



Social ecological influences on treatment decision-making in men diagnosed with low risk, localised prostate cancer

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Abstract

Objective: Individuals diagnosed with low risk, localised prostate cancer (PCa) face a difficult decision between active surveillance (AS) and definitive treatment. We aimed to explore perceived influences on treatment decision-making from the patient and partner's perspectives.

Methods: Patients (and partners) who met AS criteria and had chosen their treatment were recruited. Semi-structured individual interviews were conducted via telephone to explore experiences of diagnosis, impact on patient lifestyle, experiences with physicians, treatment preferences/choice, treatment information understanding and needs, and overall decision-making process. Interviews were audio recorded, transcribed verbatim, and analysed using Reflexive Thematic Analysis.

Results: Twenty-four male patients (18 chose AS) and 12 female partners participated. Five themes relating to social-ecological influences on treatment choice were identified: (1) partner support and direct influence on patient treatment choice, (2) patient and partner vicarious experiences may influence treatment decisions, (3) the influence of the patient's life circumstances, (4) disclosing to wider social networks: friends, family, and co-workers, and (5) the importance of a good relationship and experience with physicians. Additionally, two themes were identified relating to information patients and partners received about the treatment options during their decision-making process.

Conclusions: A range of individual and social influences on treatment decision-making were reported. Physicians providing treatment recommendations should consider and

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discuss the patient and partner's existing beliefs and treatment preferences and encourage shared decision-making. Further research on treatment decision-making of partnered and non-partnered PCa patients is required. We recommend research considers social ecological factors across the personal, interpersonal, community, and policy levels.

KEYWORDS

active surveillance, decision-making, prostate cancer, qualitative research, supportive care, treatment decision-making

1 | INTRODUCTION

Prostate cancer (PCa) is one of the most commonly diagnosed cancers in men worldwide (Sung et al., 2021). The majority of patients are diagnosed early with low to intermediate risk PCa, with a low risk of metastases and PCa-specific mortality (Albertsen, 2015). In 2017, the American Urological Association (AUA) (Sanda et al., 2018) recommended that individuals diagnosed with very low or low risk PCa (localised to prostate, PSA < 10, Gleason score ≤ 6) be treated with active surveillance (AS). AS involves regular monitoring of the cancer (through PSA testing and biopsies) to detect progression. However, as there is currently no widespread consensus on the most effective frequency for monitoring procedures nor triggers for definitive treatment, management is often at the discretion of treating physicians (Bruinsma et al., 2016; Kinsella, Helleman, et al., 2018). Definitive treatments with curative intent, such as prostatectomy or radiation, may also be appropriate for low-risk patients depending on patient preference and clinical factors (Sanda et al., 2018). However, definitive treatments can cause varying degrees of significant, potentially long-lasting physical side-effects including erectile dysfunction and incontinence (Hamdy et al., 2016). AS therefore allows patients to delay or avoid definitive treatments and their associated side-effects until clinically necessary (Chen et al., 2016). The lack of both clear treatment recommendations and clarity regarding expected outcomes from different treatments can result in a more difficult and distressing treatment decision-making process for patients (Owens et al., 2019).

A variety of factors have been found to influence patients' decisions on which treatment to undergo and when (Kinsella, Stattin, et al., 2018). Both quantitative research and qualitative research suggest patient treatment decisions are prominently influenced by their physician's recommendations (Brooks et al., 2018; Feldman-Stewart et al., 2011; Kinsella, Stattin, et al., 2018). Research has also explored the role of romantic partners in the decision-making process, given they often attend clinical appointments with the patient and assist in treatment decision-making (Zeliadt et al., 2011). Emerging evidence suggests partners also experience anxiety related to their partners PCa and potential outcomes and tend to favour definitive treatments over AS (Couper et al., 2006; Srirangam et al., 2003). However, prior qualitative research has often interviewed couples together (which may preclude participants from sharing information), and therefore, their individual experiences, treatment preferences, and needs require further research (Stewart et al., 2021). There is also emerging

evidence that patients may be influenced by opinions beyond their partner's when making treatment decisions (Berry et al., 2003). For example, one study comparing the use of online versus face-to-face support groups in PCa survivors found that men participating in online support groups were more likely to use peer support for treatment decision-making and more often revised their treatment choice after consulting their support group (Huber et al., 2018). Another study reported that patients who involved close allies (i.e., friends or family in who the patient confides and whose opinion the patient considers important) in the decision-making process were more likely to choose definitive treatment over AS (Reamer et al., 2017). However, much of this research reflects treatment preferences and decision-making experiences prior to the 2017 AUA recommendations. Gaining an updated understanding of the range of influences on treatment decision-making now, with AS a more common and recommended option (Sanda et al., 2017), is important for informing development of effective decision-making support strategies for physicians to utilise with patients and their partners/close allies. Contextualising these factors through the lens of a theoretical model which extends beyond the individual and social levels, such as the social-ecological model (SEM), may be beneficial (Bronfenbrenner, 1979). The SEM proposes individual behaviour, and decision-making is influenced by the interaction of personal, interpersonal, community, and policy/society levels and is commonly used in cancer research (Beesley et al., 2008; McIntosh et al., 2019; Mitchell, 2011; Woods et al., 2006).

