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Active surveillance for prostate cancer is a shared journey: the dyadic perspective

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ABSTRACT

Active surveillance for prostate cancer monitors disease progression, with a view to actively treat only if progression is evident. Living with an untreated cancer can negatively impact psychological wellbeing. Partners can influence decisions to convert to active treatment in the absence of disease progression, it is, therefore, important to consider partner reactions and responses to prostate cancer treatment options. We explored the experiences of men on active surveillance and their partners and the impact partner feelings, responses and reactions to active surveillance have on the patient. Semi-structured personal communication were conducted with nine male–female couples ($n = 18$). All male participants were on active surveillance for prostate cancer. Data was analysed using an adapted version of the Collaco et al. (2021) Framework Method for dyadic data analysis. Dyads function as an interconnected unit with interlinked emotional responses. Differing feelings about active surveillance within the couple were common; men prioritised avoidance of active treatment side effects, partners prioritised minimising the chance of disease progression. Partner inclusion is important, but they sometimes felt excluded by their partners and/or health care professionals. More support is needed for this population. Dyadic support is bidirectional and complex with partners often less comfortable with active surveillance than their partners. More research is needed to explore how partners can be better included and supported.

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KEYWORDS

Prostate cancer; active surveillance; significant other; qualitative; dyad

Introduction

Prostate cancer is the second most common cancer diagnosis in the UK after breast cancer, and the most common cancer diagnosis in men (Smittenaar et al., 2016). Due to the progress of prostate cancer screening programme incidences have increased alongside a decrease in mortality rates (Yu & Li, 2021). Men with localised, low grade, slow growing prostate cancer may be offered a monitoring programme known as active

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surveillance. The active surveillance protocol aims to help patients avoid or delay the unwanted side effects of active treatment (such as urinary incontinence and erectile dysfunction) by providing regular checks (such as biopsies, scans and blood tests) with a view to actively treat only if disease progression is evident. This type of prostate cancer can be so slow growing that active treatment is never needed clinically, however, living with the uncertainty of an untreated cancer can have an impact on psychological wellbeing (Alvisi et al., 2020; Biddle, 2021; Watts, 2015; Watts et al., 2015).

It is well recognised that living with a chronic and/or potentially life-threatening condition impacts more widely than the individual alone, with partners experiencing detrimental illness-related effects (Arden Close et al., 2010). Not only does the diagnosis impact those around the patient, but the opinions of friends and family with regards to the illness and proposed treatment plan can be influential in terms of both patient decision making and psychological wellbeing (Gorin et al., 2011). Partners of men with prostate cancer report similar psychosocial experiences, including feelings of uncertainty, to the patients themselves (Harden et al., 2002; Northouse et al., 2007). Serious illnesses such as prostate cancer can lead to changes in family communication and hence family relationships (Arrington, 2005). It is clear from previous research that spouses play a major role in helping men negotiate the illness, and should be included in programs of care (Harden et al., 2002; Kershaw et al., 2008) and treatment decision making (Schumm et al., 2010). The bulk of research in this area is not specific to active surveillance and is not UK-based (mostly studies originating from the US). Research applicable to the UK healthcare system is needed to explore partner and significant other involvement specific to active surveillance for prostate cancer.

The current investigation aims to explore the experiences of men on active surveillance and their partners, and to go one step further than previous literature by exploring the impact partner feelings, responses and reactions around the diagnosis and active surveillance plan have on the patient. We aim to provide a novel insight into the tangled web of emotional influences impacting patient outcomes. It is hoped improving understanding around the way patients and partners are intertwined when it comes to illness-related experiences, psychological wellbeing and decision making could inform and improve support for this population.

Methods

Objective

To explore the experiences of men on active surveillance and their partners, and to explore the impact partner feelings, responses and reactions around the diagnosis and active surveillance plan have on the patient.

Study design

This is a pragmatic, inductive and qualitative interview study; semi-structured personal communication were conducted with men of any age living on active surveillance for prostate cancer and their partners. Ethical approval for the study was granted by The University of Southampton Ethics Committee on 29 September 2017: ERGO 29 805.

Selection and recruitment of study population

Data collection

Participants were recruited via three UK-based prostate cancer charities; Prostate Cancer Support Organisation (PCaSO) (charity number 1 170 536), Prostate Cancer UK (charity number 1 005 541) and Tackle Prostate Cancer (charity number 1 163 152). The charities recruited by advertising in newsletters, on Facebook, Twitter and email circulation.

