themes and subthemes were assessed among patients with PCa.
**Results:** Two themes and 5 subthemes emerged from the interview data. The first theme was "altered sexual life and attitude" with 3 subthemes: (1) undesirable sexual function and altered sexuality, (2) sexual attitudes and sociocultural cognition, and (3) behavior adjustment and intimacy. The second theme was "scarce information sources" with 2 subthemes: (1) uncertainty and lack of information support and (2) barriers to access sexual information.
**Clinical Implications:** The present findings suggest that the following may help patients with PCa manage treatment and develop appropriate sexual attitudes: a tailored sexual health education program, well-equipped consultations rooms, and information delivery innovations.
**Strengths and Limitations:** Strengths of this study included adding unique evidence among patients with PCa within an Asian context to reveal the understudied topic of sexual health and information needs after ADT treatment. This study was limited in being representative of all Chinese patients with PCa, with different marital statuses, treatment therapies, sexual orientations, and barriers of information seeking.
**Conclusion:** Sexual life and attitude among patients with PCa were affected by their sociocultural cognition and ADT treatment, and most patients received insufficient information and sexual health education from health care providers.

**Keywords:** prostate cancer; sexual experiences; information seeking; Chinese.

## Introduction

Worldwide trends in prostate cancer (PCa) incidence have increased, which made it the second-most common malignancy in 2020.[1] Even though PCa incidence in Asia is the lowest around the world at 6.3%,[1] it has been growing rapidly in China. Estimated newly diagnosed PCa cases rose from 60 300 in 2015 to 115 427 in 2020.[2,3] Despite the fact that the development of PCa treatment had a positive effect on PCa survivorship, nearly 70% of cases at the time of diagnosis were locally advanced or metastatic owing to the low rate of antigen screening in China.[4] Androgen deprivation therapy (ADT) is an essential and promising approach to treatment for patients with intermediate- to high-volume metastatic hormone-sensitive PCa or as a combined therapy for radiotherapy, as well as adjuvant therapy after radical prostatectomy.[5] ADT serves as a widely used treatment for patients with PCa in clinics, whereas the treatment can give rise to a series of side effects, such as sexual dysfunction, loss of desire, and reduced masculinity.[6,7] These sexual problems adversely affect not only patients but also their intimate partners.[8-10] Toward these adverse aspects, supportive care is emerging not only in body health indication but also in sexual health and psycho-oncology. It is imperative to explore the current situation of sexuality and care needs for patients with PCa and ADT treatment.

Sexual issues with ADT treatment have been well depicted in rich literature. As shown in research, ≤20% patients with PCa kept some degree of libido and sexual function after long-term continuous ADT treatment.[11] With the sequelae of treatment, erectile dysfunction (ED) was frequently reported, and most of the men with an active sexual life and good sexual function before diagnosis and ADT treatment experienced the inability to maintain erection functions and sexual intercourse after treatment by 3 and 5 years.[12,13] Furthermore, these sexual difficulties harmed their masculinity and enhanced their psychological distress, which gave rise to the loss of self-confidence, a diminished link to society, and low physical activity.[14-16] Some studies pointed out the significance of educational support, physical activity, and penile rehabilitation for adjusting sexual dysfunction among patients with ADT treatment,[17-19] but how Chinese patients with PCa cope with these issues has not been explored yet.

Evidence revealed that approximately one-third of survivors of PCa were still interested in sex despite the declined

**Received:** September 14, 2023. **Revised:** February 20, 2024. **Accepted:** March 8, 2024

sexual function.[20] Based on the available evidence regarding the management of sexual dysfunction, enhanced communication—including spousal communication and communication with health care practitioners (HCPs) or sexual specialists—assists patients in getting information and support and improving their sexual well-being.[8,21] Nonetheless, it is not easy for Chinese to open their minds to talk about sex, as sexual life has been private and taboo given the deeply rooted traditional thinking and cultural background, which disrupt the communication between patients with PCa and HCPs.[22] This barrier poses restrictions on information delivery between patients and HCPs with professional sexology knowledge. Moreover, many primary care practitioners knew less about the information needs of patients with PCa and the side effects of ADT treatment (ED, loss of libido, and hot flashes) due to the lack of communication, thereby neglecting sexual education for patients.[23] Thus, it is urgent to know the information needs of patients with PCa with ADT treatment and to develop more ways to break communication barriers.