The present study used separate interviews with patients and their partners/close allies to explore the range of perceived social-ecological influences on treatment decision-making and examine decision-making processes after a low risk PCa diagnosis.

2 | METHODS

2.1 | Study design

This qualitative study was part of a mixed methods investigation into decision-making by patients with low risk PCa and their partners/close allies. Patients were recruited from the urology clinic at Memorial Sloan Cancer Center (MSK), a private cancer hospital in New York, USA. The quantitative part of the study used patient-reported outcomes to investigate decision-making pre- and post-treatment decision by patients diagnosed with low risk PCa who met criteria for AS

and their partners or close allies. The results from the quantitative part will be reported elsewhere (manuscript in preparation). The present study is the qualitative part of the mixed methods study, comprising semi-structured interviews with a subset of participants after their treatment decision had been made. This study followed COREQ criteria for qualitative research (Tong et al., 2007). See supporting information for checklist. The larger mixed methods study received ethics approval from the Memorial Sloan Kettering Cancer Center (MSK; 13-076).

2.2 | Participants

To be eligible to participate in the present study, patients and partners/close allies needed to have participated in the first part of the study and have made and disclosed their treatment decision to study staff. Partners/close allies could participate in the interviews regardless of patient involvement in this study. Patient inclusion criteria for the first part of the study included meeting eligibility criteria for AS at Memorial Sloan Cancer Center (MSK) (Gleason score of ≤ 6 or clinical stage $\leq T1c$; and PSA level < 10 ng/ml; and biopsy indicated < 3 positive cores with $\leq 50\%$ cancer in each core; or documented physician discussion of AS as a treatment option), English proficiency, aged 18+ years, no history of other cancers (except for non-melanoma skin cancer), and no significant psychiatric or cognitive disturbance (as assessed by chart review) that would preclude providing informed consent or participation. Partners/close allies were eligible if they were viewed by the participating patient as being their partner/close ally, proficient in English, and aged 18+ years.

2.3 | Procedure

Participants were invited to participate in an interview once the patient had disclosed their treatment choice study staff. The first 102 participants in the main study ($N = 66$ patients and $N = 36$ partners/close allies) who disclosed their treatment choice were invited to participate in qualitative interviews. In total, 33 patients and 15 partners agreed to participate and were interviewed. No close allies participated. Nine patients and three partners were found ineligible for AS during interviews and analysis and were therefore eliminated from the study. All interviews occurred via telephone and were audio-recorded and transcribed verbatim. Transcribed interviews were not returned to participants for comment/correction. Interviews were semi-structured and aimed to explore experiences of diagnosis, impact on patient lifestyle, experiences with physicians, treatment preferences/choice, treatment information understanding and needs, and overall decision-making process (see supporting information for interview guides). Interviewers also kept field notes during interviews. All participants were interviewed once by a female research staff member ($N = 4$, all with bachelor/master's degrees in related fields) who had prior interview experience or had received training. Interviewers had no prior relationship with the

TABLE 1 Participant demographics

	Patients (n = 24)	Partners (n = 12)
Age: Mean (SD)	59.6 (6.2) years	59.9 (5.5) years
Treatment choice: % (N)		
Active surveillance	75.0% (18)	66.7% (8) ^a
Prostatectomy	20.8% (5)	8.3% (1) ^a
Cryotherapy	4.2% (1)	25.0% (3) ^a
Days since treatment decision: Mean (SD)	47.8 (37.4)	59.3 (47.4) ^a
Ethnicity: % (N)		
Caucasian	83.3% (20)	100% (12)
African American	4.2% (1)	0%
Other	12.5% (3)	0%
Education: % (N)		
Completed high school	16.7% (4)	25.0% (3)
Completed college	83.3% (20)	75.0% (9)
Current employment: % (N)		
Employed	79.2% (19)	50.0% (6)
Retired or unemployed	20.8% (5)	50.0% (6)
Marital status: % (N)		
Single/divorced/separated	12.5% (3)	0
Partnered (married, de facto)	87.5% (21)	100% (12)

^aThe disclosed treatment choice of the patient in the partner-patient dyad.

participants outside of study interactions. Interviews lasted an average of 26 min with patients and 23 min with partners.

