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REVIEW

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The experiences of men on active surveillance for prostate cancer and their significant others: A qualitative synthesis

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Abstract

Background: Active surveillance (AS) for prostate cancer (PCa) is a monitoring pathway for men with low-grade, slow growing PCa and aims to delay or avoid active treatment by treating only in the case of disease progression. Experiences of this pathway vary but living with an untreated cancer can have a negative psychological impact on both the patient and their significant other (SO). Literature suggests partners are the primary source of support for men on AS, and therefore it is important to consider SO experiences alongside those of the patient. To the best of our knowledge this is the first UK-based qualitative review looking specifically at experiences of AS for both men with PCa and their SOs.

Methods: MEDLINE (Ovid), EMBASE, PsychINFO, CINAHL and Cochrane Library were searched for literature reporting qualitative experiences of AS for PCa for either men on AS or SOs (or both). 2769 records were identified and screened, with 28 meeting the eligibility criteria. Qualitative data were synthesised and included men on AS ($n = 428$), and SOs ($n = 51$).

Results: Experiences of the AS pathway vary but reports of uncertainty and anxiety were present in the accounts of both men on AS and SOs. SOs are intertwined throughout every part of the PCa journey, and couples presented as a unit that were on AS together. Both patients and SOs expressed a need for more support, and highly valued peer support. Despite this finding, men expressed a dislike towards ‘support groups’.

Conclusions: Increased recognition in clinical practice of SO involvement in AS is needed. Further research is required to explore the specific types of support that would be most acceptable to this population to address the unmet support needs uncovered in this review.

KEYWORDS
active surveillance, cancer, couples, experiences, oncology, partners, prostate cancer, qualitative, spouses

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1 | INTRODUCTION

There is a dearth of literature exploring experiences of active surveillance (AS) for prostate cancer (PCa) qualitatively, and an even smaller pool of literature including experiences of significant others (SOs), despite it being frequently reported that partners are the primary source of support for men with PCa.[1,2] Prior to this review a psycho-educational support intervention for men on AS for PCa, named PROACTIVE,[3] identified a gap in the evidence base regarding the role of the SO as part of a dyad facing AS rather than active treatment for PCa. SH was a researcher involved in the PROACTIVE intervention development and feasibility study. It is well recognised that living with a chronic and/or potentially life-threatening condition impacts more widely than the individual alone, with SOs experiencing detrimental illness related effects,[4] and providing both medical and emotional influences impacting patient outcomes.[5–9]

It is somewhat easier to find qualitative literature about dyadic experiences of PCa not specific to AS, and although AS specific experiences may differ, such literature provides some valuable insights into how dyads navigate this disease together. For example, a 2018 review collated qualitative literature (37 studies) on experiences of couples affected by PCa[10] and included SO experiences to describe the challenges they endure.

This 2018 review reported partners feel unsupported and sidelined both by their partners with PCa and healthcare professionals. SOs often felt their contributions were not acknowledged, and their needs were not addressed. Some partners described how the men with PCa withdrew emotionally and physically and sometimes asked them not to discuss the illness with others. This led to partner feelings of isolation and being unsupported, and some would have liked to have sought support outside of the dyad to help them process the situation themselves.[10] These feelings of isolation were not unanimous, and a contrasting theme titled 'the value in facing PCa together' depicted a different picture. The literature included found a strong presence of the word 'we' when talking about the illness; couples faced PCa as a team, recognising the diagnosis will impact them both individually and as a couple. For some, the illness brought them closer together and provided perspective on the things that were most important to them.[10] This 2018 review provides insight into how couples negotiate PCa and PCa treatment, and although there may an overlap between experiences of this population and those specifically on the AS pathway, there is also likely to be differences.

The limited existing reviews reporting experiences of men on AS do not explore SO experiences and include few UK-based papers.[11,12] A USA review reported patient and health care provider experiences of AS in PCa ($n = 61$) and three other types of cancer (ductal carcinoma in situ ($n = 2$), chronic lymphocytic leukaemia ($n = 4$), renal cell carcinoma ($n = 6$)).[11] 22 of the 61 PCa papers reported findings related to the psychosocial aspects of AS which were mixed and conflicting. Compared to men undergoing radical prostatectomy or radiotherapy some studies ($n = 10$) showed men on AS reported lower levels of anxiety and better mental and physical health-related quality of life. In contrast, other studies ($n = 4$) reported higher levels of anxiety and depression in AS than those undergoing active treatment. The authors stated the need for future research to explore why the findings are so polarised, and to evaluate interventions aiming to improve factors which may influence experiences of AS, for example, interventions to improve AS communication.[11]

A Canadian review of 36 articles explored the psychosocial needs of men on AS for PCa and the barriers to its uptake.[12] They reported that men with low-grade slow growing PCa displayed lower levels of distress compared to those with advanced PCa or those with other cancers, and only slightly more distress than the general population. Their findings indicate a lower age at diagnosis as an independent predictor of increased distress. Feelings of anxiety in this population were mostly attributed to fear of disease progression, and concern around the inaccuracy of monitoring prostate-specific antigen (PSA) test results. This review revealed men on AS often felt alone with the disease and experienced a negative impact on close personal relationships. The men worried that asking for help may be seen as a sign of weakness, and suggestions of support groups were disliked. However, the authors placed high value on the potential impact of support groups and advised the development of interventions to adjust ingrained attitudes about support groups to reduce the barriers to men on AS seeking peer support.[12]

Themes of uncertainty, anxiety and depression are present in the existing reviews reporting experiences of AS for PCa,[11,12] and suggestions have been made to help improve the psychological wellbeing of this population such as; increased education and good communication in relation to AS[10]; interventions to reduce anxiety and uncertainty; support groups; the involvement of partners[12]; and increased use of cancer nurse specialists.[13]

This is the first qualitative systematic review to specifically focus on both experiences of men on AS for PCa, and of their SOs. Having a better understanding of SO role in AS has the potential to inform clinical care and support for men on AS for PCa.

2 | AIM

To synthesise the evidence exploring patient experiences of undergoing AS for PCa, and the experiences of their SOs.

3 | METHODS

3.1 | The search strategy

A systematic search identified papers containing experiences of men on AS, and/or experiences of SOs. Search terms were created using the PCO framework (Population, Context, Outcome),[14,15] (see Appendix 1), and was used to design the research question for this qualitative synthesis.

The following databases were searched: MEDLINE (Ovid), EMBASE, PsychINFO, CINAHL and Cochrane Library. Each database was searched by lead researcher SH, in consultation with an expert librarian. Truncations and Boolean operators were used. See Appendix 2 for the full search terms used in each database.

3.2 | Article selection

Retrieved articles were exported into EndNote and de-duplicated. Remaining articles were exported into Rayyan and screened.

To be eligible for inclusion articles had to be published in English, after 1990 and include: data from men (over 18) diagnosed with PCa being managed using AS or data from their SOs; experiences of AS; a qualitative component. (See Appendix 3 for more detailed inclusion/exclusion criteria.)

The screening process is described in Table 1.

3.3 | Quality appraisal

All included papers were assessed for quality using the Critical Appraisal Skills Programme (CASP)[16] framework for quality appraisal (see Appendix 5). Papers were not excluded based on quality; rather the assessment was used to provide an indication of how each paper should be weighted. None of the included papers were sponsored by drug companies.

3.4 | Analysis

Eligible papers were imported into NVivo, and thematic analysis was performed on the 'results' section of each paper. The Thomas and Harden (2008)[17] method for performing thematic synthesis was chosen as the majority of the included papers had been analysed using thematic analysis, aiding the process of interpretation. Thematic synthesis allows emerging themes to be grounded in the data, minimising the influence of the researcher's previous knowledge. Table 2 describes the three-step analysis process.

TABLE 1 The screening process.