Semi-structured personal communication lasting 15–53 min were conducted by an experienced qualitative researcher (SH). A topic guide (see Appendix 1) was used flexibly to allow the interviewer to further explore any relevant topics raised by the participants. Individual interviews (dyads interviewed separately) were chosen to allow the participants to discuss their thoughts and feelings without censoring their answers due to the presence of their partner. It was felt this method would elicit the most open and honest accounts of experiences. Dyadic interviews were conducted as close in time as possible (one straight after the other when possible) to minimise cross-contamination. Whether the patient or partner was interviewed first was participant choice. Recordings were transcribed verbatim and anonymised by removing identifiable information.

Data analysis

The analysis process followed an adapted version of The Framework Method for Dyadic Analysis (Collaço et al., 2021). This method provides a clear, replicable process for organising dyadic data for analysis. The points at which the original method was adapted

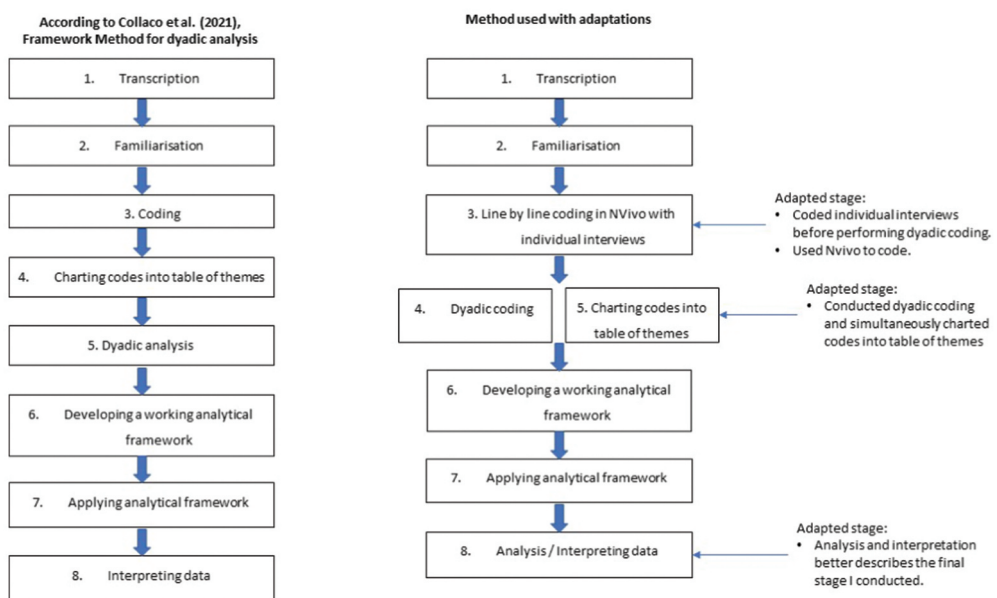


Figure 1. Adaptations to the Collaço et al. (2021) method.

Table 1. Description of data analysis process.

Stage	Description
(1) Transcription	Interviews transcribed verbatim into a word document.
(2) Familiarisation	The interviews and analysis were both completed by SH, aiding familiarisation. In addition, interview transcripts were re-read multiple times to maximise familiarity.
(3) Line by line coding with individual interviews in NVivo	Transcripts were coded using NVivo (QSR International: version 11). Codes were applied line by line, for example, where a participant was talking about a lack of prostate cancer support the relevant sections of the transcript would be coded to the parent code 'Supportive care needs' and the child code 'lack of support offered'.
(4) Dyadic coding	To conduct the dyadic coding each pair of interviews were displayed side by side. Dyadic codes were created based on the individual interview codes, and new ones added as they arose. Where the same/similar topics were being addressed across the two transcripts, for example, 'prostate cancer related communication', overlaps and contrasts were examined and noted. Where a topic was discussed in one interview, but absent from the other, this was included and noted.
(5) Charting codes into table of themes	While coding the paired interviews side by side relevant quotes were copied over to a table of themes (in MS Word) and a dyadic summary for each code was created.
(6) Developing a working analytical framework	Dyadic summaries were transferred into a working analytical framework (in MS Excel). Separate tabs were created for each broad topic, for example, 'supportive care needs' and 'prostate cancer related communication'.
(7) Applying analytical framework	The analytical framework was used to develop a Framework Matrix in word which summarised each broad topic with sub themes and subcodes. The Framework Matrix provided a clear summary overview facilitating discussions around possible themes within the study team.
(8) Analysis/interpreting data	Sub themes and subcodes in the framework matrix were explored alongside the dyadic summaries, allowing the study team to assess the strength of each emerging theme. The similarities between the couples' experiences, along with the way in which they varied were explored.

can be seen below in [Figure 1](#) and a descriptive breakdown of the process can be seen in [Table 1](#).

