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Running Head: Unmet Supportive Care Needs of Men on Active Surveillance

A systematic review of the unmet supportive care needs of men on active surveillance
for prostate cancer.

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Abstract

Objective: Understanding the unmet supportive care needs of men on active surveillance for prostate cancer may enable researchers and health professionals to better support men and prevent discontinuation when there is no evidence of disease progression. This review aimed to identify the specific unmet supportive care needs of men on active surveillance.

Methods: A systematic review following PRISMA guidelines was conducted. Databases (Pubmed, Embase, PsycINFO, and CINAHL) were searched to identify qualitative and/or quantitative studies which reported unmet needs specific to men on active surveillance. Quality appraisals were conducted before results were narratively synthesised.

Results: Of the 3,613 unique records identified, only eight articles were eligible (five qualitative and three cross-sectional studies). Unmet Informational, Emotional/Psychological, Social, and 'Other' needs were identified. Only three studies had a primary aim of investigating unmet supportive care needs. Small active surveillance samples, use of non-validated measures, and minimal reporting of author reflexivity in qualitative studies were the main quality issues identified.

Conclusions: The unmet needs of men on active surveillance is an under-researched area. Preliminary evidence suggests the information available and provided to men during active surveillance is perceived as inadequate and inconsistent. Men may also be experiencing unmet psychological/emotional, social, and other needs; however, further representative, high-quality research is required to understand the magnitude of this issue. Reporting results specific to treatment type and utilising relevant theories/models (such as the social ecological model) is recommended to ensure factors which may facilitate unmet needs are appropriately considered and reported.

Keywords

Prostate cancer; active surveillance; supportive care needs; systematic review

Background

Prostate cancer (PCa) is one of the most prevalent cancers in men worldwide^{1,2}. The majority of men diagnosed with PCa are classified as having localised, low-to-intermediate risk disease, and receive active treatment immediately upon diagnosis^{3,4}. Active treatments for low-risk PCa include radical prostatectomy and radiation, which often cause significant and ongoing side effects (including erectile, urinary, and rectal dysfunction) that can reduce quality of life⁵. Alternatively, men with low-risk, localised PCa may commence active surveillance (AS). AS involves closely monitoring biological markers of the disease (through regular prostate specific antigen tests, biopsies, magnetic resonance imaging, and digital rectal examinations) until progression is detected, wherein the patient is offered curative treatments⁶. According to the American Urological Association/American Society for Radiation Oncology/American Society of Urologic Oncology, AS is recommended as the best available option for patients with very low-risk PCa, and as a preferable option for patients with low-risk PCa^{7,8}. Research suggests that AS poses no greater threat to patient mortality or wellbeing than active treatments⁹⁻¹² when recommended and adhered to correctly. However, there is some concern men on AS experience psychological burdens¹³⁻¹⁶, which may contribute to AS non-adherence¹⁷. Emerging research suggests approximately 10%-20% of men transition from AS to treatment without evidence of disease progression¹⁸⁻²⁰. Empowering men to adhere to AS until they are medically recommended to transition to treatment requires consideration of their unmet supportive care needs.

According to the Supportive Care Framework²¹, needs that remain unmet may continue to cause the patient emotional distress or difficulty, thus negatively impacting their wellbeing²¹⁻²⁴. Measures of unmet needs, such as the Supportive Care Needs Survey²⁵, seek to identify the extent to which support needs have been met, thereby assisting in the improvement of support, resources, and services²². Studies evaluating PCa supportive care needs have recently been synthesised in comprehensive reviews. These reviews suggests up to 80% of PCa survivors experience at least one unmet supportive care need²⁶⁻²⁸, including physical needs (e.g., addressing

urinary symptoms)²⁶, social needs (e.g., unable to participate in social activities due to side-effects)²⁶, and informational needs (e.g., poor information on treatments and side effects)²⁷. While these reviews are informative, they have focused predominantly on men who have received curative treatments. Given AS does not involve any immediate intervention, the unmet needs of men on AS may significantly differ from those receiving curative treatments. Therefore, a deeper review of the unmet needs reported by men on AS is warranted, as is investigation of factors that may influence or explain these unmet needs. Together, this information may assist in the development of evidence-based interventions to support men on AS.

The present study aims to systematically review the literature to (1) Identify the unmet supportive care needs experienced by men during AS; (2) Identify factors, which may predict, relate to, or influence men's unmet supportive care needs during AS; and (3) Identify gaps in the literature and assess the quality of available evidence.

Methods

This systematic review has been conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines²⁹. The review protocol was registered a priori with PROSPERO (ID # CRD42018097177).