Utility tools for help and information seeking are various. One qualitative study investigated that tailored supportive care can be delivered by the internet,[24] but little is known about how Chinese patients find information to fulfill their needs. Meanwhile, none of the studies identified how Chinese patients with PCa tackle sexual and intimacy changes. Hence, on one hand, this article aims to investigate the sexual health status and altered intimacy in survivors of PCa. On the other, it intends to explore the experiences of coping with the alternations and information seeking from the perspective of patients with PCa, which can shed light on sexual education, change the awareness of HCPs, and lay a foundation for subsequent posttreatment management.

## Methods

### Design

This study applied an interpretive phenomenologic qualitative approach based on the philosophical tenets of postpositivists and constructivists.[25] This approach allows investigators to deeply understand the subjective perception of humans in various contexts,[25] thereby improving sexual education and providing guidance for clinical practices. No ethical approval was obtained, for the current study was nonintervention and without any harm. All participants signed the informed consent before the study, and 2 researchers set different passwords to keep the personal data confidential. The COREQ guidelines (consolidated criteria for reporting qualitative research) were followed to report the research findings[26] (Appendix 1).

### Participants and settings

Eligible participants were recruited from 3 urology inpatient units in Henan Provincial People's Hospital, Zhengzhou, China. Men were included in the research from the patient information system if they (1) were diagnosed with PCa and had received ADT treatment for >3 months, (2) were ≥18 years old, (3) were able to listen and speak Mandarin, (4) had a regular partner, and (5) were able to sign the informed consent. In contrast, participants with cognitive impairment and >1 type of cancer were excluded. Study recruitment was accomplished between January 2022 and August 2022. An adequate sample size in the study was adopted by a purposive sampling method and the model of "information power," which gained sufficient information based on the narrow aim of the study, including dense specificity, quality of dialogue, and analysis strategies.[27]

### Procedures

The researcher (Z.H.N.) was a urology nurse who had a master's degree and had received training in interview skills in qualitative research. A urologic nursing specialist (Z.X.L.) with 30 years of working experience introduced the informed consent and conducted a rapport conversation with potential participants before formal interviews. Once the eligible patients agreed to attend the interviews, the researcher (Z.H.N.) obtained the signed informed consent and collected the demographic and clinical data of the participants. Most were patients who went through reexamination regularly in urology inpatient units; thus, the face-to-face formal interviews individually took place in the physician-patient communication chat room with no one else present. Additionally, some of the participants accepted an interview by telephone following their preference.

A semistructured interview guide was applied to encourage a deeper exploration of participants. The outline of the interview was based on a review of literature and experiences from a urologic nursing specialist, a sexologist, and a professional urologist. To ensure the sensitively of the questions, before the formal interview, we found staff who were not involved in the study and conducted a mock interview. The main questions of the interviews were as follows: What has changed in your sexual life after ADT treatment? How would you describe the impact of treatment on the intimate relationship between you and your partner? Would you mind talking about how you cope with those changes? How did you obtain the information of PCa and ADT treatment? The question sequence was alterable and flexible depending on the responses from participants. The interview processes were recorded for deidentification in data analysis.

### Data analysis

Data analysis and collection began with the first interview. After each participant finished the interview, the recorded audio would be transcribed to simplified Chinese verbatim. Then, the transcripts would be analyzed according to the following steps: (1) reading the transcript several times to gain a sense of the whole, (2) writing the synopsis of each interview, (3) using NVivo software (version 12) for analysis and making initial coding decisions (Z.H.N. and Z.X.L.), and (4) comparing and contrasting the codes and converting them into themes and subthemes. Subsequently, a group-level discussion was conducted, and a consensus on coding decisions was reached among all authors. Quotes reflecting code themes were translated into English by the first author (Z.H.N.) while the coauthors were responsible for proofreading. Data analysis and data collection were carried out concurrently.