Stage	Description
1	Articles were included/excluded based on the title and abstract. If eligibility was unclear from the title and abstract alone, the full text was reviewed. The process, obtained articles and decisions were discussed with all authors at regular team meetings
2	The full text was obtained for all included and uncertain articles. The uncertain articles were reviewed, and an inclusion/exclusion decision was made
3	A data extraction form was used for eligibility screening which included: study authors, year of publication, sample, country of origin, setting, study design, analysis and main themes. See Appendix 4 for extraction form, and Table 3 for summary characteristics. To minimise bias double screening was undertaken by HE, BS and RB on 20% of articles

4 | RESULTS

4.1 | Search results

Searches and references from literature reviews provided a total of 28 eligible papers (Figure 1). The CASP analysis raised no major methodological concerns and the papers were treated equally throughout the analysis. See Appendix 4 for detailed characteristics of each included paper and Table 3 for a summary.

4.2 | Themes and subthemes

Figure 2 shows the main themes and subthemes that developed from the data.

4.3 | Theme 1: A speck of insignificant cancer versus a frightening disease

4.3.1 | Polarised perceptions of prostate cancer

Patient perceptions of PCa varied, but the majority of participants described their cancer with words such as 'small' or 'insignificant', with a minority perceiving their cancer as serious or life threatening. One participant explained how he told his family that his localised PCa was different to other types of cancer[18]:

> Now remember, we've been through a cancer episode before … this is a very different story than the other

TABLE 2 Thematic analysis process.

Stage	Description
Coding text	The results and findings sections of each paper were coded line by line
Developing descriptive themes	The first five papers initial codes were used as a guide to form new codes and a coding manual was developed which was used to analyse subsequent articles. Amendments were made to the manual when considered necessary. After all revisions were complete the final coding manual was created and applied to the whole data set
Generating analytical themes	The descriptive themes that had developed inductively from the results and raw data, were grouped and analysed to answer the research question. Existing themes within the published papers were not used to shape the results, rather the themes for the synthesis were developed from the results and sections and quotes published in the papers

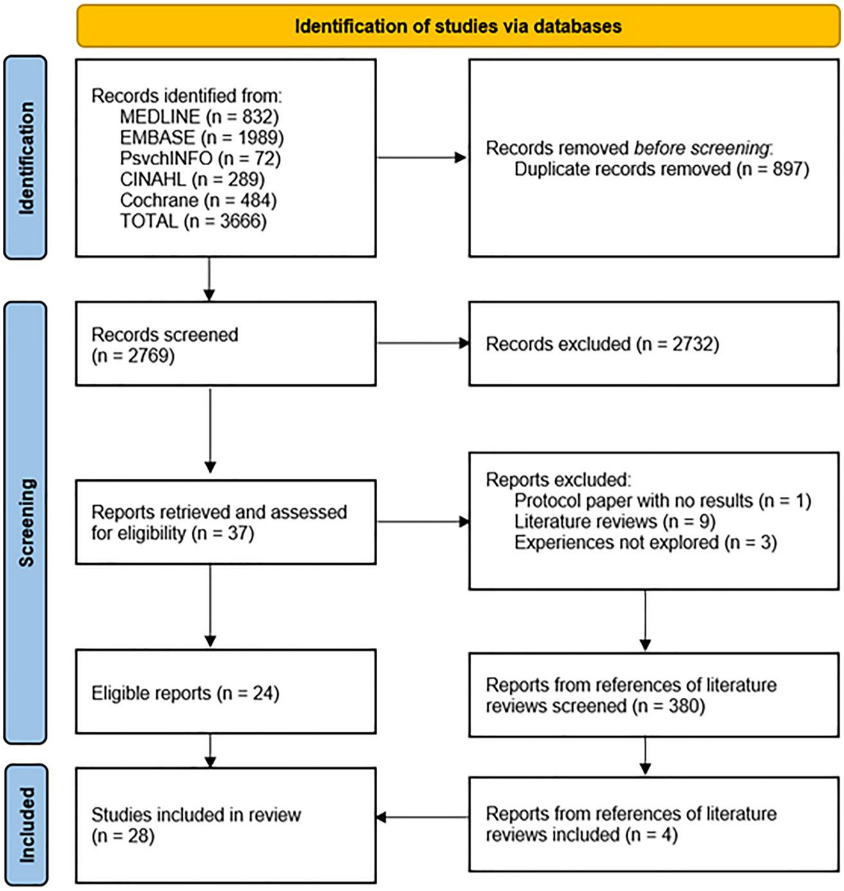

FIGURE 1 PRISMA to show screening results. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

> one was [kidney cancer]. I told my children, and my wife as well, different game with this one. And then tried to put them at ease, somewhat … it didn't somehow indicate a flare-up or immediate problem.[18]

Mroz et al. identified a pattern of patients 'minimising' the threat by using phrases like a 'speck of cancer' or 'having signs of cancer', and interpreted this minimisation as a mechanism to assist AS acceptance.[19]

However, not all men across the studies felt this way, and, although a minority stance, some felt scared by 'even the word cancer'.[20] One participant described his fear as follows:

> Well, that [dying from a heart attack] really don't bother me as bad as thinking about cancer. Anytime that cancer is mentioned, it's frightening. A heart attack or stroke or something doesn't worry me as much as knowing that I've got this.[18]

4.3.2 | Mixed feelings about active surveillance

Reflecting the pattern of patient perceptions of PCa, feelings about AS and living with cancer seemed to vary across the sample with the majority of men feeling comfortable living with cancer and content being managed with AS, viewing it as safe. Participants felt the regular monitoring of AS provided reassurance and confidence that they were doing the right thing[21]:

> Maybe you can call me crazy … I feel very confident in the approach that I'm on with [my urologist] … I haven't experienced anxiety. I mean, it hasn't really distracted [me] for more than a second, occasionally, from my normal routine … I know some people that worry. I've just never been that way.[21]

Davison reported specialists recommending to 'just watch it for now' or 'keep an eye on it' gave patients a sense of relief, indicating that their cancer was low risk and slow-growing.[22] Other reasons for being content with AS included the opportunity to avoid the unwanted side effects associated with radical treatment,[21,23–25] giving themselves more time to better understand the disease,[23,26] giving time for new treatments to potentially become available,[18,27,28] and avoiding the need for time off work to recover from radical treatments such as surgery.[29,30]

A small number of participants reported struggling with living with an untreated cancer and expressed that AS takes 'an emotional toll over time',[27,31,32] and can be like living under a shadow, always 'in the back of their heads'.[33]

TABLE 3 Summary characteristics table.

Characteristics	Participants
Sample, *n*, (%)	
Total	479
Men on AS, previously on AS, or eligible for AS	428 (89.4%)[a]
Spouses/partners	51 (10.6%)
Year of publication, *n*	
2003	1 (3.6%)
2005	1 (3.6%)
2009	2 (7.1%)
2011	1 (3.6%)
2012	1 (3.6%)
2013	1 (3.6%)
2014	3 (10.7%)
2015	1 (3.6%)
2016	3 (10.7%)
2017	4 (14.3%)
2018	1 (3.6%)
2019	4 (14.3%)
2020	2 (7.1%)
2021	1 (3.6%)
2022	2 (7.1%)
Country of origin, *n*, (%)	
USA	11 (39.3%)
Canada	4 (14.3%)
Denmark	2 (7.1%)
Finland	1 (3.6%)
Australia	2 (7.1%)
Northern Sweden	1 (3.6%)
UK	6 (21.4%)
The Netherlands	1 (3.6%)
Design, *n*, (%)	
Semi structured interviews	17 (60.7%)
Focus groups	3 (10.7%)
Mixed (focus groups and interviews)	2 (7.1%)
Structured interviews	1 (3.6%)
Interviews (structure not specified)	1 (3.6%)
Mixed (semi structured interviews and open dialogue)	1 (3.6%)
Other (mixed methods using HLQ as a framework)	1 (3.6%)
Longitudinal serial in-depth qualitative interviews	1 (3.6%)
Unclear	1 (3.6%)
Analysis, *n*, (%)	
Thematic analysis	17 (60.7%)
Constant comparative analysis	1 (3.6%)
Fundamental qualitative methodology	3 (10.7%)
Modified grounded theory	1 (3.6%)
Qualitative description analysis	1 (3.6%)
Phenomenologic-hermeneutic approach	1 (3.6%)
Interpretive description	1 (3.6%)
Iterative content-driven approach	1 (3.6%)
Other (unlabelled)	2 (7.1%)
Recruitment site, *n*	
Hospital setting	21 (75%)
Unclear (referred to as 'clinical sites')	1 (3.6%)
Database of cancer registrations	3 (10.7%)
Mixture (hospital setting + advert in magazine)	1 (3.6%)
Mixture (hospital setting and local cancer registry)	1 (3.6%)
Unclear	1 (3.6%)

Abbreviation: HLQ, Health Literacy Questionnaire.