Eligibility criteria

Studies which met the following pre-determined criteria were included for review: (1) sample included men currently on AS for PCa and reported results specific to those men; (2) explored unmet supportive care needs of men on AS; (3) available in English; and (4) original research utilising a qualitative and/or quantitative design. Grey literature (e.g., dissertations, protocol papers or conference abstracts) was considered only if it met the above criteria and final results were available. Studies which reported men as being on 'watchful waiting' (WW) were considered as this term is often confused and used interchangeably with AS in the literature. However, such studies were only included if the participants were actually on AS rather than WW. This was established either by contacting study authors or when the provided definition of WW actually reflected AS (e.g., 'deferred' or 'delayed' treatment). Although very similar to AS, WW is often reserved for men with limited life

expectancy (≤ 5 years), as the aim is to monitor and manage the disease, rather than monitor with curative intent^{8,12}. Studies were excluded if they: (1) explored supportive care needs of men deciding whether to commence either AS or curative treatment, and/or (2) if the sample of men on AS also included men with metastatic disease, high-risk disease, or those whose treatment information was not available, and the AS-related results were not reported separately. Additionally, studies which only reported on quality of life or those that compared patient outcomes (e.g., urinary symptoms, anxiety) across treatment types were excluded as such measures only identify the prevalence or existence of an issue, rather than whether these issues are being adequately addressed.

Operational definition of unmet supportive care needs

The Supportive Care Framework²¹ was utilised to operationalise the unmet supportive care needs domains investigated. The framework identifies six domains of need; physical, informational, emotional/psychological, social, spiritual, and practical. Systematic reviews on the supportive care needs of cancer survivors have used similar justifications and definitions^{22,26}.

Search strategy

The following electronic databases were searched: PubMed, Embase, PsycINFO, and CINAHL. Boolean logic search strategies were created, piloted and refined with the assistance of a medical research librarian from The University of Adelaide. Search terms related to “prostate cancer” AND “active surveillance” AND “supportive care needs” were incorporated into a systematic search strategy tailored for Pubmed and adapted for the remaining databases (Appendix 1: Search Strategy). As there were no database headings (e.g., MeSH) for unmet supportive care needs in the included databases, related keywords and free text were included in the search. Previous systematic reviews investigating the supportive care needs of men with PCa were referred to when constructing the search strategy^{26,27}. All searches were conducted by a single author (MM) and were run from database inception to July 2018.

Study selection and data extraction

Identified articles from each database were imported and managed in Endnote. After removing duplicate records, the titles and abstracts of remaining publications were reviewed against the eligibility criteria by one author (MM; Figure 1). Full-text versions of the potentially eligible studies were then reviewed and screened

against the eligibility criteria the same author (MM). Those deemed to meet eligibility criteria were then also checked for eligibility by a second reviewer (HE). There were no disagreements to resolve.

Separate qualitative and quantitative data extraction forms were developed. Each form captured the following information regarding each study: study design, aims, hypotheses, population and setting, data collection and methods, measurements, participants, raw results/author conclusions, and evidence of supportive care needs characterised by domain. The form was reviewed and revised by MM, CES and MO before being pilot tested by MM on one quantitative and two qualitative articles (one of which was included in the review) and adjusted where necessary. Data from all included studies were then extracted by one author (MM).

Quality appraisal

Quality appraisal of the included literature was conducted using the Joanna Briggs Institute (JBI) checklists for prevalence and qualitative studies^{30,31}. The appraisals were conducted independently by two researchers (MM and AF), and discrepancies were resolved by consensus with a third reviewer (CES).

Data synthesis

This review utilised thematic synthesis to analyse and report the results. Thematic synthesis involves three key stages: (1) line-by-line coding of primary study results; (2) organisation of codes into descriptive themes; and (3) development of analytical themes³². Results from each of the included studies were organised under the relevant supportive care need domain and then subsequently analysed to identify the key themes.

Results

Study selection & characteristics

The searches identified 3,613 unique records, of which 3,574 were excluded after reviewing titles and abstracts (Figure 1). Of the remaining 39 studies, eight met eligibility criteria and were included for review: five qualitative studies³³⁻³⁷ and three cross-sectional studies³⁸⁻⁴⁰. Study characteristics can be found in Table 1. Three studies were from the United States^{33,34,39}, two from Canada^{36,40}, and one each from the United Kingdom³⁵, Sweden³⁸ and Australia³⁷. Sample sizes of AS patients in cross-sectional studies ranged from three to 431 ($M=169$, $SD=229.6$), and in qualitative studies ranged from four to 37 ($M=20.8$, $SD=11.2$). The majority of

studies (5/8) recruited men via their treating physicians. While one study³⁹ reported their patients were on WW, this was included as the authors' definition of AS ("deferred treatment") appeared to more closely reflect AS.