### Trustworthiness and rigor

The study followed the strategies of prolonged engagement, triangulation, and audit trail to guarantee trustworthiness and rigor.[28,29] To address the issue of credibility, a urologic nursing specialist (Z.X.L.) who was familiar with most of the participants (reexamination patients) communicated with them before the interview to gain trust, and a researcher (Z.H.N.) gave an overview summary to confirm the findings after each interview. Furthermore, credibility was established

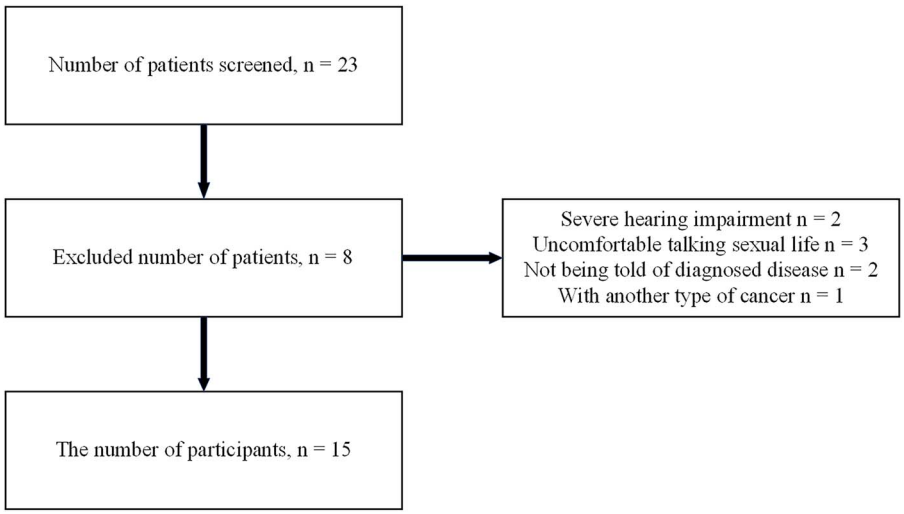


**Figure 1.** Participant screening flowchart.

through investigator triangulation, where 2 authors (Z.H.N. and Z.X.L.) conducted coding and analysis, and all authors participated in making interpretation decisions.

Dependability and confirmability, which can guarantee the stability of findings and the extent to which other researchers agree with findings, were achieved by audit trail. The research steps were described transparently from the beginning of the study, while notes of research group discussions and records of the research paths were kept throughout the study.

## Results

In total 31 patients were approached and examined, and 15 were included as described by the flowchart (Figure 1). Their mean age was 71.8 years. All were married and had received ADT treatment within the most recent 2 years. The mean length of diagnosis was 3.14 years (range, 0.58-15), and the mean time of ADT treatment was 0.94 years (range, 4 months–2 years). The average most recent total prostate-specific antigen result among all participants was 25.23 ng/mL, with the lowest index at 0.17 ng/mL and the highest at 178.22 ng/mL. The Gleason scores of participants ranged from 6 to 9, and the median score was 7.0 (Table 1).

Interviews lasted 31 to 107 minutes (mean, 62.5), and patients' experiences were reflected in 2 main themes: "altered sexual life and attitude" and "scarce information sources." Five subthemes were also extracted: undesirable sexual function and altered sexuality, sexual attitudes and socialcultural cognition, behavior adjustment and intimacy, uncertainty and lack of information support, and barriers to access sexual information (Figure 2). In the quoted interviews that follow, participant number, age, and length of diagnosis are provided in parentheses.

**Table 1.** Participants' characteristics ($N = 15$).

| Variable | Median (IQR) | No. (%) |
|---|---|---|
| Age, y | 73 (12) | |
| Date of diagnosis, y | 1.25 (3.17) | |
| Years of ADT treatment time | 0.9 (1) | |
| Marital status: married | | 15 (100) |
| Education level | | |
| Primary school or lower | | 8 (53) |
| Middle school | | 3 (20) |
| Diploma or higher | | 4 (27) |
| TPSA, ng/dL (most recent) | 2.8 (12.99) | |
| Gleason scores | 7.0 (2) | |
| Grade group 1: ≤6 | | 6 (40.0) |
| Grade group 2: 7 (3 + 4) | | 1 (6.7) |
| Grade group 3: 7 (4 + 3) | | 3 (20) |
| Grade group 4: 8 | | 4 (26.6) |
| Grade group 5: 9-10 | | 1 (6.7) |

Abbreviations: ADT, androgen deprivation therapy; TPSA, total prostate-specific antigen.

