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'What is this active surveillance thing?' Men's and partners' reactions to treatment decision making for prostate cancer when active surveillance is the recommended treatment option

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Abstract

Objective: **In the past decade, localised prostate cancer (LPC) management has been shifting from three radical treatment options (radical prostatectomy, external beam radiotherapy, or brachytherapy) to also include active surveillance (AS). This study examines men with LPC and partners' experiences of choosing between AS and radical treatments, and their experiences of AS when selected.**

Methods: **A qualitative descriptive research design was used. Interviewed participants were men, and partners of men, who either had chosen radical treatment immediately following diagnosis or had been on AS for at least 3 months. AS was the recommended treatment. Transcribed interviews were thematically analysed and inter-rater reliability integrated.**

Results: **Twenty-one men and 14 partners participated. Treatment decisions reflected varied reactions to prostate cancer information, regularly described as contradictory, confusing, and stressful. Men and partners commonly misunderstood AS but could describe monitoring procedures. Partners often held the perception that they were also on AS. Men and partners usually coped with AS but were sometimes encumbered by treatment decision-making memories, painful biopsies, ongoing conflicting information, and unanswered medical questions. Radical treatment was selected when cancer progression was feared or medically indicated. Some preferred doctors to select treatments.**

Conclusions: **To reduce distress frequently experienced by men diagnosed with LPC and their partners during treatment decision making and ongoing AS monitoring, the following are needed: improved community and medical awareness of AS; consistent information about when radical treatment is required; and consistent, unbiased information on treatment options, prognostic indicators, and side effects. Regularly updated decisional support information/aids incorporating men's values are imperative.**

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Background

Until prostate-specific antigen (PSA) testing was introduced in the mid-1980s [1], detected prostate cancers (PC) were usually advanced and incurable [2]. PSA testing has dramatically increased PC incidence; however, many detected cancers are localised and well-to-moderately differentiated [3]. Those with well-differentiated disease often survive

10–20 years without intervention [3]. Until recently, curative treatment was offered to most men with localised prostate cancer (LPC) [4]. Options include radical prostatectomy (RP), brachytherapy (BT), and external beam radiation therapy (EBRT). Urinary or bowel incontinence and sexual dysfunction, however, are common side effects [5]. In 2001–2002, active surveillance (AS) emerged as an alternative [4].

Active surveillance is a proactive management plan that aims to delay or prevent radical treatment (RP, BT, and EBRT) by closely monitoring low-risk PC until PSA tests and/or repeat biopsies indicate disease progression [6,7]. AS differs from 'watchful waiting', which is usually reserved for older men with limited life expectancy and involves conservative PC management until disease progression warrants non-curative hormone therapy [8]. In 2009, the Urological Society of Australia and New Zealand formally acknowledged AS as a treatment option for suitable men [9]. In 2012, the National Comprehensive Cancer Network (NCCN) recommended that men with very low-risk^1 PC (expected survival <20 years) be managed with AS and men with low^2 or intermediate[9] risk PC (expected survival <10 years) be managed by AS or radical treatment [10]. In 2014, the NCCN guidelines were amended, removing the option of AS for those with intermediate risk PC [11]. Up to 12-year survival rates are similar for men with LPC randomised to either observation or RP [12], and RP and radiotherapy survival outcomes are also similar [13]. Despite this, estimated AS uptake rates for men with LPC are 10% [14] and 42% [15] in American and Australian men, respectively. Some men with LPC are still not offered AS [16]. Amongst those offered AS, some believe that LPC should be immediately removed when cancer is curable [17], and families and friends may have similar concerns [6].

Previous studies have examined the *reasons* underpinning men's choice between LPC treatments including AS. Decisions reflect beliefs about cancer, knowledge of others' cancer experiences, partners' distress, and peer pressure [6,18]. Those choosing AS usually believe their cancer is not aggressive [18], received a trusted urologist's recommendation [18,19], considered their age and potential treatment side effects [19,20], and expected to maintain life quality [20]. AS is typically rejected because of fear of cancer progression, frequent check-ups [20], the need to 'do something' [18], and contradictory physician treatment opinions [6].