Quality appraisal

Only three of the studies included had a primary aim of investigating unmet supportive care needs^{33,34,39}, and only two of these looked specifically at AS patients^{33,34}. A detailed summary of the quality appraisal results can be found in Appendix 2. Whilst the overall quality of the three cross-sectional studies was good based on their primary aims, some limitations were identified in relation to our reviews aims; particularly regarding the representation of men on AS and the validity of the unmet need measures. One study⁴⁰ did not use a validated measure to assess unmet needs, and the two others^{38,39} did not assess or report the validity or reliability of their unmet needs measure. Sample size was also an issue in the cross-sectional studies. Adequate sample size was determined by both the number of men on AS in the study, and whether the study reported a sample size calculation. None of the studies reported a sample size calculation, and Boberg et al's³⁹ study included only n=3 men on AS in their sample.

In the five qualitative studies, congruity was consistently shown between the research methodology used and the philosophical perspective, research question, data collection method, analysis, and interpretation of results. The conclusions drawn in the studies flowed logically from the results presented. However, detail on reflexivity and researcher bias was insufficiently provided across all studies. For instance, information on the authors research experience/background and the possible effects this may have had on their analysis was rarely disclosed. Finally, two studies did not report whether saturation was reached^{34,37}, though the use of quotes to represent participant voices was adequate across studies. These limitations should be considered when interpreting the results.

Unmet supportive care needs of men on active surveillance

Unmet needs were identified in the following domains; informational, emotional/psychological, social, and 'other'. These needs are discussed in turn below.

Informational

Seven of the reviewed studies (two cross sectional; five qualitative) identified unmet informational needs^{33–38,40}.

Thematic analysis revealed two key themes, which explored to men's unmet informational needs; (1) existing information was inadequate, and (2) existing information was inconsistent and confusing.

Existing information available/provided to men on active surveillance is inadequate.

Unmet information needs were commonly attributed to inadequate information being provided or available to men on AS. Information on PCa, signs of progression, future treatment options, and adjuvant treatments (such as diet and exercise) were reported as inadequately provided by the treating physicians and/or unavailable to patients^{33–37}. For instance, one man in Loeb et al's study explained he wanted to “*know what progresses the cancer*” as he currently felt “*ignorant about the whole thing*”³³. Several participants in the qualitative studies also reported that information regarding AS was too limited^{33,34,36,37}. Loeb et al³³ noted men often needed more information regarding the follow-up protocol, such as the ideal frequency and reason for performing tests. Mróz et al³⁶ suspected several men in their study had utilised the interviews to get information on AS. Additionally, several men in Kazer et al's³⁴ study felt information on AS was difficult to find, as one explained; “*when I was in my peak of information seeking, I couldn't find information about [active surveillance]; I could not [find] anything meaningful*”. This suggests existing information may be perceived as inadequate in regard to both quantity and quality.

Inadequate information was also discussed in two of the cross-sectional studies^{38,40}. Bergengren et al³⁸ reported that 26.1% of the men on AS ($N = 431$) reported receiving little to no information regarding their treatment options. Similarly, Davison and Goldenberg⁴⁰ ($N = 73$) found 55% of men on AS reported a great deal of unmet need on information about future treatment options. In addition, 27% of participants reported a great deal of unmet need on receiving information on non-traditional treatment options, and 26% reported a great deal of unmet need in relation to receiving information on eating a ‘prostate-friendly diet’⁴⁰.

Existing information available to men on active surveillance is confusing & inconsistent.

Participants in four qualitative studies reported that information on PCa and AS was contradictory, confusing, overwhelming, and inconsistent^{33,34,36,37}. Those in Loeb et al's³³ study were often confused by their prognosis

and the purpose/results of tests. One man stated; *“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”*³³. In Mróz et al’s³⁶ study, lack of specificity regarding their prognosis resulted in confusion and sometimes left men wondering if they actually had cancer. Confusion was also reported by patients on the difference between AS and watchful waiting^{33,36}. Both the researchers and participants attributed this confusion to the inconsistency of information, especially those from differing sources. For example, men in Loeb et al’s³³ investigation suggested the most trustworthy websites were those sponsored by their urologists’ clinic/hospital, as they believed these might more closely align with their doctor’s views and advice; *“it’s more likely that your doctor will be aware of what’s on that website and in a better position to respond to questions from that website as opposed to just the popular press in general”*³³. Men in Mroz et al’s³⁶ study also reported that inconsistent information and recommendations *“was not only confusing it was stressful”*, suggesting unmet informational needs may have led to additional unmet emotional/psychological needs.

Emotional/Psychological

One qualitative study discussed men’s unmet emotional and psychological needs whilst on AS³⁷. O’Callaghan et al³⁷ found that a lack of emotional support coupled with unmet informational needs appeared to contribute to feelings of depression, irritability, anxiety, fear, worry, embarrassment, and stress in men on AS³⁷. For instance, one man summed up his AS experience as *“death, dying”*, awaking some mornings *“really depressed”*³⁷.