2.4 | Analysis

Transcribed interviews were analysed by the research team (MM, CES, and RT) using reflexive thematic analysis (Braun & Clarke, 2006). Analysis was conducted in NVivo version 12 (QRS International Pty Ltd., 2020) and Microsoft Word. This process involved both MM and RT each independently conducting a close reading of all transcripts and identifying initial codes. MM, CES, and RT then analysed the same five transcripts (three patients and two partners) to identify and combine coding and create themes. Transcripts were then re-analysed using those themes by MM and RT. Finally, themes were formally defined, summarised, and supported by extracts from the transcripts. A thematic map was also created, reviewed, and refined by all authors to illustrate the themes. As per Braun and Clarke's reflexive thematic analysis approach, data saturation was not the intention of recruitment and data analysis (Braun et al., 2019). Rather, we endeavoured to recruit and interview a high volume of eligible participants (aiming for $N = 20$ patients and $N = 10$ partners/close allies) to ensure a broad and meaningful exploration of participants experiences.

3 | RESULTS

3.1 | Participants

Interview data from $N = 36$ participants were included in the analysis ($N = 24$ male patients and $N = 12$ female partners). The average patient was 59 years old, Caucasian (83%), had a college degree or higher (83%), was employed (79%), had chosen AS for their treatment option (75%), and were married (88%). Patients were interviewed on average 48 days after reporting their treatment decision to the study staff. Partners were on average 60 years old, had a college degree or higher (75%), were employed (50%), Caucasian, married (both 100%), and were partner to a patient who had chosen AS (67%). See Table 1 for a complete breakdown of participant demographics.

3.2 | Overview of themes

A thematic map is presented in Figure 1. Participants described a variety of factors as influencing treatment preferences and choice. Five major themes were identified related to influences on the treatment decision: “Partner support and direct influence on patient treatment choice,” “Patient and partner vicarious experiences may influence treatment decisions,” “The influence of the patient’s external circumstances,” “Disclosing to wider social networks: friends, family,

co-workers,” and “The importance of a good relationship and experience with physicians.” Two further themes were identified related to additional considerations during the decision-making process: “Learning about PCa and treatments” and “Weighing up the risk and benefits of treatment options.” Extracts from the transcripts to support each theme are presented in Table 2.

3.3 | Partner support and direct influence on the treatment choice

3.3.1 | Partner support and influences on the patient and the decision

Patients described receiving emotional and practical decision-making support from their partners. For many, this meant attending appointments together, sharing new knowledge learnt from their own research or friends, family, or co-workers, and discussing treatment options. Partners felt it was their responsibility to provide emotional and practical support whenever possible to the patient. Whilst many patients felt the treatment decision was solely theirs, they wanted their partner to support their choice and considered their concerns and opinions when making their decision. Often, partners deliberately withheld expressing their treatment preference until the patient had expressed theirs.