## Themes

### *Altered sexual life and attitude*

*Undesirable sexual function and altered sexuality.*

Undesirable sexual function and altered sexuality appeared in patients with PCa who received ADT treatment, particularly in their sexual characteristics and sexual life. All men reported a series of negative changes in their sexual function and body image after treatment, such as the loss of sexual desire, ED, the inability to ejaculate and achieve orgasm, testicular shrinkage, and thickening of the breast. The decrescent erectile function of the penis and the inability to ejaculate were reported the most, which drastically impeded sexual intercourse.

> I am old, it [the erectile function] is not as functional as it was when I was young. ... The ability of that [erection] has gone away after ADT treatment, and we [the participant and his wife] haven't had sex after treatment. (No. 1, 73 years old, 1 year)

> I have received ADT treatment for several years, and it [penis] can erect very rarely . . . a few times. In the first few years of my treatment, I tried to have sex, but I could not finish it [ejaculation]. (No. 3, 67 years old, 15 years)

As considered by some participants, an inactive sexual life resulted from the subsequent manifestation of ADT treatment on their deteriorative body image and masculinity, which exerted a negative impact on the continuity of sexual intercourse.

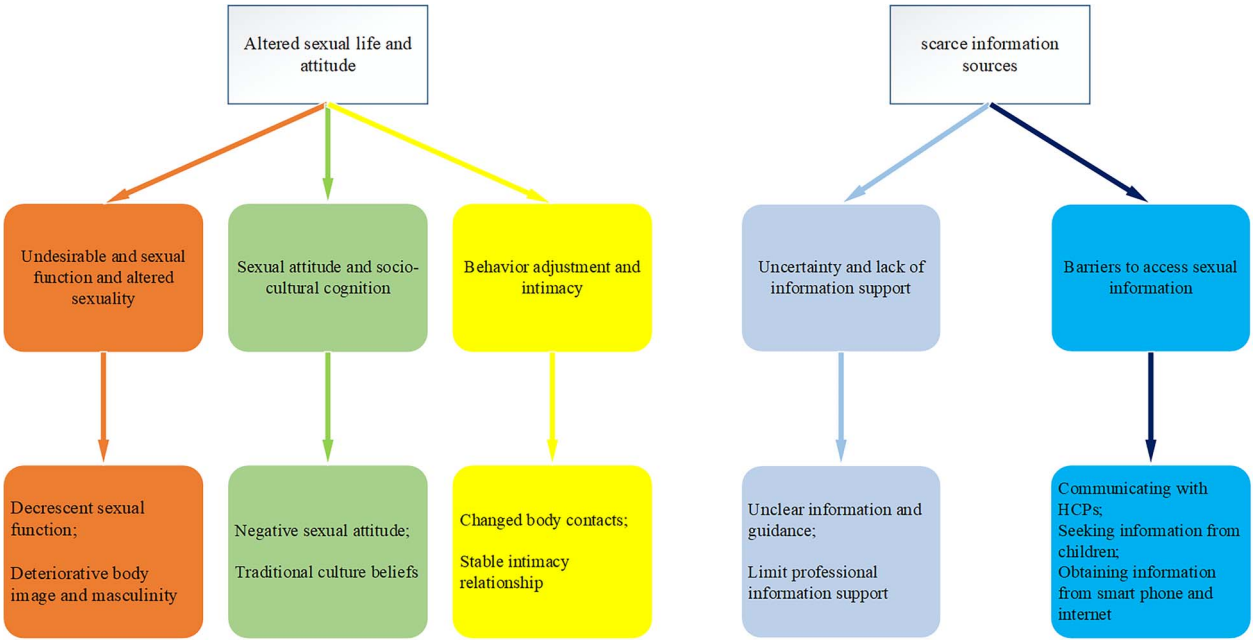


**Figure 2.** Themes and subthemes of this study.

> I measured my testicles, and they are much smaller than before . . . they seem like 2 peanuts. My breast is getting bigger. I think I am not a man and I was castrated. (No. 4, 79 years old, 8 months)

> I feel like I am not as strong as I used to be, and I am always sweating and feeling the asthenia. I can't feel any libido. (No. 8, 86 years old, 1 year)

> To be honest, my androgen is controlled very well and even lower than that in women's bodies. How are we [the participant and his wife] supposed to have that [sex]? (No. 11, 63 years old, 15 months)

On the contrary, despite the negative effects on sexual conditions, most participants reported a peaceful mind and accepted those changes as their cancer cells were controlled by ADT treatment.