Two of the quantitative studies explored unmet psychological/emotional needs^{39,40}. In Boberg et al’s³⁹ study ($N=3$), some need was reported for support dealing with fears associated with AS. Specifically, these men rated their level of unmet need and perceived importance on a Likert scale (0-10) for two items. Results showed that for receiving support to deal with the fear of leaving cancer in the body, the level of unmet need was rated 4.3/10, and the level of importance was rated 7.8/10. The second item measured unmet needs and importance for support to deal with fears of ‘doing nothing’ for now to treat their cancer (unmet need = 4.2/10; importance = 7.5/10). Davison and Goldenberg’s⁴⁰ survey ($N = 73$) reported that 49.3% of men in their study reported some unmet need (from very little to a great deal) regarding accessing web-based anonymous support groups for men on AS. Additionally, 50.7% reported some need for separate support groups for men on AS⁴⁰. In relation to

factors which may influence unmet needs, Davison and Goldenberg⁴⁰ found that compared to men with none or little anxiety symptoms, men experiencing greater anxiety reported that having adequate access to formal and informal support from other men on AS and receiving adequate information on future treatment options, was important for them (all $p < 0.05$).

Social

One quantitative study reported unmet social needs. Davison and Goldenberg⁴⁰ ($N = 73$) found that 59% of men had some level (very little to a great deal) of unmet need to socialise with other men on AS. However, only 4% reported a great deal of need in this area. This suggests that whilst this unmet need may not be strongly endorsed; socialising with other men on AS is certainly desired by some.

Other

Two studies identified unmet needs in relation to strategies for self-managing health. In Kazer et al's³⁴ qualitative study, one man expressed a need for a monitoring tool specially for tracking his PSA results. The authors proposed that by implementing disease-self management strategies, men's self-efficacy over their treatment may be enhanced. Davison and Goldenberg⁴⁰ ($N = 73$) identified that 20.8% of men strongly desired to participate in exercise programs for men on AS. It was not reported whether the men were currently exercising or if programs were offered.

Discussion

The aim of this systematic review was to identify and summarise the unmet supportive care needs of men on AS, identify factors that may contribute to unmet needs, and highlight the research gaps of this area. Of the 3,613 studies identified, only eight explored men's unmet needs during AS, reflecting the infancy of this area of research. This preliminary evidence suggests men on AS may have a variety of unmet needs, particularly informational. However, these findings are largely based on qualitative work that is not intended for generalisation. Further, no cross-sectional study explored unmet needs utilising a supportive care framework, well-validated measures, or unmet needs over time, therefore limiting the findings. Lastly, none of the cross-

sectional studies included a control group, and none utilised a mixed methods approach within a single study, which would better facilitate triangulation of the data⁴¹. Consequently, the magnitude of the issue of unmet needs in AS is unknown, and further research utilising large, representative samples is required to measure prevalence. Many of these issues have also been identified in previous systematic reviews of unmet needs in PCa^{26,27} patients who have undergone treatment. Understanding men's unmet needs during AS may assist researchers and health professionals in empowering men to adhere until treatment is medically necessary. With approximately 10-20% of men who begin AS discontinuing without disease progression¹⁸⁻²⁰, interventions that considers men's experiences and unmet needs are required.

Due to the limited research exploring the unmet needs of men on AS, identifying the factors that may be contributing to onset of these needs is difficult. Further investigation of these factors may best be done utilising a theoretical model, such as the social ecological model (SEM)⁴². The SEM is often adapted for use in health research to facilitate the exploration of how human behaviour and experience is influenced by the interaction of personal, social, community, and societal/policy levels (see Figure 2). The SEM has been used in the cancer context previously, for instance, to identify predictors of screening for PCa in African-American men^{43,44} and to identify correlates of social-ecological factors and unmet needs in gynaecological cancer survivors⁴⁵. In this context, we can use the SEM to hypothesise factors outside the biomedical area which may contribute to the identified unmet needs for men on AS, such as social or community factors, which may be essential given men on AS spend little time in-hospital or at clinics receiving cancer care. In doing so we can simultaneously summarise the available literature and identify research gaps.

According to the reviewed literature in our study, unmet informational needs appear to be the most reported need in men on AS. This unmet need was discussed in seven of the eight studies included in our review (two cross-sectional, five qualitative)^{33-38,40}. We identified two major themes within this domain; (1) Existing information is inadequate, and (2) Existing information is confusing/inconsistent. Information regarding PCa, AS, treatment options, and healthcare recommendations was perceived as confusing, inconsistent between providers/resources, and/or inadequately available or provided to men. Similar informational needs were also

reported as unmet in systematic reviews for PCa survivors across treatments^{26,27}, and in a recent mixed-methods paper investigating psychological impact of AS⁴⁶.