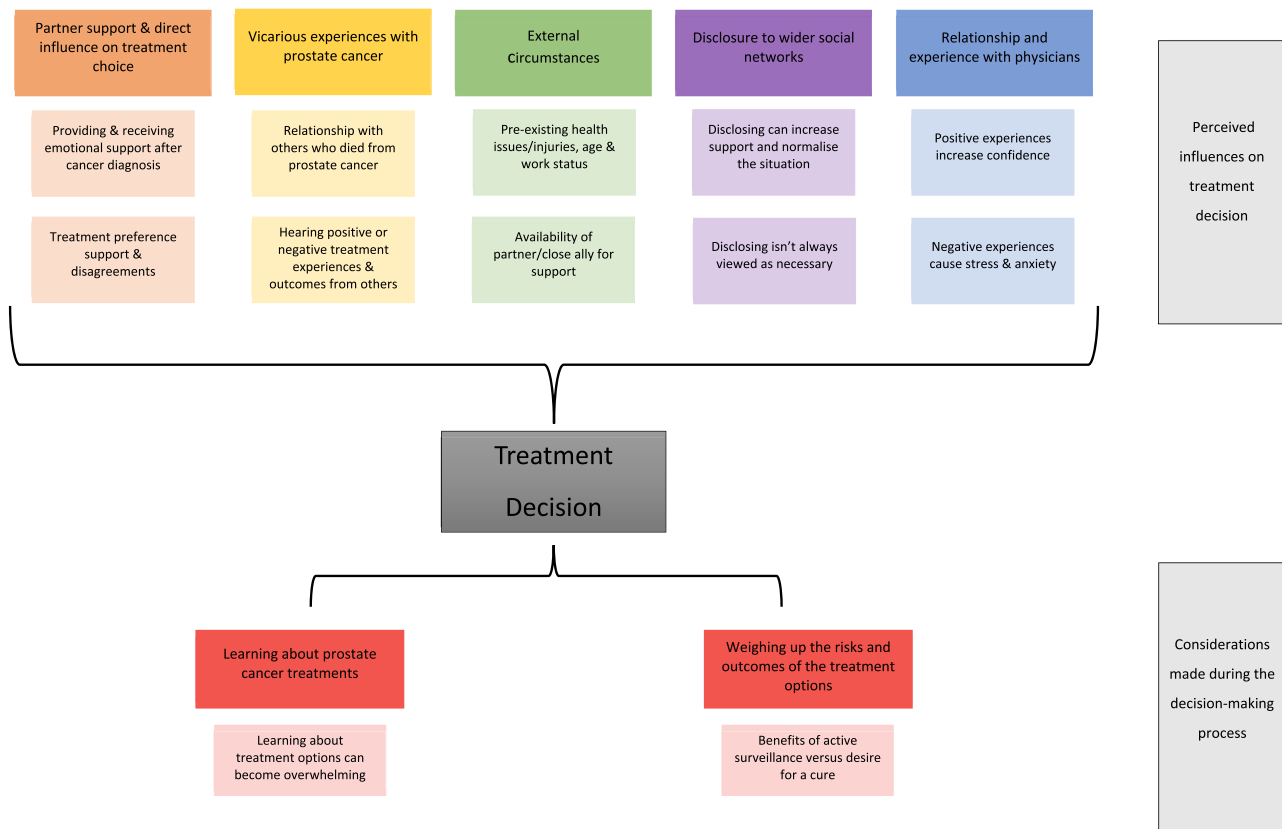


FIGURE 1 Thematic map

TABLE 2 Illustrative quotes extracted from transcripts**Partner support and direct influence on treatment choice**

Partner support and influences on the patient and the decision.

- “I have to be sensitive to her feelings as well. We've been married 38 years already ... So we have always come to some kind of decision together or at least we try to accept each other's opinion. And, and it was important to me that she accept why I wanted to do this and understood it, and I think she finally did.” Participant 1008, Patient, AS.

Partner disagreement about treatment choice.

- “I'm feeling the same thing that, what I've always heard, with cancer, you need to take care of it, you know, time is the essence. You take care of it fast, and you do whatever you can to get rid of it. And to me, it's like surgery. That's where the cancer is. You get rid of the prostate, and you are done. Um, but for him, it wasn't that, you know, that clear-cut process. So it's been a little frustrating for me, because we are really not on the same page as far as how we'd approach treatment” Participant 2017, Partner.
- “My wife actually had a very strong opinion and, and we were surprisingly once again on different sides of the table about it. And it wasn't until she came around to my side, which made my decision a lot easier because then I knew that she was supportive and understood it.” Participant 1008, Patient, AS.

Patient and partner vicarious experiences may influence treatment decision

- “I've heard cases from all extremes, as I'm sure you all have. I've heard cases of, ‘[the prostatectomy] was no problem. I did it and within two months I was fine and I'm so glad I did it’. And I've heard other cases of people who years later are still dealing with the side effects and have said, ‘I would never do it again’. I've heard both experiences.” Participant 1002, Patient, AS.
- “I will not say it's the sole reason, but it's one of the main reasons that I made the decision to do the surgery. I just looked at it and said, you know what? I do not know that I can go day-to-day and not know, okay, what if it progresses and it steps out of the host organ, and all of a sudden, now I'm like my brother where he was sick and let it go and let it go and let it go, and then he all of a sudden was faced with a stage four advanced disease that there was nothing he could do about it.” Participant 1207, Patient, Prostatectomy.
- “I guess I always thought because I had a close friend of mine that had prostate cancer and he had surgery that I always thought in the back of my mind that that was the option I would take.” Participant 1138, Patient, Prostatectomy.

The influence of the external circumstances

- “The biggest difficulty for me is that my wife has not been available for me ... The problem was I got diagnosed at a time when my wife is out of the country, she's working overseas ... The biggest problem I have in dealing with the whole thing is not the condition itself, but how I was going to let my wife know about it” Participant 1021, Patient, AS.
- “[If] they told me that there would not be really any side effects to the surgery I would have had it taken out already ... At my age I cannot, I cannot live with the incontinence ... I'm working and I just cannot live with it.” Participant 1010, Patient, AS.