[a] Unclear sample overlap between two papers, and unclear sample size in one paper. Sample size likely to be larger.

Those with a more negative view of AS tended to see it as temporary management protocol and considered it as an 'irrelevant' period of 'head in the sand' which avoided 'the inevitable'.[21,34]

4.4 | Theme 2: Anxiety or uncertainty about disease and treatment

4.4.1 | Men are anxious about missing the opportunity to treat

Although some participants appeared to be content with the AS plan, there were a high number of references to participant anxiety and uncertainty about the disease. By far the biggest concern was missing disease progression and consequently the opportunity to treat.[18,20,26,27,29,31,32,35–38] One participant described hypervigilance around symptom perception due to this anxiety:

> I noticed that every time I went to the bathroom, I was wondering if it [prostate cancer] was any worse … I was constantly concerned … was it getting worse.[18]

Another participant said simply:

> My 'fear' is that it (cancer) would get away. You'd miss your window of opportunity.[29]

A common pattern of increased anxiety around the time of surveillance checks was apparent.[3,21,30,31,36,39] This pattern was described by one participant as follows:

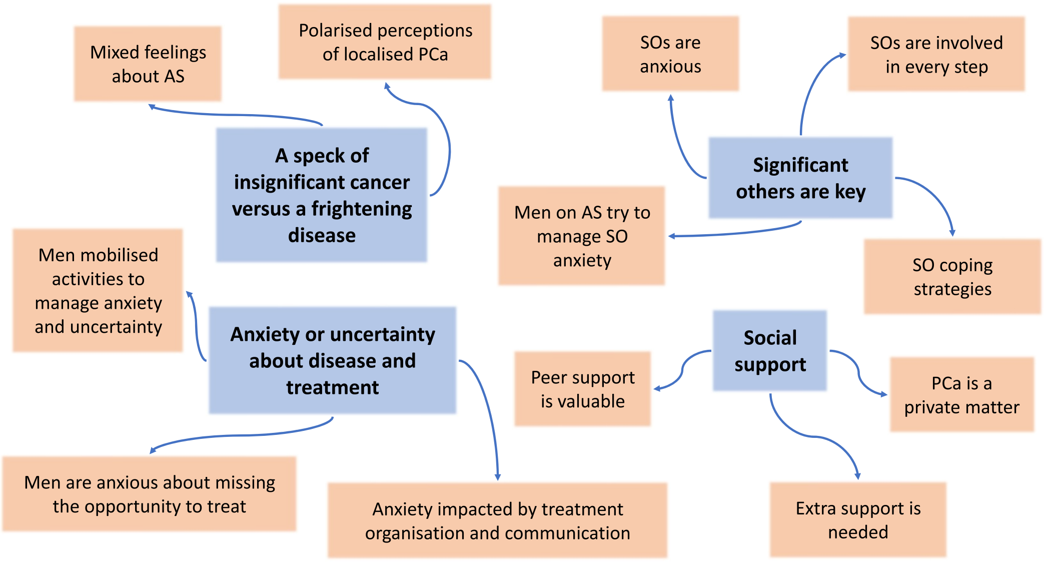

FIGURE 2 Themes and subthemes.

> six months from now, I gotta get another test. I'd start thinking about it, and there'd be a little anxiety in the week or two before, but I really didn't think very much about it in between.[21]

Some men felt worried about whether AS was the right decision for them.[18] One participant explained:

> I just don't know if I'm doing the right thing or not, just based on my age—I'll be 70 years old in May. But I just don't know to be honest with you. It's really a major decision … I still don't know if I'm doing the right thing, by observing.[18]

Contributing to this anxiety was the perception that PSA tests are unreliable, and participants described them as 'useless'.[34] The unreliability of these tests worry some men to the point of considering repeated checks:

> I keep saying to my wife, 'Should I go and get another opinion … the best of three?'[34]

4.4.2 | Anxiety impacted by treatment organisation and communication

Negative experiences of treatment organisation and communication from medical teams were present in one paper originating from the UK.[37] One participant reported how clinics were sometimes cancelled or rearranged, resulting in poorly timed scans and increased feelings of anxiety:

> … I would go to the effort of re-organising my scans so that they fitted around my appointments as often the scan date fell after the appointment, and then the hospital would call or send a letter cancelling the clinic. … That's definitely an area they could improve: at least reassuring the patient that their scan was ok, instead of leaving them in limbo …[37]

Men felt anxious waiting for test results, and these feelings were exacerbated when results were not returned in a timely manner, or communication from the hospital was lacking. Men on AS were left feeling of low priority:

> … When I had to go for the MRI scan, I would be very anxious waiting for those results because it often took weeks to hear from the hospital. I don't know how long it takes for someone to review these things but if they knew how we felt waiting perhaps it wouldn't take so long. I felt quite resentful, like my cancer was being de-prioritised because it didn't need treatment …[37]

Poor communication from the medical teams felt like a lack of consideration for how the patient may be feeling:

> … the doctor said he would ring me in a couple of days. A week went by so I rang the hospital and asked what was going on. I was told that the doctor would call me as soon as he was available as the nurse 'wasn't allowed' to give results over the phone … I wasn't very happy with that, I felt that anybody facing a possible

> cancer diagnosis is going to be stressed … so to leave me sitting there like a mug …[37]

4.4.3 | Men mobilised activities to manage anxiety and uncertainty

To manage anxiety men mobilised activities such as lifestyle changes,[31,33,38–41] information gathering,[27,31,34,40,41] continuing with work[18] and participating in religious activities.[18,33] This theme was common throughout much of the data.

The two most prominent activities men mobilised were lifestyle changes and information gathering.[40] One participant described said:

> I immediately changed my diet … we had greatly reduced the consumption of red meat and other fatty foods and our diet was pretty much chicken, fish, pasta, salads and then when I was diagnosed with prostate cancer and getting information off the web, they were suggesting more soy-type products, tomato-type products—tomato sauce, three times a week … I've added shitake mushrooms, which supposedly is a cancer fighter.[40]

Many of the participants were organised in their PCa related information gathering[18]:

> I read continually on this … I've got a folder probably half an inch thick on it.[18]

There was a desire for clearer and simplified information to help patients understand and interpret clinical results[41]:

> There's a lot of jargon, and it's putting all the pieces together. Remembering what the Gleason score is. All I remember is that it exists and higher is bad.[41]

There were a minority of participants however who did not feel the need to gather any additional information and were content with just the information provided by their physicians[19]:

> He (doctor) went straight for active surveillance. It didn't make any sense going around looking for other opinions really … I was quite happy with the deal sort of set up here and I wasn't going to be bothered running around looking for alternatives.[19]

4.5 | Theme 3: Significant others are key

4.5.1 | Significant others are involved in every step

Throughout the papers the importance of involvement of SOs in the PCa journey of patients on AS was evident. Even papers that did not directly study SO experiences reported data emerging from the interviews and focus groups corroborating their importance. Spouses usually attended medical appointments and were heavily involved in treatment decision making[23,42] saying for example:

> We say it's a joint effort—we are in this together. And, you know, figure out what is the best decision for us.[23]

Men on AS valued the support from spouses:

> They all haven't got a supportive wife; without her, it wouldn't have been such an experience for me where I felt confident about going forward. I think men who are on their own will find it much more difficult than maybe men who are married.[39]

In concordance with this, spouses viewed themselves as important in their role[29] and stated that their husbands were sometimes 'overwhelmed' or 'unable to manage the large amount of information about PCa that they gained while making a treatment decision',[29] highlighting their essential support and guidance.