> I am in a stable condition now, and it doesn't matter if it [sexual function] is gone away, I can accept it. (No. 2, 88 years old, 8 years)

> I hope I can be cured, so I don't care if it [sexual function] still exists. (No. 7, 63 years old, 10 months)

*Sexual attitudes and sociocultural cognition.*

Sexual attitudes were influenced by social and cultural cognition, and most participants expressed negative opinions when they were asked whether they could have sex. They considered it harmful to have sexual love making after ADT treatment and assumed that sexual desire and libido would stimulate androgen secretion.

> I don't think I can have that [sex], it is forbidden. The androgen will be improved if I have sex with my wife. (No. 7, 63 years old, 10 months)

> No. No, I can't do that [have sex]. It is harmful. You can't do this if you want to keep your life. (No. 6, 73 years old, 7 years)

> Harmony must be changed if I do that [have sex] or have desire of sex, I have a firm goal of being cured. . . . I can't do that. (No. 2, 88 years old, 8 years)

Several participants represented their sexual attitudes deferring to their cultural cognition, which is implicit but gives them support. At the meantime, these beliefs prevented them from having a sexual life.

> I read Yijing [Chinese Philosophy of Change]. It tells me that if I want to keep the balance of Yin and Yang in my body, no desire is better . . . so I give up doing it [the sexual intercourse] now. (No. 7, 63 years old, 10 months)

> I have been practicing Qigong [a mind-body exercise form] for many years. Every morning I practice it in the park and it is indeed helpful to my mental and physical health. Practicing Qigong requires calm and no desire in mind. It is irrelevant and not need at all for those Qigong masters to . . . to have sex with women. (No. 3, 67 years old, 15 years)

Medication and tools, which help erection and ejaculation, were rejected by most participants. Only 1 participant showed hesitation of sexual love making and would like to find a helpful tool.

> I am not sure if I could have sex with my wife. . . . My results of blood were pretty good these times. . . . Actually, I am a bit of afraid of that [having sex]. If my wife requested that [the sexual life] I would like to use tools. (No. 5, 52 years old, 2 years)

*Behavior adjustment and intimacy.*

Behaviors changed but intimacy was more stable. Given the negative sexual attitude, several participants changed their life patterns to decrease body contact with their wives to avoid their libidos. Some even decided to sleep in separate beds or in other bedrooms without their wives.

> We don't sleep together now. . . . I still make dreams of sex sometimes, and I think it is inevitable to touch my wife at night. It is not helpful to my recovery. (No. 2, 88 years old, 8 years)

> We sleep separately after ADT treatment, I still have thoughts . . . [of having sex], but I am a husband and a father, I need to control myself. (No. 15, 68 years old, 8 months)

Regarding intimate relationships, almost all participants possessed solid emotional foundations and had stable relationships with their wives. Those participants reported a close intimacy after treatment, even if without a sexual life.

> We have married for about 60 years. We trust and accompany each other and it is more important than sexual life. My wife gave me support and encouraged me to fight against cancer. (No. 13, 79 years old, 4 years)

> We have always been a close intimacy. The most important thing is that she stays with me and accompanies with me. (No. 14, 71, 15 months)

Only 1 participant disclosed the alternative intimacy, which was affected by marriage.

> She is my second wife. When I was diagnosed, she started getting agitated. Maybe she was worried about money. We never walked hand in hand. (No. 9, 75 years old, 21 months)

***Scarce information sources***

*Uncertainty and lack of information support.*

In the interviews, uncertainty originated from a lack of information supports, which gave patients unclear guidance and perplexed them. Although all participants reported that they had received information of ADT treatment options and plans, few had gotten guidance of a sexual life. The participants attributed their uncertainty about having sex to multiple factors, with the limited professional information support from HCPs being the major cause.