Disclosure to wider social networks: friends, family, co-workers

Disclosing can increase support and normalise the situation

- “Then when you find out how many people are indeed experiencing the same thing ... then it becomes a big support network and I think that's extremely helpful as well because you, you each share information as you learn new things, because you cannot obviously catch everything that's out there in the world and ... now you are getting your friends letting you know, hey, do you know about this? Have you heard about that?” Participant 1008, Patient, AS.

Disclosing is not always seen as necessary

- “I internalized a lot of it. That's just the way that I am. I do not like to worry [people], even as close as my wife and my children. I initially just kept it from them to be honest with you. I mean I let my wife know right out of the gate. I think I called her as soon as I got into the parking lot. But for example, my mother to this day does not know. She's just elderly and she has some health issues herself... I do not feel that it's necessary for her to even know about it at this point ... I really did not tell a lot of people before my wife initially and that's just the way that I function, I guess. I try to resolve things. I do not like to worry other people until I know exactly what's going on.” Participant 1127, Patient, AS.

The importance of a good relationship and experience with physicians

Positive experiences increase confidence

- “He comes across as very confident, competent, knowledgeable, and just makes me—gave me a confidence level that for now I do not need to worry. See you in six months.” Participant 1002, Patient, AS.

Negative experiences cause stress and anxiety

- “I felt that initially out of the gate at the initial urologist I was not given any information whatsoever. And that added to a lot of my stress. I can understand why some people may not want to know. To be honest with you, I understand it, but that's not how I—that's not my process.” Participant 1127, Patient, AS.

Seeking a second opinion can assist decision-making

- “I have a lot of friends that went through different types of cancer, not only prostate cancer, but also other kinds of cancer. So obviously you are familiar with the facility. You're familiar with their reputation. You're getting word of mouth as far as the quality and it is where you want to be. I feel confident going there.” Participant 1127, Patient, AS.

Learning about PCa and treatments

Learning about PCa and treatments is essential, but sometimes overwhelming

- “I felt there was enough information out there. And at times, there's almost too much information. Okay, I know what I know. And there always seems to be another piece of information you can find. And at some point, you just have to cut the turmoil and say, I'm going to make a decision on what I know ... Sometimes it's too much. Sometimes it absolutely can be too much information.” Participant 1034, Patient, Prostatectomy.

(Continues)

TABLE 2 (Continued)

Learning about PCa and treatments

Information sources used

- “I did not want to read the nonsense and the noise that would be on the Internet. I tried to find good articles and good data to help me make the decision.” Participant 1245, Patient, Prostatectomy.
- “Well there’s just so much news out there. There’s been so many, you know, famous people what have had it, um, that, you know, immediately I went on the web and started reading about, you know, their stories.” Participant 1014, Patient, AS.

Weighing up the risks and benefits of the treatment options

Avoiding the side effects of definitive treatments

- “That was really the main concern about why I’m leaning towards active surveillance right now, because I’m 55 years old, I’m young – in my mind I’m young – and things are fine physically, so why should I – why do I risk complications when nothing’s really a problem right now” Participant 1021, Patient, AS.

Making a treatment decision can take time

- “There are so many options, and it’s almost like there are too many options. I almost wish it was more cut and dry, and the doctor would say this is the way to do it, and this is the best way, the only way, and you have to do it now. Um, the fact that there are so many options and so many opinions, and that you have time ... it gets very confusing.” Participant 2017, Partner.

Strong desire to remove or treat the cancer

- “I thought that the term active surveillance was kind of marketing bullshit, frankly. Let us, let us sit and wait and hope nothing bad happens. And, and I guess that’s a philosophy that I cannot ever embrace. For me, it was like saying, oh, I have a hole in my roof. Let us not repair it now. Let us repair it in ten years and hope it does not get any worse. That’s not, that’s not who I am.” Participant 1348, Patient, Prostatectomy.

3.3.2 | Partner disagreement about treatment choice

Not all participating partners supported the treatment choice that had been made. Dissatisfaction with treatment choice was particularly prevalent when the patient had chosen AS. Many partners expressed a preference for prostatectomy, believing it to be the “gold standard” treatment option, and felt concerned the patient was risking their health if they chose AS. Consequently, patients found the decision-making process difficult when their partner disagreed with their preferences or choice.