With the aim of enhancing reliability and reducing researcher bias (Roulston & Choi, 2018) the research team met regularly throughout the analysis process to critically review the findings, ensure developing themes were reflective of the data and discuss any differences in perspectives.

Results

Participants

Nine dyads (18 participants), all male–female spousal couples took part in the personal communication. See [Table 2](#) for characteristics.

Themes

Four main themes were iteratively developed throughout the analysis process: 1) the dyad is an interconnected unit, 2) factors driving emotional responses differ within dyads, 3) partner involvement is crucial, 4) more support is needed. See [Table 3](#) for a description of each theme and the subthemes present within each theme.

Table 2. Characteristics of participants.

Characteristics	N	%
Age		
• 51–60	3	16.7
• 61–70	14	77.8
• 71–80	1	5.6
Relationship status:		
• Married	16	88.9
• Unmarried partners	2	11.1
Employment status:		
• Retired	14	77.8
• Employed part-time	2	11.1
• Employed full-time	2	11.1
Ethnicity:		
• White British	17	94.4
• White other	1	5.6
Education level:		
• Left school before 15	2	11.1
• Completed secondary education	4	22.2
• College/specialised training	7	38.9
• University	5	27.8
Time between dyad interviews		
• 0 (interviews conducted directly one after the other)	16	88.9
• 7 days	2	11.1

Table 3. Themes and subthemes.

Themes	Definition	Subthemes
The dyad is an interconnected unit	The way patients and partners react to the diagnosis and negotiate the illness are complex and interlinked	<ul style="list-style-type: none"> – Cyclical triggering of emotional responses – Staying strong for each other – Support two-directional
Factors driving emotional responses differ within dyads	Couples did not always feel the same way about active surveillance and the decision not to pursue active treatment	<ul style="list-style-type: none"> – Different dyad feelings – Men more concerned about treatment side effects than partners
Partner involvement is crucial	Both patients and partners felt it is beneficial for partners to be included in all parts of the prostate cancer journey	<ul style="list-style-type: none"> – Varying levels of contentment with partner inclusion
More support is needed		<ul style="list-style-type: none"> – Inadequate access to a Cancer Nurse Specialist – Prostate cancer charities provide valuable support – What support is needed?

To maintain anonymity of the participants, pseudonyms have been used throughout the results.

Theme 1: the dyad is an interconnected unit

The overarching theme of shock, anxiety, distress and dismay hovered over most accounts regarding reactions to the diagnosis, but participants' reactions to the prostate cancer diagnosis (for either themselves or their partner) were influenced by a complex set of interlinked thoughts and feelings around negotiating the illness as a couple.

Cyclical triggering of emotional responses

Participants described feelings of worry and concern for each other and indicated negative emotion in one partner triggered a reaction and emotional response in the other. For example, Ben explained a cycle of concern and worry that existed between himself and his wife Betty:

She could see how I was handling or not handling it mentally and – that was causing – she was concerned and worrying about me and I was concerned and worrying about her. And we have an uncanny ability to transfer our emotions on to each other . . . it really is uncanny about how one can impact on the other. (Ben, 78)

Ben's wife Betty finds it hard to see Ben anxious or upset:

I would say that it's about the uncertainty, and difficult for me, seeing when he does get anxious about it or upset about it. (Betty, 66)

Along with the dyadic cycle of emotions there was a sense of the dyad as a unit, i.e. anything that negatively impacts one impacts them both. Feelings of protectiveness and unjustness were described by one partner following perceived poor care throughout the diagnosis period:

I hate to see somebody not listened to; I hate to see somebody disempowered, whether that's through their own condition or through outside lack of awareness or taking advantage. Yes, I guess protective, very protective – sums it up. (Sue, 54)

Staying strong for each other

It was common for participants to describe the desire to stay strong for each other, often by hiding their own anxieties. Sophie describes trying to mask her concern in front of Alex, feeling that she needed to support him:

'Well obviously I was upset for him. I tried to support him best I could and tried to show that I wasn't – you know – too worried; tried to support him. But again, you know, I mean it's hard isn't it, because you don't know if it's going to flare up or get worse or whether it's going to go on like that for years. So, it's always hanging over you, isn't it?' (Sophie, 60)