Should AS be selected, reports on men coping are mixed. For example, men and partners have reported low anxiety [21], and only 2–18% of men have sought treatment without disease progression [7]. Nonetheless, some Canadian men on AS found biopsies distressing, feared illness progression, and were uncomfortable talking about PC [22]. Partners' role in men's treatment decision making is inconsistently reported [22], but they usually wanted men to make the final decision [23]. Only one study investigating uncertainty associated with AS was identified, which included only four partners [24].

Each treatment option for LPC has specific advantages and disadvantages [6]. Increasingly, AS is likely to be the recommended management option; however, there have been no studies identified that investigate the psychological aspects of treatment decision making *when the AS management option is recommended by the treating urologist*. In this context, we need to clarify men's and partners' needs for decisional support so that interventions can be developed to help men select the best treatment for their individual situation. Partners' views are important because they are affected by treatment decisions and often significantly impact men's experience of care and decisional satisfaction [25]. This study examined Australian men's and partners' experience of treatment decision making following LPC diagnosis and their experience of AS when AS was the recommended treatment option.

Methods

Setting and participants

A qualitative descriptive research design with 'grounded theory overtones' [26,27] was used. This means that techniques associated with grounded theory were included, that is, inductive, cyclic, and constant comparative data analysis. Participants were recruited from a private urology practice, an integrative cancer centre, and a public hospital's oncology service following ethics approvals. Two urologists involved in the study recommended AS as the preferred treatment option to eligible men. Clinical eligibility criteria for AS recommendation were as follows: T1-2a tumours, Gleason score ≤ 6, and PSA <10 ng/mL. Additionally, one urologist included men with one of the following: T2b-T2c tumour, PSA 10–20 ng/mL, or Gleason score 7. Additional inclusion criteria comprised two groups: men newly diagnosed with LPC who declined AS in favour of radical treatment and men who had been on AS for at least 3 months following LPC diagnosis (they may have since ceased AS). Men could invite partners to participate if available. Exclusion criteria comprised men older than 18 years and/or experiencing cognitive, physical, or psychological difficulties that precluded participation, as determined by treating doctor/team.

Sampling intent was purposive, which means that recruitment focused on potential participants believed to provide a range of understanding of the research phenomenon [28]. Qualitative sampling strategies are not intended to achieve statistical generalisations. Urologists identified patients according to varied age, treatment choice, time on AS, reason for ceasing AS, socio-demographic

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background, and rural/urban dwelling. Between September 2012 and April 2013, 85 invitations to participate were sent to men across eight mail-out waves with later invitations to men with characteristics less evident in earlier collected data. Participant consent forms were returned to a research assistant, promoting urologist blinding of participation. Interviews were between October 2012 and end of April 2013.

Data and analysis

Consenting participants engaged in individual, semi-structured telephone interviews that invited discussion about the following: helpfulness of information, AS understanding and experience, reactions to treatment decision making, support required/received, and suggestions for others dealing with treatment decision making and AS. Demographic information was collected from participants and medical details from men's medical records.

Analysis of transcribed interviews was managed by qualitative data management software [29]. Interviews were initially coded, and comparable codes grouped into categories that separately represented men's and partners' responses. Comparable categories from the two data sets were then grouped into themes representing both men's and partners' responses. Coding labels were created by researchers (i.e. not predetermined) to denote text segments, as informed by grounded theory. To promote rigour and trustworthiness, an inter-rater reliability strategy was integrated [30]: All interviews were coded and categorised by either C. O. or T. D. (first and second authors), both experienced qualitative researchers. They then examined each other's analyses, discussed different code and category interpretations until reaching agreement, and together finalised themes. Additionally, A. H. (third author and trained qualitative research interviewer) examined and agreed with the findings.

Results

Twenty-one men and 14 partners participated. Participants' demographic characteristics are in Table 1. Figure 1 illustrates treatment decision-making pathways undertaken. Two partner participants were invited by non-participating men who either chose immediate treatment on diagnosis or ceased AS on medical advice. Twenty-seven percent of invited men and/or their partners participated. Interview mean lengths were 38 (men) and 34 (partners) min. Men had been or were on AS for mean 22 months (range 3–96 months).

Findings are organised into the following three themes and seven categories, and participants' recommendations (Table 2). Details in parentheses signify participants' ages, if they were partners (P), and whether men were still on AS (AS), had received non-medical reason radical treatment (NT), medical reason radical treatment (MT), or after diagnosis chose radical treatment (DT): for example, (70PMT) denotes 70-year-old partner of a man who received medically indicated radical treatment following at least 3 months on AS.