These unmet informational needs may occur for a variety of reasons, which can be categorised according to the SEM. For instance, personal factors such as health literacy may influence a patient's ability to seek out and understand information regarding AS from various resources. If the information is perceived as confusing or inadequate, this may contribute to unmet informational needs if not properly addressed. Research has suggested PCa patients may find it difficult to locate high quality information online, due to both their ability to search for the information and the lack of gold-standard information being readily available⁴⁷. Interpersonal factors, such as their doctor's expertise, and community factors such as the availability of resources/services, may further contribute unmet informational needs. Finally, unmet informational needs may be influenced by policy-level factors such as the inherent uncertainty regarding the most suitable cancer grade for AS. Whilst AS is generally recommended for men with low-risk, localised disease, there is often no clear consensus, and therefore the adoption and practice of AS varies greatly across countries and urological communities⁴⁸.

Unmet emotional/psychological needs were reflected in men's fears/worries associated with cancer, feelings of uncertainty in relation to AS and unmet information needs, and the accessibility of appropriate support groups/resources specific to men on AS^{37,39,40}. While research comparing men on AS to men who have received curative PCa treatment generally show that depression and anxiety are comparable and scores decrease over time, recent research suggests anxiety may be higher in men on AS⁴⁹. In line with this recent research, the present analysis suggests some men may be inadequately supported psychologically/emotionally. Addressing unmet emotional/psychological needs again will require the consideration of the social-ecological factors which may contribute, including personal factors (e.g., pre-existing health issues) and community factors such as the existence and availability of appropriate support (e.g., support groups for AS).

Lastly, unmet social and 'other' needs were identified in our review. Social needs included a desire for socialisation with other men on AS⁵⁰. Other needs included a desire for exercise programmes and cancer tracking tools^{34,40}. Again, these unmet needs may exist due a combination of social-ecological factors, such as community (i.e., existence/access to support groups and exercise programmes) and social (i.e., relationships

with family/loved ones). However, limited evidence for these unmet needs was found and therefore the magnitude of the issue is uncertain. Further exploration into exercise programmes is particularly recommended given the increasing evidence that exercise may slow PCa progression^{51,52}, the majority of men with PCa are inactive⁵³, and exercise may assist in supporting men physically, psychologically, and socially⁵⁴. Evidence suggests men on AS would be interested in receiving exercise-based support⁵⁵. Such programmes are currently being researched⁵⁶, but are not yet widely available.

Other systematic reviews of unmet needs in PCa identified a number of social, physical, spiritual, and practical needs which were not investigated or identified by the studies in our review^{26,27}. Furthermore, a study investigating the unmet psychosexual needs of PCa patients found that the men on WW (n=4) experienced unmet psychosexual needs (e.g., healthcare providers discussing sexual health) and unmet social needs (e.g., support available for partners/family)⁵⁷. It is unclear the extent to which unmet needs on AS and WW are similar, though given the similarities in treatment method consideration of these unmet needs should be given to these findings. In addition, social-ecological factors found to influence unmet supportive care needs in cancer survivors also require consideration. For instance, evidence suggest poor social support²², time since diagnosis⁵⁸, rural locality²², time since the last clinical appointment²² and experiencing unrelated significant/distressing events⁵⁹ may predict greater unmet needs in cancer patients post-treatment.

Clinical Implications

It is clear from our review that further research into the unmet needs of men on AS is required to both identify the magnitude of the issue and to investigate whether the hypothesised factors influence men's unmet needs. We recommend future research in this area do so utilising a theoretical model (such as the SEM) a priori, to ensure factors outside the biomedical area are considered and contextualised effectually. Meanwhile, it is essential health care professionals ensure they provide clear, evidence-based information to their patients on AS. Furthermore, healthcare professionals must re-check patient needs and provide referrals to allied health services where possible, to ensure needs outside of their area of expertise are addressed. This is especially important as research suggests it is common to overlook referrals to allied health services during cancer care. For instance, less than 20% of men with PCa are referred to exercise physiologists/specialists^{60,61}. On a larger scale, it may be

beneficial for prostate and/or cancer registries, hospitals, and other large health services to include patient-reported outcome measures, including unmet supportive care needs and psychological wellbeing. Some registries and large trials have already incorporated measures to assess psychological wellbeing (ProtecT study⁶²) and health-related quality of life (PCOR-ANZ⁶³). However, the measurement of unmet needs in particular is recommended both to assist health professionals to address these unmet needs, and to assist researchers and policy-makers by gathering representative data which can be used in the development of multidisciplinary, comprehensive interventions.