3.4 | Patient and partner vicarious experiences may influence treatment decision

The influence of vicarious PCa treatment experiences on the decision-making process was significant. Participants who had directly or indirectly known others with PCa often considered those people’s treatment experiences whilst weighing up their own treatment options. Patients and partners who knew others that had negative experiences with a particular treatment often reported an aversion towards it, especially when that person had died. On the other hand, those who had known others to have a positive experience with a particular treatment felt reassured of its safety and effectiveness. For some, another’s positive treatment experience heavily influenced their own treatment preferences.

3.5 | The influence of the external circumstances

The decision-making process and treatment preference were sometimes affected by external circumstances. Some patients had other health issues or injuries at the time of diagnosis. Several patients delayed their treatment decision-making due to external circumstances such as separation, working overseas, or undergoing their

own medical treatment. Some patients felt choosing AS and delaying definitive treatment was necessary as they were still working, which would be difficult with treatment-related side effects.

3.6 | Disclosure to wider social networks: friends, family, co-workers**3.6.1 | Disclosing can increase support and normalise the situation**

Deciding whether to share their diagnosis and discuss treatment options with others was another decision for participants. Many who discussed the diagnosis and treatment preferences with others, such as friends, family, or co-workers, explained that it helped them connect to others currently going through a similar experience, bringing feelings of normalisation, hope, and support.

3.6.2 | Disclosing is not always seen as necessary

However, some patients chose not to share their diagnosis and treatment choice with others, thereby deliberately limiting potential outside influences on the decision-making process. This was most often mentioned by patients who chose AS.

3.7 | The importance of a good relationship and experience with physicians**3.7.1 | Positive experiences increase confidence**

Feeling comfortable, confident, reassured, and well-informed about the physician’s treatment recommendation and expertise was noted

by participants as essential for a positive experience with their physician, which decreased decision-making difficulty. Participant's reported positive experiences with their physician when their physician had taken time to explain the different treatment options, appeared confident in their treatment recommendation, and rechecked or performed additional diagnostic tests. Patients who chose AS often mentioned their physician's calm attitude and reassurance provided participants with confidence in the treatment option and their decision.

3.7.2 | Negative experiences cause stress and anxiety

Several patients reported having negative experiences with their diagnosing physician. In such circumstances, patients reported it had made their decision-making more difficult and confusing. Physicians who had not provided the desired amount of information or reasoning for their treatment recommendation, appeared uninformed or biased, had not followed-up with the patient in a timely manner, did not consider the patient's treatment preferences, and who were seen as lacking compassion were viewed poorly by the participants and often led them to pursue a second opinion. These experiences prolonged the treatment decision-making process and caused stress, anxiety, and frustration.

3.7.3 | Seeking a second opinion can assist decision-making

Approximately half of the participants mentioned the importance of getting a second opinion regarding their diagnosis, often from a Memorial Sloan Cancer Center (MSK) physician, to assist in their decision-making. Often the desired outcome from the second opinion was to support the first recommended treatment, to learn about or get support for other treatment options, or because they had an unsatisfactory experience with their first physician. Participants often mentioned the credibility and well-known reputation of Memorial Sloan Cancer Center (MSK) and for many this had a considerable influence on their decision-making. A treatment recommendation from Memorial Sloan Cancer Center (MSK) was considered credible and trustworthy, and increased participants' confidence in their treatment decision.

3.8 | Learning about PCa and treatments

3.8.1 | Learning about PCa and treatments is essential, but sometimes overwhelming

Learning about PCa was an essential step for participants in their decision-making process. Most participants, especially those without prior knowledge of PCa, began researching and seeking information

once the shock of the diagnosis had passed. Participants sought information to better understand their diagnosis, test results, the different treatment options and their side-effects, to investigate physicians and their clinical expertise, and to read other patients' experiences. In general, participants felt they had access to enough information about PCa and their treatment options, and receiving information often made them feel calmer and in more control. However, it was also noted that too much information or conflicting opinions could be overwhelming and had the potential to confuse and delay decision-making.

3.8.2 | Information sources used

Patients and their partners sought information from multiple sources, including the internet (e.g., hospital websites, information found via Google searches, and YouTube videos), physicians and nurses, books, newsletters, research papers, radio, and online discussion groups. Many noted the importance of specifically looking for information from credible sources. Participants reported that other patients or partners of patients who had PCa were also valuable sources of information. For some, this was accessed by attending support groups or looking to celebrity accounts of their experiences.