Support two-directional

Further demonstrating the interconnectedness of the dyads, support throughout the illness journey was not one directional (partner to patient). It was common for the men with the diagnosis to be the support for their partner too. This was true for Mark and Mandy. Although Mandy described the need to be strong for Mark and refrain from displaying too much emotion about the situation, she feels that Mark has been the one to support her, rather than the reverse:

I think he responded very well. I think perhaps he's been a bit more supportive of me than . . . he's been very reassuring most of the time; it's only now and again he gets a bit cross and a bit angry, and it's the – why me – sort of question that you're asking yourself. But, yes, I think he's perhaps been – I think he's been very positive; he's been more positive than I would have been. (Mandy, 62)

Theme 2: factors driving emotional responses differ within dyads

Differing reactions to the diagnosis. Among couples interviewed it was common for each partner to have different reactions to the diagnosis. The men on active surveillance often described feelings of relief that their diagnosis was not more serious, and they would not need to undergo imminent active treatment. Partners on the other hand felt more anxious about the implications of the diagnosis.

Stephen had been concerned he was going to be diagnosed with a higher grade, more aggressive cancer and describes feeling relief:

I remember the day very well and I felt like it was a weight lifted off my shoulders – because it was – it was just . . . a very minor amount of cancer cells on the biopsy samples . . . and I thought, well, that’s fantastic, nothing serious happening because that might never do anything that affects me. (Stephen, 62)

Stephen’s wife, Sarah, felt very differently, partly due to her previous experiences with the disease:

My dad had prostate cancer and died very quickly, so . . . my reaction was less of a sigh of relief, more of a – oh my God – reaction. (Sarah, 66)

Similarly, Alex and Sophie reacted differently to the diagnosis. Alex felt the diagnosis was relatively minor compared to his other health issues:

Well, I suppose, particularly with all the other things, it felt like, in the scheme of things, it was actually – I wouldn’t say trivial, but relatively minor compared with the other things and it seems that [at this early stage] that it was an early catch and therefore, you know, the prognosis was good. So, from the beginning, didn’t feel too bad, in the scheme of things, too bad. (Alex, 60)

Sophie, however, felt very concerned and worried he should be operated on to remove the cancer straight away:

I wondered whether they should do something straightway – you know – cut out all that. (Sophie, 60)

Mark had been conducting his own research prior to receiving the diagnosis and had become convinced the diagnosis was coming. He felt the process of gathering his own research and expanding his understanding allowed time for his acceptance of the situation to grow, and when the diagnosis came, he did not feel shocked or surprised:

Well, I’d been sort of expecting it, because I’d looked up through all the different effects that it was having on me; I thought it’s not just an enlarged prostate, it probably is something else . . . I just [continued] to accept it in my own way, that that’s what it was going to be, so I wasn’t really surprised when they sat me down . . . and told me I had got it. (Mark, 64)

Mark’s wife Mandy felt confused about the extent to which she should be concerned,

it’s difficult to say really, because – as I say – you’ve got different angles coming at you. So, you don’t want to be overdramatic but you don’t want to be dismissive. So, it’s kind of – quite a fine line in between the two, really, and then – sometimes you fear the worst and then other times you’re quite optimistic. (Mandy, 62)

The concern she felt was mixed with worry about how it would affect her, and guilt that she was worrying about herself rather than solely Mark:

I found it difficult – you know – thinking about it, because ... it's not me that's got the problem, but, at the same time, it would affect me and then you start thinking, you know, you're being selfish and – so it's all sorts of thoughts. (Mandy, 62)

Differing reactions to the idea of active surveillance

After the diagnosis choosing the active surveillance treatment pathway brought about a new wave of feelings for each couple. Often there were different beliefs and emotional responses for individuals within couples regarding the decision to monitor the cancer rather than intervene, for example, Mark was keen to proceed with active surveillance, whereas his wife Mandy felt opting for surgery would be more sensible. Mark explains:

... radical surgery or radiotherapy, I think that's something I'm hoping to avoid, and I'm pleased that I'm on active surveillance because I'm hoping that it will stay like that, because I am worried about the side-effects if I have either of those treatments – or any of the alternative treatments, which I know are available. (Mark, 64)

Mandy, however, views Mark's survival as the priority and is less concerned about the possible side effects of intervention:

The only thing I've ever said to him is that, if he needs to have treatment, I'd rather he have it, I don't care what – as long as you're here, does it really matter? We can manage. (Mandy, 62)

Similarly for Bridget and Max, Bridget is not worried by the possible side effects:

I would have said, well probably it's best removed, but I know that causes a lot of problems and Max would do anything to have that avoided, because he's heard so many stories and it wouldn't bother me either way ... So, if they took it out ... then he may become incontinent, I understand that – and all the sort of sexual parts of it ... you know, it doesn't bother me. (Bridget, 69)

Why are the reactions within dyads so often different?