Study Strengths and Limitations

This review has strengths and weakness that should be considered when reflecting on the findings. Whilst other systematic reviews have summarised the unmet needs of PCa patients, this is the first to specifically focus on the particular needs of men on AS. Understanding the unique challenges and needs of this group is likely to be important for minimising overtreatment, promoting adherence, and optimising wellbeing. Our systematic review aligned with the PRISMA²⁹ guidelines, recommend future research directions utilising an established theoretical model⁴², and has made suggestions for enhancing current practice for health professionals managing men on AS. The review was registered a priori, involved several reviewers to screen and analyse the data, and utilised standardised quality assessment tools. However, our findings were limited due to the nature of available evidence and that many studies did not report findings specific to men on AS despite including them in their sample. Future research would benefit from separately examining the experiences and needs of men undergoing different PCa treatments, in order to better tailor recommendations and support.

Conclusions

While the unmet needs of men on AS are still somewhat unclear, preliminary evidence suggests the information available and provided to men during AS is often perceived as inadequate and inconsistent. Men may also be experiencing unmet psychological/emotional, social, and other needs during AS. To address current knowledge gaps, it is recommended that unmet needs among men on AS are explored in a representative sample using a validated measure, and that possible determinants of unmet needs be assessed and explored in line with the

SEM. Based on currently available evidence, the provision of clear, consistent, and comprehensive information provided to men on AS is encouraged to address unmet informational needs.

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Conflict of Interest Statements

Conflict of Interest: The authors declare that they have no conflict of interest.

Ethical Approval: Ethical approval was not applicable for this study.

Informed Consent: Informed consent was not applicable for this study.

Data Sharing

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

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Figure Legends

Figure 1. PRISMA Flow Diagram

This PRISMA Flow diagram details the search and selection process applied in our systematic review.

Figure 2. Social-ecological model

This model represents the interactive factors which may influence the unmet supportive care needs of men on active surveillance for prostate cancer. It has been adapted from Bronfenbrenner's Social Ecological Model⁴⁵.

Tables

Table 1: Study Characteristics

Source (Author)	Location	Sample Characteristics	Study Aims	Study Design	Recruitment	Data Related to Unmet
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Year & Year)		Participants	Age of men on AS (mean and/or range)	Time since diagnosis of men on AS (mean or range)	Time on AS (mean and/or range)		& Method	source & method	Needs
Berggren et al, 2018 ^[38]	Sweden	<i>Mixed sample</i> Total <i>N</i> = 1288 (PCa patients diagnosed with low-risk PCa and treated with RP, RT, or AS). Total <i>N</i> on AS = 431	<i>M</i> = 64	7 years (all patients diagnosed in 2008 and surveyed in 2015)	7 years (all AS patients still at time of survey).	Investigate the overall satisfaction with healthcare among men with low-risk PCa across 3 treatment options (RP, RT, or AS), as well as identify possible explanatory factors for their satisfaction.	Quantitative; cross-sectional study utilising a paper-based survey.	Eligible men identified on National Prostate Cancer Register of Sweden were invited to participate via letter. Response rate = 1288/1720 (74.9%)	Survey included EPIC-26 measure and 49 study-specific questions. All results reported by treatment type (AS, RP, RT). One study-specific item related to unmet needs; "Information on treatment" with response options (a) little/no, (b) moderate, (c) substantial. Missing data for this item reported as n=16 (3.5%) for men on AS.