3.9 | Weighing up the risks and benefits of the treatment options

3.9.1 | Avoiding the side effects of definitive treatments

Most patients favoured AS because it delayed definitive treatment and its associated side effects until necessary, allowing them to maintain their health and vitality for as long as possible. The potential side effects of definitive treatments weighed heavily on patients' minds and was often reported as being their main reason for choosing AS. Patients who chose AS frequently viewed the potential long-term side effects of definitive treatment as burdensome and hoped to completely avoid treatment altogether because of this.

3.9.2 | Making a treatment decision can take time

After diagnosis and being told their treatment options, participants reported deliberately taking their time to gather second opinions and research treatments. For some, AS was a relatively simple choice; many were accepting of the protocol and were relieved when their physicians and the diagnostic tests supported the treatment option. Delays in treatment decision-making were usually due to weighing up the potential negatives of AS (e.g., fear of progression, regular biopsies, potential treatment regret) against the potential negatives of definitive treatment (e.g., experiencing short- and long-term side effects, taking time off work to recover), rather than a focus on the possible benefits of either option. Others were simply overwhelmed.

3.9.3 | Strong desire to remove or treat the cancer

Some patients who elected to undergo definitive treatment were open-minded about going on AS, but the desire to act was too overwhelming. Others reported being strongly opposed to AS, due to distrust in its ability to detect progression.

4 | DISCUSSION

This study aimed to investigate patients' and partners' perceived influences on treatment decision-making after a low risk, localised PCa diagnosis. Patients and partners discussed a range of influences, particularly social influences, on treatment decision-making. Immediately after diagnosis participants relied strongly on the opinions of medical professionals to drive their treatment choice. However, participants' treatment preference was also influenced by prior knowledge and vicarious experiences of PCa journeys. Whilst patients ultimately made their own treatment decision, both patients and partners acknowledged the importance of discussing the options and gaining support for the chosen treatment from each other. However, many partners in the study expressed disappointment or dissatisfaction with the patient's choice of treatment. These findings have implications for medical professionals regarding communicating with patients and partners after diagnosis and during the treatment decision-making phase.

Healthcare and health promotion has been criticised for focusing largely on influencing factors related to the individual, whilst ignoring contextual factors that can influence health and health-related behaviours (Golden & Earp, 2012). We therefore utilised the social-ecological model (SEM) to assist in contextualising our results across the various levels outlined by the SEM (Bronfenbrenner, 1979). Our study showed participants were strongly influenced by personal (pre-existing knowledge of PCa treatments and preferences), interpersonal (vicarious experiences of PCa, partner support and treatment preferences, relationship/experiences with physicians) and community/organisational factors (physician expertise and MSK reputation). Some of these factors have been previously identified in the literature. For instance, the process of information-seeking and weighing the benefits/consequences of AS versus definitive treatments has been previously described (Kinsella, Stattin, et al., 2018). Research has similarly established that physicians' attitudes towards AS, the level of trust forged with the patient, and the amount of information they provide are considered influential by patients when making their PCa treatment decision (Kinsella, Stattin, et al., 2018). In our study, patients and partners emphasised that trust and the quality of their relationship with physicians was essential for confidence in treatment recommendations and their treatment choice. Participants were particularly satisfied with their physicians when they openly disclosed biases regarding particular treatments, provided clear and thorough information, were well-informed of recent research, listened to the preferences and worries of the patient, provided ample appointment time, offered reassurance and compassion, and conducted further testing

where appropriate. Physician attitude towards AS and their comfortability in managing patients who are delaying treatment until further disease progression occurs, has likely improved significantly since the AUA updated their treatment guidelines in 2017 (Sanda et al., 2018). Since the early 2000s, AS uptake has steadily increased as it becomes a more refined protocol (Kinsella, Helleman, et al., 2018). For instance, uptake of AS in the United States between 1990 and 2010 was approximately 10%, and increased to 40% by 2013 (Cooperberg & Carroll, 2015). Given the AUA treatment guidelines were again updated in 2017, it is not surprising that 75% of patients in the present study selected AS for their treatment. Participants in the present study may have been further influenced by the reputation of Memorial Sloan Cancer Center (MSK), given it is considered to specialise in AS management.