The differing reactions to the diagnosis and plan of active surveillance within the dyads seemed to be driven by different factors. It seems the men's reactions were driven by relief they had escaped (at least for the time being) the side effects of active treatment such as erectile dysfunction and urinary incontinence. Partner responses seemed to be driven more by a feeling of panic at the prospect of losing their partners, and the long-term implications the diagnosis may have.

Theme 3: partner involvement is crucial

Universally all participants agreed that partner involvement in the prostate cancer journey is necessary and important. It was felt their involvement was most important at the point of treatment decision making, although participants were keen to stress the patient should make the final treatment plan decision. The way in which significant others were involved varied from couple to couple, for example, for some it seemed the partner was driving the process (encouraging their husband to go for investigations, keeping track of Prostate-Specific Antigen (PSA) results, organising and initiating

appointments) whereas for others, the partners were more in the back seat, with their husbands/partners taking the lead.

Varying levels of contentment with partner inclusion

Generally, dyads were satisfied with the level of partner inclusion in their prostate cancer journeys, however, there were feelings of discontent described by some. This discontent sometimes stemmed from the level of inclusion (or exclusion) demonstrated by the prostate cancer patient, and sometimes it stemmed from the seemingly reluctant inclusion of partners by healthcare providers. Most partners attend medical appointments, however, for one couple the man prefers to go alone, causing tension:

Sophie: He likes to do it on his own. I will go if he wants me to, I'd be happy to go, but he likes to go on his own. And I take him in the car if he needs to be driven, but usually I wait outside. I think if it was worse, he'd let me in with him, but he goes on his own.

Interviewer: And how do you feel about that?

Sophie: Again, I'd quite like to be in there with him but it's his choice. (Sophie, 60)

Sue and Mike felt dissatisfied with the level of partner inclusion by healthcare providers:

Yes, I'm his advocate, if anything. I was never asked, I was never even considered, he was never even asked – have you got a partner, I was not asked my name at the results appointment; I was not asked who I was, I wasn't offered a chair. . . That's not how people should treat each other, let alone medics to vulnerable patients. So [partner inclusion is] 120% crucial. (Sue, 54)

For Sue and Mike partner involvement was especially important because, as Sue explains, Mike suffers with Post Traumatic Stress Disorder (PTSD) and needs an advocate. It seems this was not taken into consideration throughout Mike's diagnosis period:

I don't know how familiar you are with PTSD, but it can manifest in all sorts of ways; he's somebody who acquiesces very easily, because it's the path of least resistance and he almost disappears sometimes, as an individual, when put under pressure. So, I think that's what happened, largely and, yes, he needs an advocate; he needs somebody to sit and just establish what it is he might like and want and that wasn't offered, that wasn't there. I've had to fill that role and it's been bloody hard, every step of the way has been a battle, even just getting to speak to relevant people, establishing who is in charge, establishing how we can talk to them. (Sue, 54)

Sue and Mike were not the only couple to describe dissatisfaction with the level of partner inclusion by healthcare professionals; Jan felt unwelcome in the department while Alan was taken for his biopsy:

I went up to the ward with him when he was going to have the biopsy and they said, oh right, off you go, you're not needed here now. And that I didn't like; I would like to have been able to stay in that area and read, rather than feel – I better go shopping (Jan, 61)

Theme 4: more support is needed

Many of the participants felt their support needs were not met. Although most were given leaflets to take away from clinic, participants often described feeling lost

between appointments. Mark explained that it is hard to ask all necessary questions in the context of an appointment where anxiety might be running high and there are time pressures:

Of course, at the time you're there, because it's done so quickly, you can't think straight away because you don't know to ask, I suppose; that's the only problem. It's after you've gone, you realise, oh I wish I'd asked this; I wish I'd asked that. Why didn't they tell me this? (Mark, 64)

Inadequate access to a cancer nurse specialist

The majority of participants felt the support offered post-diagnosis was inadequate. Interviews revealed a dissatisfaction with access to a Cancer Nurse Specialist (CNS). Some couples were not aware of an allocated CNS, or there was a delay in allocation, or they had an allocated CNS, but they were uncontactable. Stephen and Sarah were allocated a CNS, but found it difficult to reach them:

'Even in the early days when we wanted to contact him, you couldn't get hold of him, he was never there. So, I think that needs to be addressed, that professional support needs to be improved'. (Sarah, 60)