> The plan of ADT treatment was introduced by my doctors, but nobody told me whether I could have that [sex] or not. I am not sure. (No. 5, 52 years old, 2 years)

> My doctor told me it [the sexual dysfunction] was normal after treatment. He didn't say anything of whether I could have that [sex]. (No. 14, 71 years old, 15 months)

> I found it [the sexual dysfunction] by myself. Doctors and nurses didn't say anything. (No. 4, 79 years old, 8 months)

However, some patients with PCa thought that, because treatment of disease was priority, HCPs did not normally initiate communications about sexual issues.

> It would be nice if they [HCPs] give the information about that [sexual guidance], but I think I'm more focused on be cured. (No. 2, 88 years old, 8 years)

*Barriers to access sexual information.*

Barriers to access sexual health information after ADT treatment were identified. Patients with PCa obtained sexual information limited by the cultural background, the inability to use a smartphone, and health service factors. Talking about sex openly and directly is taboo in Chinese culture. Some patients with PCa indicated that they would not ask HCPs about sexual issues on their own initiative because it was embarrassing and inappropriate.

> I heard somebody said that having sex is harmful to cancer patients. I wanted to ask doctors, but there were always so many people in their office. How could I raise questions of that openly? (No. 12, 68 years old, 2 years)

> Uh . . . I would not ask them [HCPs]. It is a little bit indecent. (No. 7, 63 years old, 10 months)

Only 3 participants could use a smartphone to communicate with others and search for information. Exchanging treatment experiences and side effects with patients with PCa via an online chat group or through applications not only spread information but also helped them gain confidence. But sexuality information exchanges were infrequent.

> I set up a chat group within the members of PCa. We shared our experiences and thoughts. Some members of group spoke highly of the ADT treatment. . . . Uh . . . they advised me not to have sex. They said it is harmful. (No. 3, 67 years old, 15 years)

> I entered a chat group. Every week, there are 2 to 3 public lectures links in group. I got a lot of information from those lectures . . . including a little of this [sexual information]. (No. 4, 79 years old, 8 months)

> I followed a radio station in my phone. This application collected anticancer stars to share their experiences. Their experiences encouraged me. . . . This aspect [sexual health] was not mentioned. (No. 1, 73 years old, 1 year)

Health service was mentioned by some patients as well.

> It is difficult to communicate with doctors, they are too busy and have little time to talk with me. (No. 10, 73 years old, 7 months)

> Actually, give a QR scan code is good. Patients can scan and read that [information about sexual issues] by themselves. (No. 3, 67 years old, 15 years)

## Discussion

In this study, Chinese patients with PCa were surveyed regarding their experiences of sexual life and seeking sexual information after ADT treatment. According to the respondents and their disclosure, some key findings were identified. For the theme of altered sexual life and attitude, the comparison of this research's findings and similar studies in different cultural contexts has been discussed. In terms of the theme of scarce information sources, the findings highlighted the quality and efficiency of communication between patients

and HCPs, and the significance of information acquisition pathways indicated that it is imperative to innovate the tools and ways of information delivery.

Chinese men with PCa experienced altered sexuality and undesirable sexual function, including ED, loss of sexual desire, changed body image, and decreased masculinity. Similarly, a qualitative study in Chinese patients with PCa showed that most men experienced ED in the posttreatment phase.[30] In addition, sexual dysfunction and body change associated with ADT treatment were depicted by Hayashi et al among Japanese men.[31] Moreover, consistent with studies in Western countries, this study reported the similar experiences of adverse effects on sexual function following ADT treatment.[13,21] However, different from the Western cultural contexts, the findings may reflect the unique sexual attitudes and coping styles based on a traditional Chinese cultural background. In this study, it is priority to preserve health, and decreased sexual function is not so critical for men with PCa. In traditional Confucian cultural society, men are empowered with more responsibility, and they have a duty to carry on the family lineage rather than get pleasure from a sexual life.[32] Furthermore, forgetfulness and weakness were attributed to loss of semen by the folk belief that the kidney is the source of the semen and the essence of the energy (Qi) in one's body,[33] and this traditional thinking plays a critical role in men's sexual attitudes after ADT treatment and hinders them to have a sexual intercourse. In this study, we also found that patients with PCa who mentioned specific Chinese cultural forms of Yijing (a Chinese traditional philosophy) and Qigong (a mental and physical exercise developed from Taoism) chose a conservative attitude by avoiding sex with their partners to cope with the sexual dysfunction. These 2 traditional cultural forms are profound and were proven to be a benefit in mental and physical health.[34,35]