Table 1. Participants' demographic characteristics

	Men	Partners
	(*n* = 21)	(*n* = 14[a])
Age (years)		
≤50	1	4
51–60	6	2
61–70	11	7
71+	3	1
Origin		
Australia	15	8
Others[b]	6	6
Educational background		
Post high school qualifications	16	10
Completed high school	3	0
Had not completed high school	2	4
Mean partnership length (years)	28 (range 3–50)	22 (range 0–50)
Treatment decisions		
Still on AS	11	
RP after ≥3 months on AS	7	
EBRT after ≥3 months on AS	1	
BT after ≥3 months on AS	1	
RP immediately after diagnosis	1	
Reasons for ceasing AS treatment		
Medically indicated	8	
Non-medically indicated	1	

RP, radical prostatectomy; AS, active surveillance; EBRT, external beam radiation therapy; BT, brachytherapy.

[a] One male partner.

[b] Men were born in England (3), Scotland, Holland, and Ethiopia. Partners were born in England (2), China (2), Scotland, and Indonesia.

LPC treatment decisions are affected by information gathered and varied emotional and relational reactions

Information was satisfactory, contradictory, stressful, and/or misunderstood.

Twelve men were satisfied with PC information received from urologists, even when not understanding it. One man stated, 'Sometimes (PC) can get better' (59AS). Eight were dissatisfied, and one could not remember. One man said,

> The original urologist I saw gave me some information … more than five years old. … that wasn't current and I found searching the net, … two options, … radical prostatectomy and radiotherapy (and) …, there was something else … high intensity focused ultrasound …. Am I reading stuff that's incorrect or is it the difficulty because it's an evolving thing and there's research … the people I've seen aren't on top of? (60AS)

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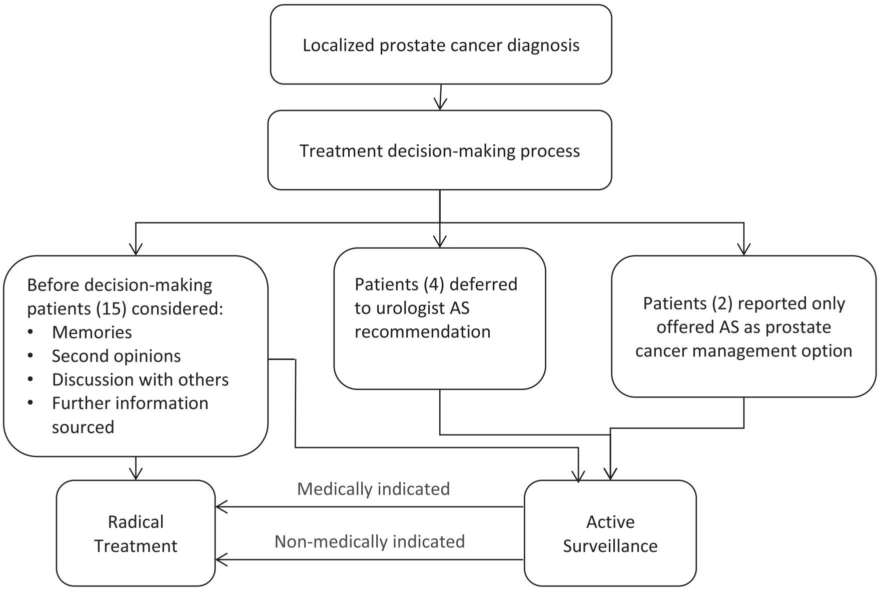

Figure 1. Reported treatment decision pathways by men (patients) at time of interviews

Table 2. Men and partner LPC healthcare recommendations[a]

LPC treatment decision making	
	Men and partner LPC stories
	Quality, clear, consistent, information
Assisting AS	
	Advice on managing medical appointments (especially biopsies)
General	
	Talking to another with similar experience
	Formal one-to-one psychological supports
	Access to healthcare professionals
	Support groups

LPC, localised prostate cancer; AS, active surveillance.
[a]Made by some respondents: some may not consider the interventions are needed.