Subsequently the relationship broke down:

Well, I have got one allocated but I've never met him and the only time we spoke was when I had that new diagnosis that I wasn't informed about, when I started asking questions about why I hadn't been told and he got very aggressively defensive, so we don't speak really . . . So it does feel like we're off out on a limb, not really knowing what's happening between those three monthly spells. (Stephen, 62)

Consequently, the couple described feeling rather alone without a professional point of contact. Similarly, Sue describes finding it difficult to reach Mike's allocated CNS, and strained communication once they were in contact:

So, yes, going round in circles and no contact numbers and the clinical nurse specialist exceedingly difficult to contact. When we did contact her, she did not seem to take on board that Mike has got both memory and hearing trouble, as well as suffering PTSD, which was down on his referral letter, which was marked non-urgent and refused to, first of all, conduct any further communication by email, said, no, we can't do that; refused to send us the pathology report of the PSA graph. She did retract that eventually and then it was, oh, of course we'll – we can email you but, yes, unhappy story, a very unhappy story. (Sue, 54)

Dan and Emma also found the CNS support system did not work and feel a better relationship with the CNS would have been beneficial. Dan feels active surveillance patients are probably far down CNS' list of priorities as they are dealing with 'ill people':

The bit of support that hasn't worked . . . is what do they call it – key worker (CNS). Technically I haven't met him; there's a nurse at [city] who is supposed to be my first port of call and know all about me, but he doesn't know me from Matthew. He's dealing with ill people, I'm sure, than I and actually I think I feel slightly embarrassed ringing him up because he'd have to wrack his brains to try and work out who I was, or pretend to remember. (Dan, 70)

Although most reported teething problems as a minimum, some couples had more positive experiences with their CNS. Jan and Alan were not allocated a CNS until 4

years after Alan's diagnosis, but once they were, Jan found it helpful to have somebody to call with prostate cancer-related queries:

it wasn't until later that I realised we'd not been given a cancer care nurse and whether that was – well I don't know why – but we didn't get one, so I felt we were sort of dealing with it a bit on our own. That's helped because you're just talking to somebody without having to go to hospital to discuss things; that's much better. (Jan, 61)

Despite the CNS allocated to Ben and Betty being on holiday at the time of diagnosis, she became a supportive and beneficial support:

maybe a couple of weeks later, A got a phone call from a very nice specialist nurse at the hospital where he was diagnosed and I think it was just a blip at that time, because she had been on holiday. So otherwise she said he would have been given her name right away and I think that would be helpful. After that she was very, very helpful and that was open to me, if I wanted to speak to her. (Betty, 66)

Prostate cancer charities provide valuable support

Some of the couples interviewed sought support from prostate cancer charities and found the support they offered helpful and valuable:

I have to say – the charity [Macmillan] were very supportive. . . They were actually very supportive in saying – if you're finding it tough, if you're needing any support, we have specialist nurses available to talk to, that sort of thing. (Ben, 78)

There was a feeling that the specialist nurses were more accessible than those allocated to them by their medical team:

Certainly the specialist nurses at Prostate Cancer [UK] were very, very helpful; I phoned them on a few occasions and they've been excellent. And they've got urology nurses that the hospital who, again, has been very good in basically answering any questions and any concerns. (Max, 70)

What support is needed?

From a practical point of view there appeared to be a clear need for more guidance during the process of treatment decision making:

I just would have expected the system to – have been able to – because, you know, they're dealing with people like me all the time, so they know the questions I should be asking, because – I don't even know the questions to ask, to some extent, in the first place. So – yes. So, because of that comparison, so because – I suppose – it listed different treatments, the pros and cons are quite different, it is difficult and it will probably vary from person to person and depending on their age and their health and various other aspects, I guess as to – so – it's not easy probably to do that comparison. But that's definitely the one area where I would liked to have seen something more. (Alex, 60)

In addition to the lacking practical support and guidance, some described the need for additional emotional support. Views about how this support should be delivered were mixed, and opinions about support groups were divided. Any existing support groups offered to the participants were not specific to active surveillance, but rather prostate cancer in general. Although many concerns may overlap, men who have undergone active treatment, and those on active surveillance have different

supportive care needs. Max attended a support group, but found he was the only one on active surveillance:

I think I was a little bit sort of on my own there, on the active surveillance, because I think what happened was that they had a contact with the hospital and men then, who had gone through various treatments and so on, were given the support group details for them to join if they wanted to and get help that way. (Max, 70)