In contrast to a previous study that found that bad sex strained intimate relationships in Chinese couples,[2] the majority of the participants in this study underscored that PCa and ADT treatment had little influence on intimate relationships with their partners. A similar finding was discovered in a group of Chinese women with gynecologic cancer who maintained quality marital relationships with their partners after diagnosis.[36] In contrast to many findings in Western cultural contexts, it could be that intimacy in Chinese older couples is not mainly expressed by sexual intercourse or intimate behaviors (hand in hand, kiss and hug) but tends to be manifested in duty and obligation to support and accompany based on a Confucian ideal.[3]

Communicating with HCPs and acquiring individualized information was frequently reported, which is in line with a study among PCa groups in other countries and a study in women with breast cancer.[37,38] However, HCPs did not provide helpful support to patients' sexual information needs and effective solutions to their sexual issues. The gap between sexual information provided and needed may be due to the lack of consultations and health education,[39] as well as the influence of Chinese cultural traditions. Limited time for conversations due to the heavy workload of HCPs and an absence of awareness in sexual health education may stop information acquisition among patients with PCa, as documented in a previous study.[40] Moreover, patients with PCa prioritized their health over sexual issues, resulting in sexual information support and sexual health education being ignored by HCPs, which also discouraged HCPs from giving patients sexual information. In addition, from a Chinese traditional perspective, it is difficult for HCPs and patients to initiate a topic about sexual health, as discussing sexual issues is a taboo.[22]

## Clinical implications

This study revealed the experiences of patients with PCa and calls for a series of changes to adapt to the needs of patients in clinics. Based on Chinese culture and integration of the mode in Western countries, well-equipped consultation rooms with one-to-one conversation services are effective in initiating private topics, such as sexual education and indications.[39] Interventions to empower the knowledge of HCPs, including the provision of training courses, health education, referrals and guidelines, are crucial in tackling sexual health issues.[24] Encouraging HCPs to initiate the topic of sexual issues in health education proactively is also important; it makes patients think that sexuality is discussable and that talking about sexual problems is normal. Oncosexology care delivered by staff who are specialists in oncology and sex plays a great part in the treatment and sexual adjustment of patients with PCa, which may help reduce their uncertainty in having sex after treatment.[41] Furthermore, there is a prominent need of new reliable information pathways. Internet platforms built by official units, such as hospitals or health associations, that provide continuity information and close contact in patients and HCPs may be efficient in improving PCa screening and giving multidimensional information in the prediagnosis, treatment, and posttreatment phases.[42-44]

## Limitations

There are limitations in this study that must be noted in interpretation of the results. First, the small sample size may be due to the inclusion criteria, which restrict the generalizations of findings. Second, this study was conducted on a group of patients with PCa who were heterosexual and maintained stable marriages with their partners. Thus, the results are limited in presenting patients with a different sexual orientation and marital status (unmarried or widowed) and their barriers of information seeking. Third, even though stable intimate relationships were reported in this study, the results were not measured in a large group, which may not be applicable to groups facing challenges of intimacy. Finally, our study is limited in interpreting the needs and information seeking of patients with PCa and ADT treatment in the prediagnosis and diagnostic stages.

## Conclusion

In this study, we examined the sexual experiences of Chinese men with PCa and ADT treatment and revealed the unmet information needs of patients. The perspective of patients with PCa and their experiences will help give insights into sexual education, change the awareness of the lack of knowledge among HCPs, and lay a foundation for posttreatment management. Additionally, it highlighted that information support and tools are urgently needed for patients with PCa.

## Acknowledgments

We express our appreciation of all participants and staff from the urology department for their great support in this research.

## Funding

The study received no external funding.

## Conflicts of interest

None declared.

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