In fact, spouses not only viewed themselves as important, but described themselves as also being under AS[34]:

> 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.
>
> (Spouse in ref.34)

Some spouses expressed the opinion that their husbands or partners ignore health concerns and remain in denial about the situation,[29] and many spouses actually noticed the PCa symptoms before the men, encouraging them to get checked out.[29]

4.5.2 | Significant others are anxious

Similar to men on AS, SOs reported anxieties around disease progression and a heightened sense of anxiety around the time of surveillance checks.[43]

> It's there, but I don't think about it all the time. It always comes to the surface at some point, when you lie awake and can't sleep … But I don't think it is taking over our lives. It comes when it comes.
>
> (Spouse in ref.43)

These feelings could interfere with everyday life, for example, work, but they eased over time[43]:

> I thought sometimes at work, 'You have to get some work done now.' My thoughts were all over the place.

> The further I came along, the easier it was to talk about it.
>
> (Spouse in ref.43)

The men on AS recognised their spouse's anxiety and often viewed it to be greater than their own[32]:

> My wife and I discussed it quite a lot … she was really concerned. And I guess I was as well a little bit that yeah it was internal, which was okay, so it was contained within the prostate, but there was always that fear … if it does get our and gets into your system elsewhere …[32]

4.5.3 | Significant other coping strategies

Similar to the previously mentioned theme regarding men mobilising activities to manage uncertainty, SO engagement in certain activities to cope with the situation were apparent. Spouses often participated in, and often initiated lifestyle changes.[43] For example, a participant explains:

> Sometimes we all eat rye, but we have other things on the table as well because the other family members don't always want to eat rye pasta.[43]

SOs also conducted their own searches for information, talked to friends and family, and tried hard to remain positive.[43]

4.5.4 | Men on AS try to manage significant other anxiety

Some patients felt a responsibility to protect SOs, either by keeping their own anxieties to themselves, or by opting for treatment in an attempt to reduce ongoing worry. The Berger et al. paper interviewed men who had previously been on AS, but left the programme to pursue treatment. 3 out of the 14 participants in this situation reported making treatment decisions to limit the worry of their SOs[20]:

> But having children, and people telling me that, 'Hey, you need to be there for the kids,' that sort of thing, I kind of thought of it differently than I would've if I were single or without children, I'd say. The children were a strong consideration in the decision making.[20]

4.6 | Theme 4: Social support

4.6.1 | PCa is a private matter

Some men were open and felt happy to talk about their PCa,[30] but most men preferred to keep it between themselves and their spouses referring to their situation as a 'private matter'.[22,44]

Reasons for keeping quiet about the diagnosis included the feeling of having to justify choosing AS,[26] wanting to avoid the perceived stigma around being a 'cancer patient',[24] wanting to avoid further confusing themselves with the opinions of others,[34] and simply finding it hard to talk about.[22]

The idea of stigma around being a 'cancer patient' was demonstrated in the Pietila study. One participant explained:

> Well, you don't talk about cancer openly, no you don't. It's still like a mark burned into your skin … And it's much tougher than in cardiovascular diseases. Some people get infarcts and some don't, it's like business as usual and belongs to life, but if you have cancer then it is like you're branded, sort of 'now, that's surely a serious case, isn't it?'[24]

4.6.2 | The 'right' type of support is needed

The topic of support for men on AS, and sometimes additionally for their spouses was present in most of the papers. Despite highly valuing PCa related discussions with others in similar situations,[24,37] men on AS consistently disliked the idea of attending support groups. Reasons for this included the fear of stigmatisation and being seen as a 'cancer patient', and the idea that attending a support group would mean admitting they had cancer.[24]

Spouses felt differently about support groups and one spouse in the Rossen et al. study expressed the desire for some extra support:

> That would have been good. Getting to know, "Missus, your husband is in a very early disease stage. Don't worry so much.
>
> (Spouse in ref.43)

Peers who had experienced PCa themselves were a highly valued source of support and advice, and seen as providers of a 'second opinion'[24,36,37]:

> … Whilst there was plenty to read on the internet, it's finding people that have been through it that I found most helpful. … Often you can read and read but, at the end of the day, talking to someone, is the most important part …[37]

In fact, one participant did not see the point in discussing his situation with people who had not had experience with something similar:

> If I know that someone hasn't got it [cancer], then it's no use to talk about it at all.[24]

Similarly, opinions and advice from peers who had links to the medical community were more highly valued than those who did not.[23] It seems the type of support offered is important with men valuing peer support and support from those with PCa knowledge.

4.7 | Broader impacts on everyday life

Although the papers explored anxieties around being on AS, broader impacts on everyday life were not explicitly explored. There was one mention of a change in mood, and one about a change in sex drive:

> I'm not as happy as I was … I've always as I say been a pretty happy-go-lucky guy, and I haven't been as happy and satisfied since I found this out. My immediate family called me grouchy and this and that … it's been on my mind a whole lot.[18]

> The idea of sex after you've been diagnosed with Prostate Cancer, I just had a real problem with it. It was the idea that this ejaculating … No, it's not that, it's the fact that it could have Cancer in it, you're sitting there and you're talking about having sex with your wife and you're working through a bad piece of pipe here …[40]

The lack of reference to changes to everyday life may indicate little impact, but it is difficult to say as broader impacts were not explicitly reported in the included papers.

5 | DISCUSSION

5.1 | Main findings

This synthesis provides a comprehensive overview of the published research on the experiences of men on AS and their SOs. This is the first review exploring experiences of men and SOs specific to AS. The papers included in this study report that a large proportion of men on AS describe their experiences of being on the pathway in a positive light; as safe, organised, and non-disruptive, and describe their cancer as minimal or insignificant. Despite these findings, anxiety and uncertainty still presented strongly in the data. Those that found being on AS difficult, frightening and distressing were somewhat the minority, but nonetheless these themes were present and powerful. SOs appeared intertwined throughout every part of the PCa journey, sometimes taking a leading role in information gathering, treatment decisions, and appointment organisation, and sometimes taking a back seat, letting the men on AS lead the process and protect them where necessary. SOs are just as involved and intertwined on this pathway as they are when active treatment is chosen. It seems both men on AS and their SOs would like extra support, but the form it would take is not clear. The high value placed on peer support for men on AS is a novel finding, despite co-existing with the finding 'support groups' are unappealing. This suggests alternative ways of providing peer support need to be explored.