Information from multiple sources, including other doctors, the Internet, family, and friends, could also be limited and/or confusing. Four men and two partners were particularly stressed by conflicting information gathered. 'Everybody's got different ideas about it', one man said (53AS), and his partner indicated,

> It was very confusing to have doctors who said … "AS is definitely for you", and then to see an oncologist … who said, "Well no, your age group, highly unlikely for you"… that took away some of our confidence. (42PAS)

Disagreement with her husband about seeking second opinions also stressed their relationship. Otherwise, partners tended to be satisfied with information from medical meetings, brochures, friends, and/or the Internet, even when only receiving information on AS and RP from the urologist. Two partners with unmet information needs did not attend husbands' medical appointments.

Some men on AS and partners did not understand nor recall the term AS, but all could describe monitoring procedures. One couple described the AS monitoring experienced over almost 2 years as, 'active monitoring and watching' (65NT) and 'watch and wait' (61PNT). Other terms used for AS included 'watch and see' and, commonly, 'watchful waiting'. Two partners did not realise that the men had been on AS. One said it was a 'bit of time to think' (65PMT).

Decision making: difficulties, assistance, and rationales

Men's treatment decisions were informed by perspectives from medical staff, friends, colleagues, partners, and/or available information and affected by their emotional reactions, cancer-related memories, and lifestyle factors. Conflicting information related to treatment indicators could challenge. One man reported his urologist said,

> "You would be an ideal candidate (for AS)", …yet the brochures worried me a bit because they seemed to say that, for relatively young men my age, it was not all that recommended …. Surgeons that I sort of know, and family, friends … stared at me in disbelief and said, "What is this AS thing? … take it out as soon as possible!" … then I shopped around … I felt happy and reassured when someone told me what I wanted to hear … "You don't need to have the operation." (50AS)

Eight men sought second opinions following immediate RP recommendations. One stated, 'He (urologist) said, "Well you should have your prostate out. When do you

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want to do it?" … he's trying to push me into sort of making a decision there and then' (69MT).

Fifteen men said they made the treatment decision (Figure 1), and two partners perceived they shared it. Partners supported men's final decisions. Most couples discussed the LPC, except one couple in a new relationship and a partner who did not feel 'acknowledged' when not invited to the treatment decision-making consultation (50PAS).

A man chose and two partners supported the choice of RP on diagnosis to eradicate the cancer because of the man's youth, expected increased longevity, and/or distressing memories of cancer-related deaths. The man asserted, 'Take it away, cut it out, get rid of it. … if you're riddled with cancer and die a slow painful death it's just not worth it' (69DT), and a partner said, 'It didn't make sense to us that we would go down that (AS) path … his age, his state of mind, … he's got a young family, … we've still got a lot of things to do' (43PDT). This group believed that avoiding cancer progression outweighed concerns about radical treatment side effects.

Men and partners both experience and often cope with AS

Partners' shared experience of AS and its advantages

Men's and partners were usually comfortable with AS. Advantages included the following: time to accept diagnosis; avoidance or delay of sexual, incontinence, or infertility radical treatment side effects; increased awareness and control of men's health; and hope for improved health. By using 'we', seven partners also depicted themselves on AS. One said, 'My partner does have a cancer and we both have to live with that' (62PAS). When asked about AS advantages, another responded, 'We can delay surgery and delay the potential outcomes' (57PAS). Men sometimes used 'we' as a colloquialism or to signify doctor–patient relationship, for example, 'we had the finger routine' (58MT) to denote digital rectal examination.

Pre-existing strengths, informal supports, and maintaining 'normal' life assist coping with AS

Men and partners' strategies for coping on AS were comparable and included positive self-talk, living as normally as possible, distraction, thinking of PC survivors, rationalising that one could die of something else, hope for new PC treatments, denial (thinking it could disappear), educating others about PC, acquiring information, continuing a healthy lifestyle, seeking reassurance, and humour. One man said, 'I talk a lot with the blokes, having a beer and yap about it' (62AS). Partners also perceived that they helped men through practical tasks, attending medical appointments, reassurance, and/or hiding concern.

Men usually felt that partners, family, and friends supported AS once the decision was made and that partners could help them to remember monitoring appointments. Further, a man without a partner also found his daughter supportive.