Boberg et al, 2003 ^[39]	USA	<i>Mixed sample</i> Total <i>N</i> = 204 (men treated for PCa) Total <i>N</i> on AS = 3 (note, term WW was used)	NP <i>Of men treated for PCa:</i> <i>M</i> = 66.2	NP <i>Of men treated for PCa:</i> <i>M</i> = 21.2 months	NP	Identify the needs of men diagnosed and treated for PCa, as well as assess their perceived level of importance.	Quantitative; cross-sectional study utilising a paper-based survey.	Men recruited from 3 health-care clinics. Clinic identified eligible men and were subsequently sent the survey. Response rate = 233/500 (46%)	Survey included 135 items (all study-specific; no validated measure) aimed to identify unmet needs and assess importance. Two items specific to AS/WW and unmet needs: (1) “If you chose ‘watchful waiting’ (deferred treatment), support dealing with fear of leaving cancer in your body”, and (2) “If you chose ‘watchful waiting’ (deferred treatment), support in dealing with fears of ‘doing nothing for now”
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Davison et al, 2011 ^[40]	Canada	<i>AS only sample</i> <i>N on AS = 73</i>	≤ 60: <i>N = 22</i> 61 – 70: <i>N = 37</i> > 70: <i>N = 14</i>	≤ 5 years since diagnosis: <i>N = 64</i> > 5 years since diagnosis: <i>N = 9</i>	All on AS at time of survey	Identify the role men diagnosed with PCa assume when making treatment decisions in regard to commencing AS, as well as the factors that affect this decision and the resources they desired to access while on AS.	Quantitative; cross-sectional study utilising a paper-based survey.	Treating physicians identified eligible men, who were subsequently sent the study information and survey. Response rate = 73/121 (60%).	Of the 3-part survey, only results from Part 3 ('Need for additional support during AS') were reviewed as it was specific to unmet needs. This section included 7 items and responses were recorded across a 5-point Likert scale (0=not at all, 4=a great deal).
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<p>Avery et al, 2014 ^[35]</p>	<p>U.K.</p>	<p><i>Mixed sample</i></p> <p>Total <i>N</i> = 89 (PCa patients, men at risk of PCa, partners, stakeholders)</p> <p>Total <i>N</i> on AS = 15</p>	<p>NP</p> <p><i>Of men diagnosed with PCa: M = 66.5</i></p>	<p>NP</p> <p><i>Of men diagnosed with PCa: 7-42 months</i></p>	<p>NP</p>	<p>Explore patient, partner, and stakeholder views about diet, and their motivations and barriers to dietary change in men at elevated risk, and those diagnosed with PCa.</p>	<p>Qualitative; Interviews with patients and partners. Focus groups with stakeholders.</p>	<p>Participants were purposefully sampled from sample pools of 3 different studies managed by the research team.</p> <p>Stakeholders were recruited from local hospitals, academic institutions, and primary care practices.</p> <p>Response rates were NP.</p>	<p>The following themes were analysed (AS specific results/quotes were made explicit when identifying unmet needs):</p> <ol style="list-style-type: none"> 1. Perceived relationship between PCa treatment and dietary change 2. Interest in dietary advice and information following diagnosis <p>Interview questions were not made available.</p>
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Kazer et al, 2011 [34]	USA	<i>AS only sample</i> <i>N on AS = 7</i>	<i>M = 70 years</i> <i>Range = 65 - 79 years</i>	NP	NP	Explore the psychosocial and educational needs of men on AS for PCa.	Qualitative; focus groups with men on AS.	Men on AS were identified by urologists and provided with study information. Those interested contacted the research team to organise to attend a focus group. Number of men approached was NP.	All themes were analysed for this review; Themes: 1. Sources of support 2. Sources of information 3. Disease monitoring/vigilance 4. Myths, misinformation, FAQs 5. Health promotion and taking charge