5.2 | Comparison to previous literature

As reported in previous literature,[11,12] feelings of anxiety and uncertainty are common in this population. That said, not all men on AS for PCa report psychological distress and it seems men on the same pathway can have very different experiences psychologically. The differing and conflicting findings regarding the psychological impact of AS mirror those of both Kim et al. and Pickles et al., who also reported a variation in acceptance and AS related distress.[11,12] It is not clear why there is such variation in the way the pathway is experienced, but it is likely the reason is multi-factorial and may include factors such as: the extent to which SOs support the AS pathway,[23,42] previous experiences related to PCa (or experiences of people they know),[24,37] and the extent to which patients were educated and supported by medical teams.[20,22]

The current review shows SOs to be involved and crucial in the men's PCa journey, and the idea of PCa being a 'we' disease mirrors findings from Collaco et al. (2018),[10] who found a strong sense of togetherness in couples living with PCa and treatment side effects (not those on the AS pathway). The Collaco et al. (2018)[10] review revealed a contrasting theme around feelings of discontent among SOs, showing some felt isolated unsupported and sometimes excluded both by their partners and medical professionals. The feelings of isolation were sometimes exacerbated by requests from their partners that the diagnosis is not discussed beyond the dyad, restricting the SOs ability to seek wider emotional social support. The papers included in the current review did not report data about the extent to which SOs felt included or acknowledged, or how they might like things to be different, however, there may be some overlap with the subtheme 'PCa is a private matter'. This subtheme describes how some men prefer to keep their diagnosis between themselves and their spouses, uncomfortable with people in their wider circle knowing the situation. The papers in the current review did not report the SO side to this narrative, and it is not possible to say whether this is because SOs were content keeping the diagnosis within the dyad, or whether the SOs in the current review were not questioned in a way that would have elicited such information. Men in the Pickles et al. review reported the illness negatively impacted close personal relationships.[12] This finding was not supported by the current review.

Previous literature has found that couples sometimes hide their PCa worries and feelings from each other as a way of protecting each other,[10,33] for example, the idea of protecting SOs developed from interviews in the Hedestig study where participants described being solitary in their dealings with PCa with an aim to 'protect and not worry loved ones'.[33] The current review corroborates these findings demonstrated by the subtheme 'Men on AS try to manage SO anxiety', which describes how some men keep their anxieties to themselves in an attempt to shield SOs.

Support groups aim to minimise feelings of isolation by bringing people with similar experiences together, providing the opportunity to share fears and concerns and gain emotional support.[45] The finding in the current review that men dislike the idea of support groups is something that has been reported before, and the Pickles et al. review found men were vocal about their dislike for support groups, and see admitting a need for help as a sign of weakness.[12] The current review revealed men on AS value peer support (despite disliking support groups), and this is a finding which was not present in previous reviews. Previous literature indicates men prefer solution-focussed support over emotion-focussed support.[46–48] Much of the previous literature about support for men living with chronic illness focusses on gender differences, finding that men are significantly less likely to attend support groups than women.[48]

5.3 | Study limitations

The CASP process for quality appraisal[16] did not raise any major issues with the papers, and all were of adequate quality. Sharing evolving results and coding manuals within the study team throughout the process, and discussing emerging themes provided additional corroboration that the results presented are representative of the articles analysed.

The selection of studies included in this review represented PCa patients from eight developed countries (USA, Canada, Denmark, Australia, Finland, Northern Sweden, UK and The Netherlands). It is difficult to generalise the findings to other countries, especially those less developed, as differing healthcare systems, protocols for AS and cultural perceptions of AS may influence how the pathway is experienced. None of the papers originating from the UK included SO data, meaning it is not possible to generalise these findings to SOs and couples in the UK. The finding 'anxiety impacted by treatment organisation and communication' was found in one UK paper. There are not enough UK papers to understand whether this is a prominent issue, or to clarify whether it is an issue unique to the UK and UK healthcare system. However, it has been reported here because it is an important finding with the potential for implications. As well as the issue of demographic generalisability, the age of some of the included papers may pose a problem when interpreting the results. Management with AS has rapidly changed over the past 20 years, and experiences reported in older papers may be outdated as the AS protocol has been updated and understanding improved.

5.4 | Clinical implications

Due to a lack of comments on the subject in the published literature, interpretations about broader impacts living on AS may have on everyday life cannot be made. It is not clear whether participants failed to report broader impacts because AS does not significantly affect their lives day to day, or because this topic was not explicitly explored by any of the included papers. This should be explored in future research.

The idea that men on AS may convert to radical intervention without clinical indication to manage the anxiety of those close to them[20] is a strong argument for including SOs in any future AS psycho-social or educational programmes. Including and educating SOs with an aim to improving AS acceptance and understanding may allow the patients to focus on transferring to intervention only when clinically indicated.

Although men appeared to dislike the idea of support groups, the value they placed on discussing PCa related issues with men who had experience of the disease. They indicated their feelings were related to the stigma attached to the idea of attending a 'support group', rather than the activity itself. For future psycho-social interventions it would be advisable to take this into account and frame the idea of group support in a different light, perhaps refraining from the use of the term 'support group'. The acceptability of other ways of providing peer support should be explored, for example, one-to-one peer support.

5.5 | Conclusions

Patients cope with living on AS for PCa in different ways, with some requiring little support and experiencing very low levels of distress, and others finding the idea so distressing they consider converting to radical treatment. The varying degree to which patients experience anxiety, depression and uncertainty suggests a person-centred approach to managing feelings around being on AS (or having a SO on AS) may be necessary. Men on AS value peer support, and research is needed to explore the benefits of peer support delivered outside of a 'support group' setting.

The results provide insight into how future clinical practice may be adjusted to reduce the negative experiences reported, and highlights areas which would benefit from further research.

AUTHOR CONTRIBUTIONS

All authors had oversight of the review as it progressed, had full access to the data and take responsibility for the integrity of the data and accuracy of data analysis. Stephanie Hughes: Writing—original draft. All authors: Writing—review and editing. Hazel Everitt, Beth Stuart and Rebecca Band: Supervision.

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CONFLICT OF INTEREST STATEMENT

No potential conflict of interest was reported by the authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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APPENDIX 1

PICO

The acronym PICO (Population, Intervention, Context, Outcome) is often used in designing research questions for quantitative work. This can be modified to PCO (Population, Context, Outcome) to better fit qualitative methodology[14,15] (see Table 1), and was used to design the research question for this qualitative synthesis.

Modified PICO—PCO:

Population of interest	Men undergoing active surveillance for prostate cancer and their significant others
Context of interest	Active surveillance for prostate cancer
Outcome of interest	Experiences (e.g., experiences about changes to day-to-day life, feelings experienced while on the pathway, support from others, impact on relationships)

The search terms for the search were created using the PCO framework (see Table 2). The following databases were searched: MEDLINE (Ovid), EMBASE, PsychINFO, CINAHL and Cochrane Library. Truncations and Boolean operators were used.

PCO search terms for search.

Population	Context—Illness	Context—Treatment	Outcome
Significant other Partner Spouse Wife Husband Family Friend Relationship Couples Dyad Men Man Patient Support network	Prostate cancer Prostate tumour Prostate malignancy Prostate neoplasms	Active surveillance Watch and wait	Experience Perception Perspective View

APPENDIX 2

SEARCH TERMS

Qualitative synthesis search terms and results.

Ovid Medline ® Epub ahead of print, in-process and other non-indexed citations and Ovid MEDLINE	EMBASE	PsycINFO	CINAHL	Cochrane library
1. (prostat* adj3 cancer*).tw. 2. exp Prostatic Neoplasms/ 3. (prostat* adj3 tumo?r*).tw. 4. (prostat* adj3 neoplas*).tw. 5. (malignan* adj3 prostat*).tw. 6. 1 or 2 or 3 or 4 or 5 7. exp Watchful Waiting/ 8. (watchful adj wait*).tw. 9. active surveillance.tw. 10. (active* adj monitor*).tw. 11. 7 or 8 or 9 or 10 or 11 12. spouse*.tw. 13. wife.tw. 14. partner.tw.	1. (prostat* adj3 cancer*).tw. 2. Prostate Cancer.tw. 3. (prostat* adj3 tumo?r*).tw. 4. (prostat* adj3 neoplas*).tw. 5. (malignan* adj3 prostat*).tw. 6. 1 or 2 or 3 or 4 or 5 7. Watchful Waiting/ 8. (watchful adj wait*).tw. 9. active surveillance.tw.	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* 5. 1 or 2 or 3 or 4	1. TI prostat* N3 cancer* OR AB prostat* N3 cancer* 2. TI prostat* N3 neoplas* OR AB prostat* N3 neoplas* 3. TI prostat* N3 tumo?r* OR AB prostat* N3 tumo?r* 4. TI malignan* n3 prostat* OR AB malignan* n3 prostat* 5. 1 or 2 or 3 or 4	1. prostat* cancer* 2. prostat* tumor* or prostat* tumour* 3. prostat* malignan* 4. prostat* neoplas* 5. MeSH descriptor: [Prostatic Neoplasms, Castration-Resistant] explode all trees 6. #1 or #2 or #3 or #4 or #5 7. watchful wait* 8. active surveillance 9. active monitor* 10. MeSH descriptor: [Watchful Waiting] explode all trees