Cancer monitoring and confidence in health professionals assist coping with AS

Men were also supported by trusted healthcare professionals and having a treatment plan in place if needed. Monitoring results sent to men or their general practitioner could reassure. Occasionally, men and partners found psychological counselling supportive. Helpful health professionals gave men enough time, quality information, and clear answers and were contactable and reputable. One man was 'very comfortable' with his urologist adding, 'I'd googled him. … endless qualifications, he travels overseas to conferences' (64AS).

AS stressors are endured or inform radical treatment decision

AS stressors encompass illness uncertainty, monitoring stressors, and inconsistent information

Some men were saddened, grumpy, or anxiously feared disease progression while on AS. One said that many people say,

> "PSA is useless … biopsies are just not good for you." … Why would one test come back and give me a very high Gleason count and then the next biopsy actually says there's nothing there? … I've asked these questions but nobody seems to answer them. They … say, "No, no, you are fine." … I keep saying to my wife, "Should I go and get another opinion … the best of three?" (53AS)

Another man also disliked 'not doing anything' about his cancer (60AS). 'Jumping' PSA levels or memories of inconsistent treatment recommendations on diagnosis were also stressful. One man 'summed' up AS as 'death, dying' and awoke 'some mornings … really depressed' (58MT). Although initially thinking that AS was advantageous, another man now considered AS an 'irrelevant' period of 'head in the sand', which avoided 'the inevitable' and prevented potentially less invasive treatment earlier (68MT). A partner also 'worried' that AS was 'the wrong choice (because) … tests are unreliable' (42PAS).

Biopsy effects or waiting for results could distress men and partners. A partner found one of her husband's biopsies 'so distressing … bleeding, … vomiting.… Terrible' (61MT). Following one man's multiple hospital visits for biopsy-related infection, another partner considered it time to have 'the prostate removed' (57PAS). Partners also sometimes worried about disease spread and the inconvenient, costly, time consuming, or PC threat reminder of AS monitoring. Although many thought that formal support would help, two partners believed this available support should focus on the diagnosed men. One partner also stated that family and friends without experience of PC 'don't probably quite understand' (57PAS).

Men were sometimes annoyed by their forgotten or unanswered medical questions (e.g. prognostic) in medical consultations, platitudes, or conflicting information (e.g. inconsistent interpretations about PSA levels). One man also felt uncomfortable asking what he considered to be 'stupid questions' while on AS (e.g. why 'I can't pee'—76MT). Need for clarifying information was regularly evident: One man questioned whether biopsies encouraged cancer growth. Another queried how one urologist could say, 'You've still got cancer', whereas another says, 'You don't have a problem …. The most difficult thing (he added) was getting reliable and personally relevant information' (60AS). Some felt that scant information received from doctors was due to the men's medical background or geographical location (country rather than city). Occasional doctors were also perceived as fiscally focussed, too garrulous, or too brief.

Ceasing AS is informed by personal and medical factors

Although most men on AS sought, or would seek, radical medical treatment when medically indicated, only one man considered seeking treatment if anxiety about illness progression further increased. Another man had RP when not medically indicated after almost 2 years on AS because of concern about cancer progression, and the painful biopsies prevented long-term travel plans. Partners supported men's decisions.

Conclusions

This study highlights that many men and partners were upset by multiple contradictions about treatment efficacy encountered following LPC diagnosis, including medical opinions, advice from family and friends, and information in brochures and Internet sites. Decisional distress experienced by men, who chose between AS, RP, EBRT, and BT, was arguably comparable with decisional distress in men only choosing between RP, EBRT, and BT options [23], that is, the additional AS option did not make treatment decision making less stressful. Furthermore, men in this study regularly sought second opinions after RP was initially recommended, apparently aware that decision making was not urgent. This contrasts with reports that men avoided second opinions to avert treatment delay when only offered radical treatment options [18].

The findings support previously reported AS advantages [6,20], indications that men often cope[4] with AS [7,21], and reveal that many partners similarly cope with monitoring. However, even when men and women were coping, some remained encumbered by memories of contradictory LPC treatment opinions, unanswered questions about prognosis and symptoms, and distressing biopsy side effects. Some also perceived AS as 'not doing anything', as found elsewhere [6,22].