Max feels those on active surveillance are somewhat overlooked, and a support group specifically for those on active surveillance has not been considered:

Active surveillance tends to be a little bit glossed over, in other words it's summed up in a few words, in the sense that you're given a blood test every 3–6 months and then we're just keeping an eye on you. (Max, 70)

Max's wife Bridget feels joining a support group is the most important thing men on active surveillance and their partners can do for their psychological wellbeing:

You need to get a support group, which is the most important thing, I think, because then they don't feel alone and wives go along, some of the wives go along and they can see that it's just – it's just a medical thing; it's not personal, it's not sexual and all this business, it's just a thing that people have information to share. And it becomes a much more manageable thing, if you like and it's seen as, you know, commonplace almost, rather than something people get all embarrassed about talking about. (Bridget, 69)

Support groups did not appeal to all participants, and Ben demonstrated a clear dislike for the idea:

I was not inclined to go along to a session with other men and talk about prostate cancer in detail. (Ben, 78)

Instead, Ben felt it was better for his own psychological wellbeing to take a practical, proactive approach and help other men in similar situations by volunteering for prostate cancer charities:

I said I don't want to sit there with a bunch of men who are all talking about their prostate cancer, I want to think about other things . . . as I got over the anxiety part of it, I decided, no, I did want to put something back, but because I was volunteering for Prostate Cancer UK, it meant that I wasn't sitting with a group of men, talking about prostate cancer; I was supporting people who had recently been diagnosed or were in the process of going through the pre-diagnosis stage. So I was doing telephone support for people who were being offered the option of active surveillance and I was also doing telephone support for those who had been on it but just wanted to talk a bit more about it and I found that okay. (Ben, 78)

Discussion

Summary

This research explored the impact of the bidirectional relationship between partners and men on active surveillance for prostate cancer and uncovered a complicated tangle of interlinked reactions and emotional responses that exist within dyads negotiating the active surveillance pathway. Contextual factors and relationship dynamics need to be considered, and the impact of partner reactions is one contributing element. Our main

findings indicate the dyads function as an interconnected, interdependent unit with interlinked emotional responses, often triggering each other. To the best of our knowledge, this is the first UK-based qualitative study demonstrating the dyadic complexities in active surveillance for prostate cancer. Both members of the dyad experience prostate cancer-related distress, and both men on active surveillance and partners describe two-directional support.

Differing feelings about active surveillance and the decision not to pursue active treatment within the couple were common, with the men prioritising the avoidance of active treatment side effects, and partners keen to minimise the chance of disease progression, feeling less concerned about potential treatment side effects. Unanimously, participants agreed partner inclusion in all aspects of the prostate cancer journey was of utmost importance but did not always happen. More support is needed for this population, particularly between appointments. Respondents felt an accessible, reliable, professional point of contact to answer questions between appointments would be beneficial.

Strengths and limitations

The current investigation provides a novel insight into the complexities of undergoing active surveillance for prostate cancer as a dyad. While previous literature has explored partner experiences of men with prostate cancer (Collaco et al., 2018; Northouse et al., 2007), there is a lack of research exploring these experiences specifically for those on the active surveillance pathway, who are managing a different set of anxieties around living with an untreated cancer. Furthermore, previous literature fails to explore the complexities within the dyads, for example, how they feel about each other's reactions and the impact their reactions and responses have on each other. This detailed insight is important to better inform future support programs, and adjustments that may need to be made in clinical practice.

Another key strength is the rigor with which the interview and analysis process was conducted. Whilst impossible to eliminate completely, following a grounded, inductive approach to data analysis minimised the influence of the lead researcher's previous knowledge, pre-conceptions and bias. 10% of the transcripts were double coded, and the research team were consulted throughout the analytical process to ensure consistency and agreement within data interpretation.

There are some limitations to be considered when addressing the relevance of the findings. Recruitment proved difficult and resulted in a sample size smaller than we had hoped; 9 dyads (18 participants). A larger sample would have improved both reliability and generalisability. It is important to acknowledge the self-selecting nature of the participants included in this study. Our results revealed a level of 'togetherness' with couples demonstrating two-directional concern and support for each other. It is possible participants who felt less 'togetherness' in their relationships may have been less willing to take part in a dyadic interview study. Previous research has shown that when faced with prostate cancer dyads in stronger relationships report less distress than those in dysfunctional relationships, with dyadic functioning being key in the relationship between prostate cancer-related coping and distress (Banthia et al., 2003). Therefore, if

dyads spanning a wider variety of relationship quality had been included results may have been different.