(Continues)

APPENDIX 2 (Continued)

Ovid Medline ® Epub ahead of print, in-process and other non-indexed citations and Ovid MEDLINE	EMBASE	PsycINFO	CINAHL	Cochrane library
15. significant other*.tw. 16. husband.tw. 17. family.tw. 18. relationship*.tw. 19. couple*.tw. 20. relative*.tw. 21. dyad*.tw. 22. support network.tw. 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 24. 6 and 11 and 23 25. limit 24 to (English language and yr = '1990 - Current')	10. (active* adj monitor*).tw. 11. 8 or 9 or 10 or 11 12. spouse*.tw. 13. wife.tw. 14. partner.tw. 15. significant other*.tw. 16. husband.tw. (8335) 17. family.tw. (1118789) 18. relationship*.tw. 19. couple*.tw. 20. relative*.tw. 21. dyad*.tw. 22. support network.tw. 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 24. 6 and 11 and 23 25. limit 24 to (English language and yr = '1990 -Current')	6. TI watchful waiting OR AB watchful waiting 7. TI watchful N wait* OR AB watchful N wait* 8. TI active surveillance OR AB active surveillance 9. TI active N monitor* OR AB active N monitor* 10. 6 or 7 or 8 or 9 11. TI spouse* OR AB spouse* 12. TI wife* OR AB wife* 13. TI partner* OR AB partner* 14. TI significant other* OR AB significant other* 15. TI husband OR AB husband 16. TI family OR AB 17. TI relationship OR AB relationship 18. TI couple* OR AB couple* 19. TI relative* OR AB relative* 20. TI dyad* OR AB dyad* 21. TI support network OR AB support network 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 23. 5 and 10 and 22 24. limit 23 to yr = 1990-current	6. TI watchful waiting OR AB watchful waiting 7. TI watchful N wait* OR AB watchful N wait* 8. TI active surveillance OR AB active surveillance 9. TI active N monitor* OR AB active N monitor* 10. 6 or 7 or 8 or 9 11. TI spouse* OR AB spouse* 12. TI wife* OR AB wife* 13. TI partner* OR AB partner* 14. TI significant other* OR AB significant other* 15. TI husband OR AB husband 16. TI family OR AB 17. TI relationship OR AB relationship 18. TI couple* OR AB couple* 19. TI relative* OR AB relative* 20. TI dyad* OR AB dyad* 21. TI support network OR AB support network 22. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 23. 5 and 10 and 22 24. limit 23 to yr = 1990-current	11. #7 or #8 or #9 or #10 12. spouse* 13. wife* or wive* 14. partner* 15. significant other* 16. husband* 17. family* 18. relationship* 19. couple* 20. relative* 21. dyad* 22. support* network* 23. MeSH descriptor: [Family] explode all trees 24. #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 25. #6 and #11 and #24 26. Limit 1990–current

APPENDIX 3

INCLUSION CRITERIA

Inclusion criteria.

Criteria	Justification/further notes
Men (over 18) diagnosed with prostate cancer being managed using active surveillance	The study must be about men on AS for PCa. Studies about men having alternative treatment for prostate cancer will not be included
Examines experiences of AS diagnosis and treatment plan (for either patients or significant others, or both)	Experiences and needs surrounding AS for PCa must be a primary aim of each study
Articles published in English	Due to limited resources translation of studies in other languages will not be possible
Articles published after 1990	AS was not common practice before 1990
Study must have a qualitative component	For synthesis

Exclusion criteria.

	Reason	Further explanation
1	Study not specifically about AS	Sample may include men on AS, but not focussed on AS. Topic may be about AS, but study sample are not on AS (e.g., may be about treatment decision making)
2	Study does not look at experiences of AS	Papers may look at experiences of other things, for example, using a decision aid, but would still be ineligible if experiences of AS are not explored
3	No qualitative component in the study	
4	Article is not published in English	
5	Article published before 1990	
6	Other	

APPENDIX 4

PAPER CHARACTERISTICS

Qualitative synthesis included papers characteristics.

Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Mallapareddi et al.[29]	2017	12 men on AS and 6 partners	USA	Focus groups	Thematic analysis	Local cancer registry and academic urology office	• Terms used to describe AS • Influencing factors to pursue AS: Seeing their cancer as 'small' and 'low-grade' • Trust in their physician • Concerns about PSA testing and prostate biopsies • When to end AS • Medical mistrust from black men's focus groups only • Men's denial from partner's focus groups only • Sharing cancer diagnosis and justifying decision to others
Rossen et al.[43]	2016	8 spouses of patients on AS	Denmark	Semi structured interviews, which turned into an open dialogue	Constant comparative analysis	Participants in the Nordic Lifestyle Intervention Trial (NILS) study (Department of Urology at Aarhus University hospital, Denmark)	• Feeling insecure • Lack of information • Anxieties • Coping ○ Seeking information ○ Setting information aside ○ Active support ○ Communication • Feeling reassured ○ Active support ○ Confidence/hopefulness ○ Communication
Yen-Chi et al.[42]	2016	15 couples given all information about treatment options	USA	Semi structured interviews	Thematic analysis	Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Centre	• Initial reactions to the diagnosis • Information seeking • Making the decision
Bailey et al.[18]	2005	10 men on AS	USA	Semi structured interviews	Fundamental qualitative description	The urology clinic of a tertiary care medical centre located in a south-eastern state	• Uncertainty about disease and treatment • Danger appraisal • Opportunity appraisal

(Continued)

Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Berger et al.[20]	2014	14 men who self-elected to leave AS	USA	Semi structured interviews	Modified grounded theory	Brady Urological Institute at Johns Hopkins School of Medicine	• Reasons for participating: 'You've got a 25-year outlook before it's going to kill you' • Follow-up in active surveillance: 'Getting the oil changed' • Reasons for seeking treatment: 'A time to do it' • Fear of cancer: 'The word "cancer" scares me' • Loved ones' worry and experiences: 'Being there for the kids'
Davison et al.[22]	2009	25 men on AS[a]	Canada	Semi structured interviews	Thematic analysis	Vancouver Prostate Centre and the British Columbia Cancer Agency	• Patients' perceptions of their prostate cancer • Physician recommendation • Decision control—who made the decision? • Avoiding side effects of treatment • Seeking information to make a treatment decision • Advice from family and friends • Pre-existing medical conditions • Age • Coping on active surveillance
Fitch et al.[27]	2017	52 men eligible for AS	Canada	Semi structured interviews and focus groups	Qualitative description analysis	PCa programs in Montreal, Toronto, Winnipeg, Vancouver, and Thunder Bay	• An important decision is needed at a time of emotional upset and uncertainty • Information is necessary on a number of topics before a decision can be made about AS • Disease status and quality of life are important factors for men in deciding about active surveillance • Conversations with doctor (s)have significant influences on men in their decision-making about active surveillance
Hedestig et al.[33]	2003	7 men on AS	Northern Sweden	Semi structured interviews	A phenomenologic-hermeneutic approach	Database containing registration of prostate cancer in northern Sweden	• To be alone with the disease experience

(Continues)

(Continued)

Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
							• To be uncertain, afraid and worried • A masculine experience • The physician—a companion
Kayser et al.[49]	2015	8 couples where the men were on AS	Denmark	Other (mixed methods using Health Literacy Questionnaire (HLQ) as a framework)	Thematic analysis	Participants in the Nordic Lifestyle Intervention Trial (NILS) study (Department of Urology at Aarhus University hospital, Denmark)	• Involvement of their spouses and people around them • Their support from and interaction with healthcare professionals • Their use of the Internet for information retrieval
Kazer et al.[35]	2012	6 men who had undergone AS for a minimum of 6 months before converting to radical treatment	USA	Structured interviews	Fundamental qualitative methodology	Identified from the clinic schedule by participating urologists in the eastern United States	• A dangerous wait • Clinical surveillance • Need for information and support • The aftermath
Kazer et al.[40]	2011	7 men on AS	USA	Focus groups	Fundamental qualitative methodology	Identified from the clinic schedule by participating urologists in the eastern United States	• Sources of support • Sources of information • Disease monitoring/vigilance • Myths/misinformation/frequently asked questions • Health promotion and taking charge
Loeb et al.[41]	2018	37 men on AS	USA	Focus groups	Thematic analysis	Men identified through 2 'clinical sites'	• More information on PCa • More information on active surveillance • More information on complementary options • Greater variety of resources • More social support and interaction • Verified integrity of information
Lyons et al.[28]	2017	19 men eligible for AS or treatment (and 16 practitioners) [b]	USA	Semi structured interviews	Thematic analysis	Academic medical centres	• Active surveillance as a temporary decision • Active surveillance equated with inaction • Malleability of representations of active surveillance

(Continued)

Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Mader et al.[23]	2017	15 men on AS[b]	USA	Semi structured interviews	Thematic analysis	2 academic centres	• Selection of active surveillance as part of coping • Reliance on social support • Trust in the medical community
Mroz et al.[19]	2013	25 men on AS[a]	Canada	Semi structured interviews	Thematic analysis	Vancouver Prostate Centre and the British Columbia Cancer Agency	• Therapeutic communications ○ Masculine hierarchies and men of few words ○ Positioning risk in diagnosis with 'benign' cancer ○ Confident in physician • Threat based communications ○ Dazed and silent ○ The devil is in the detail
O'Callaghan et al.[34]	2014	21 men and 14 partners	Australia	Semi structured interviews	Thematic analysis	A private urology practice, an integrative cancer centre, and a public hospital's oncology service	• Treatment decisions are affected by information gathered and varied emotional and relational reactions ○ Information was satisfactory, contradictory, stressful, and/or misunderstood ○ Decision making: Difficulties, assistance, and rationales • Men and partners both experience and often cope with AS ○ Partners' shared experience of AS and its advantages ○ Pre-existing strengths, informal supports, and maintaining 'normal' life assist coping with AS ○ Cancer monitoring and confidence in health professionals assist coping with AS ○ AS stressors encompass illness uncertainty, monitoring stressors, and inconsistent information ○ Ceasing AS is informed by personal and medical factors

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Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Oliffe et al.[30]	2009	25 men on AS[a]	Canada	Semi structured interviews	Interpretive description	Vancouver Prostate Centre and the British Columbia Cancer Agency	• Locating uncertainty in AS • The self-management of uncertainty in AS
Pietila et al.[24]	2016	10 men on AS (and 10 having radical treatment [RT])	Finland	Semi structured interviews and focus groups	Unclear	Tampere University hospital and 3 volunteers from advert in a magazine	• Justifying the rationality of treatment choice • Taking an active stand to stigma • 'It was the only right choice': The unquestionability of the decision
Volk et al.[26]	2014	15 men on AS (and 15 having RT)	USA	Semi structured interviews	Thematic analysis	Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Centre	• AS is an organised, supportive process • AS prolongs current good health • Viewing their cancer as low risk and having time to decide about treatment • Avoidance of side effects of treatment • Importance of physician recommendation about AS • Justifying the decision to others • Desire for immediate cure
Beckmann et al.[37]	2021	14 men on AS	UK	Semi-structured interviews (face-to-face)	Inductive thematic analysis	The Royal Marsden Urology department	• Experience of consultations (diagnosis and follow-up) • Shared decision making • Support and information needs • Administrative and organisations issues • Partner, family and peer support
Donachie et al.[36]	2020	17 men on AS	The Netherlands	Semi-structured interviews (face-to-face)	Thematic analysis	Two Dutch Urology Clinics	• Impact of diagnosis • Relationship with physician • Coping strategies • Challenges during AS • Practical support needs • Emotional support needs
Eymech et al.[39]	2022	13 men on AS	UK	Semi-structured interviews	Thematic analysis	One London clinic	• Pathway to conversion ◦ Shaking the foundation ◦ Reminiscing over the past ◦ Rediscovering relationships • A man on my own ◦ The social stigma ◦ Nobody understands ◦ Alleviating burden ◦ Seeking belonging

(Continued)

Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Hughes et al.[3]	2019	13 men on AS	UK	Semi-structured interviews (telephone)	Thematic analysis	Two clinics (Southampton and London)	• Anxiety and living with AS • Motivation for taking part and perceived ineligibility for the intervention • Group workshops • Online modules • Perceptions of the impact of the intervention
Matheson et al.[38]	2019	24 men on AS or Watchful Waiting (WW)	UK	Semi-structured interviews (telephone)	Thematic analysis	Men identified through cancer registries in Scotland	• Appraisal of PCa as a minimal threat (vs. significant threat) • Positive reframing of the threats of PCa (vs. holding a generalised view of cancer) • Taking an independent approach and getting on with life (vs. struggling to get on with life) • Acceptance and normalisation of cancer diagnosis (vs. struggling to accept and normalise PCa diagnosis) • Preserving the normal self (vs. holding greater illness centrality) • Re-establishing a sense of security and letting go of fears (vs. struggling with uncertainty)
McIntosh et al.[32]	2022	33 men (10 on AS, 23 left AS)	Australia	Semi-structured interviews (telephone)	Thematic analysis	Men identified through Australian cancer registries	• Reasons for leaving AS • Balance of medical and personal reasons impacting decision making • Progression of PCa indicated by tests • Fear and anxiety regarding cancer progression and uncertainty • Desire to act now to cure the cancer • Vicarious experiences and advice • Long term AS becomes intrusive • Considering family • Current health is optimal for treatment • Health professional recommends treatment

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Authors	Year	Sample description	Country of origin	Design	Analysis	Recruitment site	Qualitative results and themes
Merriel et al.[25]	2019	20 interviews with stakeholders including men with and without PCa	UK	Unclear	Unclear	Unclear	• Men need more information and psychological support in the first 2 years of AS • Men need a named healthcare professional to discuss questions or concerns with
Seaman et al.[21]	2019	16 men on AS and 5 who had left AS	US	Semi-structured interviews	Iterative content-driven approach	Two academic medical centres	• Presentation of AS • Trust in urologist • Confidence in AS • Uncertainty tolerance • Biopsy schedule • Use of MRI • Importance of quality of life • Treatment inevitability • Confidence in protocol and urologist • Active engagement • Routine nature of AS • Social support • Intentions for AS • Tumour progression • Age • Treatment advances • Potential for regret
Wade et al.[31]	2020	20 men on AS	UK	Longitudinal serial in-depth qualitative interviews	Thematic analysis	4 centres in the PROTECT Trial	• Strategies: ○ Seeking clarity ○ Control ○ Reassurance • Contextual factors: ○ Influence of time in developing trust ○ Influence of caring role ○ Social context ○ Family and friends' experiences • Loss or lack of trust: ○ Conflicting advice ○ Lack of trust

[a] Potentially same sample.

[b] Potential sample overlap.