The findings reinforce that distress in men and partners following diagnosis [18] is compounded by bewilderment experienced during treatment decision making. Men's and partners' confusion is understandable given contrasting expert views on LPC management encountered in medical consultations and gathered information. This reflects international, inconsistent criteria for AS eligibility [31] and expert dissension on clinical implications of findings from ongoing trials comparing observation and radical treatment [32]. Men's and partners' confusion intensified when information was old and family and friends doubted the unfamiliar AS concept. Even participants who had been managed with AS regularly asked the research interviewer to explain AS. Men's use of multiple terms to depict AS mirrored international inconsistencies in descriptors for AS [8,22] and, possibly, their doctors' inaccurate terminology. Research participants' knowledge of AS varies [20,22] with this research supporting Davison and colleagues' finding that men are often unfamiliar with AS even when undergoing this treatment [22].

To support well-being and decision making in men diagnosed with LPC, improved community and medical education about AS is needed, alongside consistent and up-to-date information on treatment options, associated prognoses, and side effects. When combined with values-clarification exercises, this information could possibly assist men's capacity for decision making based on personal needs and may reduce pressure from misinformed family and friends. As found elsewhere, occasional partners were distressed by men's AS decisions and monitoring [24]. Hence, partners would also likely benefit from enhanced recognition within LPC information sources, treatment support, medical consultations, and decision aids emerging in this field [33,34]. Preparatory information on handling surveillance biopsy reactions is also needed, and ongoing support may be necessary for the significant minority of men who find AS difficult. This includes doctors' abilities to elicit and address their important questions.

Interestingly, men usually spoke about deciding between AS or RP, rather than all radical treatment options, possibly because urologists' options reflected their specialty [35]. It is also possible that men rapidly differentiate and consolidate options to manage decisions, as espoused by decision-making theory [34,36]. The findings also indicate that some men defer treatment decisions to their doctors [16,22]. Although doctors should offer men unbiased opportunities for shared decision making [37], which may include partners, men's self-determined choice to not make health care decisions [38] should also be respected.

Limitations and further recommendations

The findings reflect English-speaking volunteers, and the low response rate may have been due to some invitees not understanding 'active surveillance' in participant invitations and consent forms. A selection bias of people with negative experiences of LPC decision making and AS may have been present. The study also only recruited one man and two partners of men who immediately elected radical treatment. An additional six men in this category were invited but did not respond. Possibly those unable to live with LPC do not want related emotions elicited in research. Further recruitment in this cohort may have revealed more varied treatment-decision reactions. Given difficulties in recruitment, sampling was arguably more convenience despite purposive intent.

A treatment decision aid for men with LPC, which emphasises that AS is another *treatment* option and acknowledges partners/support people, is being developed for examination using a randomised controlled trial design. Integration of stories from other men and partners with LPC experiences would likely enhance information resources as study participants regularly desired hearing others' reactions to LPC (Table 2). Development of internationally agreed LPC-related descriptors and anticipated treatment biomarkers [39] would also reduce distress related to contradictory information. Future research comparing distress in subgroups involved with AS could elucidate those needing targeted support, for example, men/partners, partnered/single men, and men with good/poor AS knowledge [20].

In this new era, which recognises the pivotal role of partners in personal healthcare planning, it is essential that discussions of treatment options and decisions are tailored to patient preferences for information and decision-making involvement and include consideration of their values, life context, and desire for family/friend involvement [40]. Providing treatment information materials is also recommended [40]. There are no internationally accepted standards for treating and monitoring LPC. This study and other reports indicated that doctors offer conflicting opinions [32] and use inconsistent language [22] in information and materials given to patients. Although this may not distress men who defer treatment choice to doctors, actively involved decision makers are gathering contradictory information from different sources. Consequent distress, palpable in these findings, needs to be addressed through offering medical explanations for inconsistent information widely available and up-to-date information and decision aids relevant to the personalised needs of men, partners, and others who support them.

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Conflict of interest

The authors have declared no conflicts of interest.

Notes

1. T1c tumour; PSA level <10 ng/mL and density <0.15 ng/mL/g; Gleason score ≤ 6; cancer in <3 biopsy cores and in $\leq 50\%$ of any core.
2. T1a, T1b, T1c, or T2a tumour; PSA <10 ng/mL; Gleason score ≤ 6.
3. T2b-T2c tumour, or PSA 10–20 ng/mL, or Gleason score 7.
4. That is, had or intended to continue AS until radical treatment was/is medically warranted.

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