Another example of influential interpersonal factors was vicarious experiences of PCa, whether direct (e.g., family member or friend) or indirect (e.g., co-workers and celebrities), which helped participants learn about possible treatment outcomes. Participants usually eliminated treatment options if they heard several negative experiences with a treatment, whether or not it was relevant to their own situation and clinical factors. Participants who knew of others on AS whose cancer had progressed before definitive treatment was performed were considerably more sceptical of its safety. The influence of this interpersonal factor has been previously identified (Xu et al., 2011); however, our study also found participants were similarly influenced towards treatments by positive vicarious experiences. Influence from celebrity experiences with PCa and treatments was also identified. Research has demonstrated that celebrity endorsement of cancer screening can increase the likelihood of participation—one study found that in a sample of 87 men aged 50+ who had been exposed to a celebrity endorsement of PSA testing, 31% of participants reported they were now more likely to undergo PSA testing (Larson et al., 2005). Whilst caution is needed, it may be beneficial for PCa public health messaging to harness the effects of such interpersonal influences, by including stories from celebrities and other public figures when disseminating information on PCa. Furthermore, it is important that physicians providing treatment recommendations and information are aware of the interaction and effect such factors can have on treatment preferences. Providing clear, tailored, and evidence-based information, and exploring the patient's reasons for their choice of treatment may help physicians uncover and counter any unhelpful biases or misconceptions. This aligns with recommendations for medical professionals to utilise a shared decision-making care model (Kane et al., 2014), which urges patients and health professionals to engage in mutual sharing of information, preferences, and needs (Kane et al., 2014). The utilisation of this model has been strongly recommended by oncology researchers as part of patient-centered care. Its use can result in increased patient confidence in treatment decisions, satisfaction with treatment, and trust in providers (Kane et al., 2014).

On another interpersonal level, the experience of partners in the decision-making context was also explored. Some partners in the study expressed dissatisfaction with the patient's choice of treatment,

particularly when the patient had chosen AS. Given patients desired and placed significant importance in having their partner support their treatment choice, further research into partners' treatment preferences will assist understanding how to best communicate information and provide support to both in the dyad. Little research has investigated partner's treatment preferences after a PCa diagnosis, though prior research and the present study suggest partners often favour curative treatments over AS (Couper et al., 2006; Reamer et al., 2017; Srirangam et al., 2003). Whilst partners were generally understanding of the patient's final decision no matter their choice of treatment, some expressed feelings of anxiety and worry about the patient's health and safety on AS. Partners of men with PCa often report significant levels of anxiety and depression, and research even suggests that partners may experience more psychological distress compared to the patient (Chambers et al., 2013; Couper et al., 2006; Resendes & McCorkle, 2009). However, much of this research occurred prior to the 2017 AUA recommendations for AS as the best-available treatment option for low-risk patients. Given AS recommendations and uptake rates have since increased, further investigation on spousal psychological distress is required. In particular, research which explores treatment preference disagreements and how this is navigated by the couple and their physicians is required. Again, the utilisation of a shared decision-making model, considering both patient and their partner's views and preferences, is recommended.

In light of these findings, some limitations should be considered. This study was originally intended to investigate both partner and close ally experiences, as little research has explored the involvement and influence on treatment decision-making of non-romantic close allies in men diagnosed with PCa. Unfortunately, we were unable to recruit close allies to this study. Furthermore, no individuals in non-heterosexual relationships choose to participate in this study. Understanding the influence of close allies and exploring the experiences of non-heterosexual individuals are critical areas for future research. An additional limitation is that this was a single-site study, and many participants had the same treating physician (almost 30% of patients shared the same physician, with the remaining patients spread across an additional six physicians). All physicians involved were urologists. Notably, no patients involved in the interviews chose radiotherapy as their treatment, despite this being one of the treatment types generally discussed and recommended as a curative treatment approach. Lastly, participants were predominantly Caucasian and were highly educated, and therefore results may not be reflective of patients with lower social-economic status and minority ethnicities. Research has suggested that compared to Caucasian men, African American men have higher PCa incidence (particularly with higher grades/stages), have higher PCa mortality rates, and have differences in treatment preferences/choice (Badal et al., 2020; Desantis et al., 2016; Kan et al., 2018).

Treatment decision-making in PCa, especially when patients are diagnosed with low risk, localised PCa, can be a complex process, as often patients and their partners are faced with several treatment options and no clear "right" answer. Our study highlights that treatment preferences were influenced by pre-existing knowledge of

vicarious experiences of PCa via friends, co-workers, and public figures in the media, as well as by physician recommendations. Treatment decision-making appears to become far more complex when patients and partners are exposed to either positive or negative vicarious experiences and when there are disagreements between patient and partner about the preferred treatment. These results align with the SEM, which suggests decision-making, and behaviour, is influenced by the interaction of personal, interpersonal, community and policy/society factors (Bronfenbrenner, 1979). In practice, physicians should be aware of these interacting factors and employ a shared decision-making care model. Specifically, physicians should discuss with their patients (and partner/close ally) the various treatment option, seek to understand their treatment preferences, and address any existing biases and misconceptions, whilst ensuring they provide evidence-based, tailored information and recommendations.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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