APPENDIX 5

CASP

The CASP framework

The CASP framework.[16]

Question	Hint: Consider	Possible responses
Was there a clear statement of the aims of the research?	What was the goal of the research? Why it was thought important? Its relevance	Yes Can't tell No
Is a qualitative methodology appropriate?	If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative research the right methodology for addressing the research goal?	Yes Can't tell No
Was the research design appropriate to address the aims of the research?	If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)?	Yes Can't tell No
Was the recruitment strategy appropriate to the aims of the research?	If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study If there are any discussions around recruitment (e.g., why some people chose not to take part)	Yes Can't tell No
Was the data collected in a way that addressed the research issue?	If the setting for data collection was justified If it is clear how data were collected (e.g., focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? If methods were modified during the study. If so, has the researcher explained how and why? If the form of data is clear (e.g., tape recordings, video material, notes etc.) If the researcher has discussed saturation of data	Yes Can't tell No
Has the relationship between researcher and participants been adequately considered?	If the researcher critically examined their own role, potential bias and influence during: (a) formulation of the research questions; (b) data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	Yes Can't tell No
Have ethical issues been taken into consideration?	If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) If approval has been sought from the ethics committee	Yes Can't tell No
Was the data analysis sufficiently rigorous?	If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process	Yes Can't tell No

(Continues)

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Question	Hint: Consider	Possible responses
	If sufficient data are presented to support the findings To what extent contradictory data are taken into account Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation	
Is there a clear statement of findings?	If the findings are explicit If there is adequate discussion of the evidence both for and against the researchers arguments If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst) If the findings are discussed in relation to the original research question	Yes Can't tell No
How valuable is the research?	If the researcher discusses the contribution the study makes to existing knowledge or understanding for example, do they consider the findings in relation to current practice or policy? or relevant research-based literature? If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used	Free text

CASP results: Are the results valid?

CASP section A: Are the results valid?

Paper	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	Comments
Mallapareddi et al.[29]	Yes	Yes	Yes	Yes	Yes	Partly	They did not discuss how they decided which method to use Relationship between researcher and participants: Perhaps did not 'critically examine' their own role but considered it—used same black male facilitator for all patient focus groups, and black female facilitator for partner groups. Did not go into detail about why this person was chosen
Rossen et al.[43]	Yes	Yes	Yes	Yes	Yes	Yes	
Yen-Chi et al.[42]	Yes	Yes	Yes	Yes	Yes	Yes	
Bailey et al.[18]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Berger et al.[20]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Davison et al.[22]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Fitch et al.[27]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Hedestig et al.[33]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants

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Paper	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	Comments
Kayser et al.[49]	Yes	Yes	Yes	Can't tell	Yes	Yes	
Kazer et al.[35]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Kazer et al.[40]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors explained the facilitator was male, but no further information
Loeb et al.[41]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Lyons et al.[28]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors describe job role of each interviewer, but did not comment on relationship to participants
Mader et al.[23]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Authors describe job role of each interviewer, but did not comment on relationship to participants
Mroz et al.[19]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
O'Callaghan et al.[34]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Oliffe et al.[30]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Pietila et al.[24]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Volk et al.[26]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants

(Continued)

Paper	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	Comments
Beckmann et al.[37]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Donachie et al.[36]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Eymech et al.[39]	Yes	Yes	Yes	Yes	Yes	Yes	
Hughes et al.[3]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Matheson et al.[38]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
McIntosh et al.[32]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Merriel et al.[25]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants
Seaman et al.[21]	Yes	Yes	Yes	Yes	Yes	Yes	
Wade et al.[31]	Yes	Yes	Yes	Yes	Yes	Cannot tell	Did not describe relationship between researcher and participants

What are the results?

CASP section B: What are the results?

Paper	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	Comments
Mallapareddi et al.[29]	Yes	Yes	Yes	States ethical approval. Does not detail how study was explained to participants, just that it was done by telephone. 1–3 quotes for each theme and an adequate description of each theme
Rossen et al.[43]	Yes	Yes	Yes	Explained informed consent process and ethics committee approval
Yen-Chi et al.[42]	Yes	Yes	Yes	
Bailey et al.[18]	Yes	Yes	Yes	
Berger et al.[20]	Cannot tell	Yes	Yes	
Davison et al.[22]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Fitch et al.[27]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Hedestig et al.[33]	Yes	Yes	Unclear	Stated that ethical approval was granted, but has not discussed further. Findings quite long winded and absorbed into the conclusions/ discussion section
Kayser et al.[49]	Yes	Yes	Yes	
Kazer et al.[35]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Kazer et al.[40]	Yes	Yes	Yes	Discussed possible distress in focus groups and procedures in place
Loeb et al.[41]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Lyons et al.[28]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Mader et al.[23]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Mroz et al.[19]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
O'Callaghan et al.[34]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Oliffe et al.[30]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further. Figure to show findings good
Pietila et al.[24]	Yes	Cannot tell	Unclear	Stated that ethical approval was granted, but has not discussed further. Statement of findings quite hard to pick out, absorbed into discussion
Volk et al.[26]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further
Beckmann et al.[37]	Yes	Yes	Yes	Stated that ethical approval was granted, but has not discussed further

(Continued)

Paper	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	Comments
Donachie et al.[36]	Yes	Yes	Yes	Stated that ethical approval was granted. Describes informed consent process
Eymech et al.[39]	Yes	Yes	Yes	
Hughes et al.[3]	Yes	Yes	Yes	Stated that ethical approval was granted. Describes informed consent process
Matheson et al.[38]	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations
McIntosh et al.[32]	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations
Merriel et al.[25]	Yes	Cannot tell	Unclear	Analysis process for interview data not described. Findings are absorbed into results and discussion with no clear statement of findings
Seaman et al.[21]	Yes	Yes	Yes	
Wade et al.[31]	Yes	Yes	Yes	Stated that ethical approval was granted, but does not provide further information about ethical considerations

How will the results help locally?

CASP section C: How will the results help locally?

Paper	10. How valuable is the research?
Mallapareddi et al.[29]	Researcher states new contribution to existing findings, states where further research is needed, consider the findings in relation to current practice (e.g., that the term AS needs to be standardised, and recognised as a management plan)
Rossen et al.[43]	Statement of 'nursing implications' helpful for future practice. Discusses the findings in relation to previous literature. Suggestions for future research made
Yen-Chi et al.[42]	Authors make suggestions where changes to future practice could be beneficial
Bailey et al.[18]	Statement of 'relevance to clinical practice' and suggestions for use of the findings
Berger et al.[20]	Authors make suggestions for clinical practice change
Davison et al.[22]	Researcher states relatively new topic and further research to be done as next steps
Fitch et al.[27]	Not all of the sample was on AS, but still valuable in understanding how/why men choose AS
Hedestig et al.[33]	Authors do not make suggestions for clinical practice implications; they also do not make suggestions for future research. They claim their study is just a snapshot of experience
Kayser et al.[49]	Future research suggestions, and implications for clinical practice discussed
Kazer et al.[35]	Suggestions made for future interventions supporting men on AS
Kazer et al.[40]	Suggestions made for future interventions supporting men on AS, and for future clinical practice
Loeb et al.[41]	Suggestions made for future clinical practice
Lyons et al.[28]	Suggestions made for future clinical practice
Mader et al.[23]	Suggestions made for future research
Mroz et al.[19]	Suggestions made for future clinical practice
O'Callaghan et al.[34]	Suggestions made for future clinical practice
Oliffe et al.[30]	Suggestions made for both future research and future clinical practice
Pietila et al.[24]	Hard to tell—although interesting, they authors do not provide suggestions about what to do with the information
Volk et al.[26]	Suggestions made for future clinical practice
Beckmann et al.[37]	Suggestions made for future clinical practice
Donachie et al.[36]	Suggestions made for both future research and future clinical practice
Eymech et al.[39]	Suggestions made for future research
Hughes et al.[3]	Suggestions made for future research
Matheson et al.[38]	Suggestions made for both future research and future clinical practice
McIntosh et al.[32]	Suggestions made for both future research and future clinical practice
Merriel et al.[25]	Unclear
Seaman et al.[21]	Suggestions made for both future research and future clinical practice
Wade et al.[31]	Suggestions made for both future research and future clinical practice