Similarly, it is possible those who were more highly anxious, or those who perceived themselves as not anxious at all may have been less likely to agree to be interviewed. Participants interviewed in the current investigation were mostly open and willing to discuss the psychological and emotional impact of being on the active surveillance pathway. According to previous literature older male medical patients, including those with prostate cancer, are traditionally reluctant to discuss their psychological wellbeing (Chapple & Ziebland, 2002; Moynihan, 2002), indicating this may be another characteristic stemming from the self-selecting nature of this sample.

All participant dyads were white, heterosexual couples. Increased sample diversity to better reflect the characteristics of the population of those on active surveillance would improve the generalisability of the results.

Data in this study was collected at one timepoint and, therefore, it is not possible to assess how active surveillance-related experiences and feelings may change over time. Participants described feelings of heightened anxiety around the time of active surveillance protocol clinical tests. It is possible participants about to undergo some routine tests may have answered the questions differently to how they would have answered if interviews had taken place equidistant between progression checks.

Comparison to previous literature

The findings in the present investigation demonstrate a high level of involvement and importance of significant others and replicate findings from previous qualitative literature (Kazer, 2012; Mader et al., 2017; O'Callaghan et al., 2014; Yen-Chi et al., 2016). Previous research has shown that partner support (along with one-to-one peer support) are the most valued forms of support for men with prostate cancer (King et al., 2015), and the current investigation supports this notion. In addition, we found this support was two-directional within the dyad, with the men on active surveillance often supporting their partners, and 'putting on a brave face' for those close to them.

Although as a qualitative study, it is not possible to quantify psychological wellbeing, feelings of anxiety and discomfort around living with an untreated cancer were expressed. The active surveillance protocol requires patients to undergo investigations such as PSA tests, biopsies and MRI imaging at certain time points following diagnosis. Previous literature has documented a pattern of increased anxiety around the time of such tests (Lofters et al., 2002; Pickles et al., 2007) which was reflected in the narrative of the current investigation. According to our findings, this pattern of anxiety is not only present in the men undergoing the tests; the feelings are replicated in those closest to them, supporting previous literature showing chronic illness impacts more widely than the patient alone (Arden Close et al., 2010).

Although the majority of partners felt content with how they had been included in prostate cancer-related discussions, appointments and decisions, some felt excluded either by their partner or by medical professions, mirroring findings by Collaco et al. (2018). The partners interviewed in this investigation were supportive of their husband's/partner's choice to pursue active surveillance, even if they would prefer a more active approach. Previous literature suggests significant other opinions

and anxieties can influence treatment choice (Berger et al., 2014; Kazer, 2012); it is not possible to quantify the extent of partner influence within the current sample; however, the way each dyads presented as a unit suggests decisions were discussed and made together.

Future research

To obtain a broader, more inclusive understanding of the points raised in the current investigation future research would benefit from a larger, more varied sample of men and partners. For example, recruiting dyads recently diagnosed, and at different timepoints along the active surveillance protocol might provide a more accurate understanding of the emotional journey that runs alongside the processes of diagnosis, treatment decision making and ongoing clinical investigations. A longitudinal study utilising repeated measures may contribute valuable insights. Although it is difficult to steer clear of the bias's that exist due to the necessary self-selecting nature of sample in such studies, using a variation of recruitment methods, for example, a mixture of clinics, charities and social media may improve sample diversity.

Although the current investigation went some way to explore how partner reactions impact on men on active surveillance, a more in-depth investigation into how partner reactions impact the men's decision to remain on active surveillance would be valuable. Perhaps interviewing dyads who have converted to active treatment without clinical indication would provide a valuable insight.

Future research exploring clinician views about partner and significant other involvement specific to the active surveillance journey would be valuable. Exploring the extent to which clinicians consider, include and value partners, together with further research with patients and partners would inform changes that may need to be made in clinical practice. Such changes may include, for example, adding information to clinic letters encouraging patients to bring a partner or significant other to important clinic appointments; clinician training about the importance of including partners for improved acceptance and adherence to active surveillance; improved support aimed specifically at partners and improved information at the point of diagnosis.

Conclusion

Significant others of men on active surveillance are involved, important and potentially influential in patient acceptance, adherence and decision making. More research needs to be conducted to explore how partners can be better included and supported.

Authorship

SH conceptualised the study, led the ethics application, data collection and data analysis. HE, BB and BS contributed to data analysis, interpretation and presentation of results. All authors contributed to the writing of the manuscript and approved the final version for submission.

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Data availability statement

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

Ethical statement

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