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<p>Loeb et al, 2018^[33]</p>	<p>USA</p>	<p><i>Mixed sample</i></p> <p>Total <i>N</i> = 61 (AS patients, healthcare providers)</p> <p><i>N</i> on AS = 37</p>	<p><i>M</i> = 66</p> <p>Range = 48 - 84</p>	<p>NP</p>	<p>NP</p>	<p>Explore perceptions of existing information sources and identify recommendations for additional resources (particularly those which utilise social and digital media).</p>	<p>Qualitative; focus groups with men on AS, semi-structured interviews with healthcare providers.</p>	<p>Men on AS were identified via electronic records at 2 clinics and screened for eligibility. Those eligible were mailed an invitation to participate.</p> <p><i>N</i> invitations mailed = 235 (response rate = 15.74%)</p>	<p>All themes were analysed:</p> <p>Themes:</p> <ol style="list-style-type: none"> 1. More information on PCa 2. More information on AS 3. More information on alternative management options 4. Greater variety of resources 5. More social support and interaction 6. Verified integrity of information
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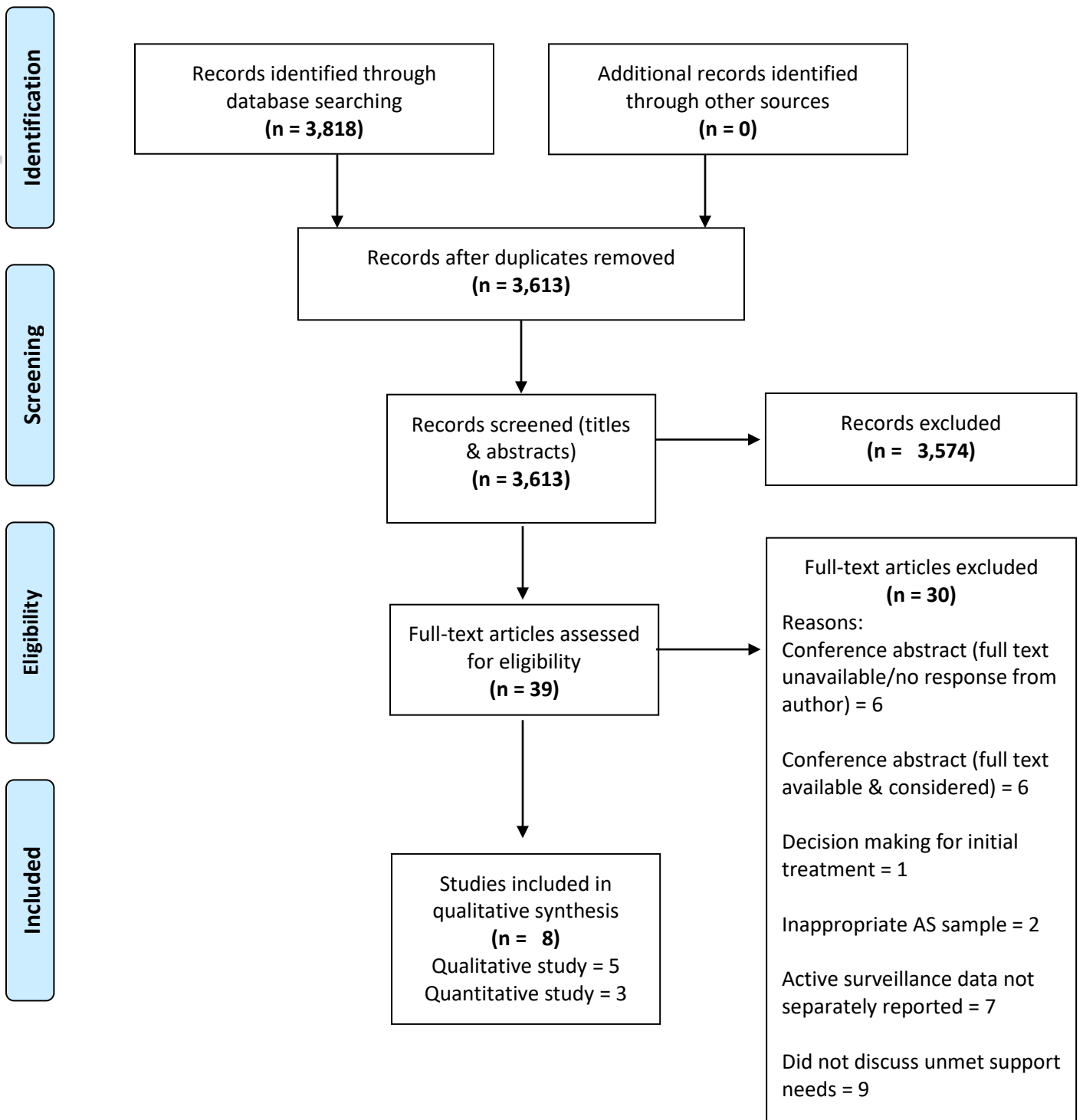
Mroz et al, 2013 [36]	Canada	<i>AS only sample</i> <i>N on AS = 25</i>	<i>M = 86</i> <i>Range = 48 – 77</i>	< 1 year: <i>N = 13</i> 1-2 years: <i>N = 9</i> > 2 years: <i>N = 3</i>	All on AS at time of interview.	Explore and describe the connection between masculinity and patients' perspectives of male patient-physician communication whilst on AS for PCa.	Qualitative; semi-structured interviews.	Participants were recruited from the Vancouver Prostate Centre and the British Columbia Cancer Agency. Eligible men were invited to participate by their treating physician. <i>N</i> invitations sent = 45 (response rate = 55.56%)	The following themes were included in analysis as they identified unmet needs: 1. Positioning risk in diagnosis with 'benign' cancer 2. Dazed and silent 3. The devil in the detail
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<p>O'Callaghan et al, 2014 [37]</p>	<p>Australia</p>	<p><i>Mixed sample</i> Total <i>N</i> = 35 (men diagnosed with PCa, partners). <i>N</i> on AS = 20 (<i>N</i> = 9 men received treatment after 3 months on AS)</p>	<p>NP <i>Of whole sample:</i> <i>N</i> ≤ 50: <i>N</i> = 1 51-60: <i>N</i> = 6 61-70: <i>N</i> = 11 71+: <i>N</i> = 3</p>	<p>NP</p>	<p><i>M</i> = 22 months Range = 3 – 96 months</p>	<p>Explore patient and partner experiences of treatment decision making following PCa diagnosis and their experiences of AS when it was the recommended option.</p>	<p>Qualitative; semi-structured interviews.</p>	<p>Men were recruited via urologists. Patients were purposefully sampled according to various characteristics (ages, treatment choice, time on AS, reason for ceasing AS, socio-demographic background, rural/urban dwelling). <i>N</i> invitations sent = 85 (response rate = 41.18%). An unspecified number of invitations were sent out after initial data collection to men with 'less evident' characteristics.</p>	<p>The following themes were included in analysis as they identified unmet needs after the decision to commence AS was made:</p> <ol style="list-style-type: none"> 1. Information was satisfactory, contradictory, stressful, and/or misunderstood 2. AS stressors encompass illness uncertainty, monitoring stressors, and inconsistent information
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Abbreviations: PCa = Prostate cancer; AS = Active surveillance; WW = Watchful waiting; RP = Radical prostatectomy; RT = Radiotherapy; NP = Not provided

Figure 1: Prisma Flow Diagram



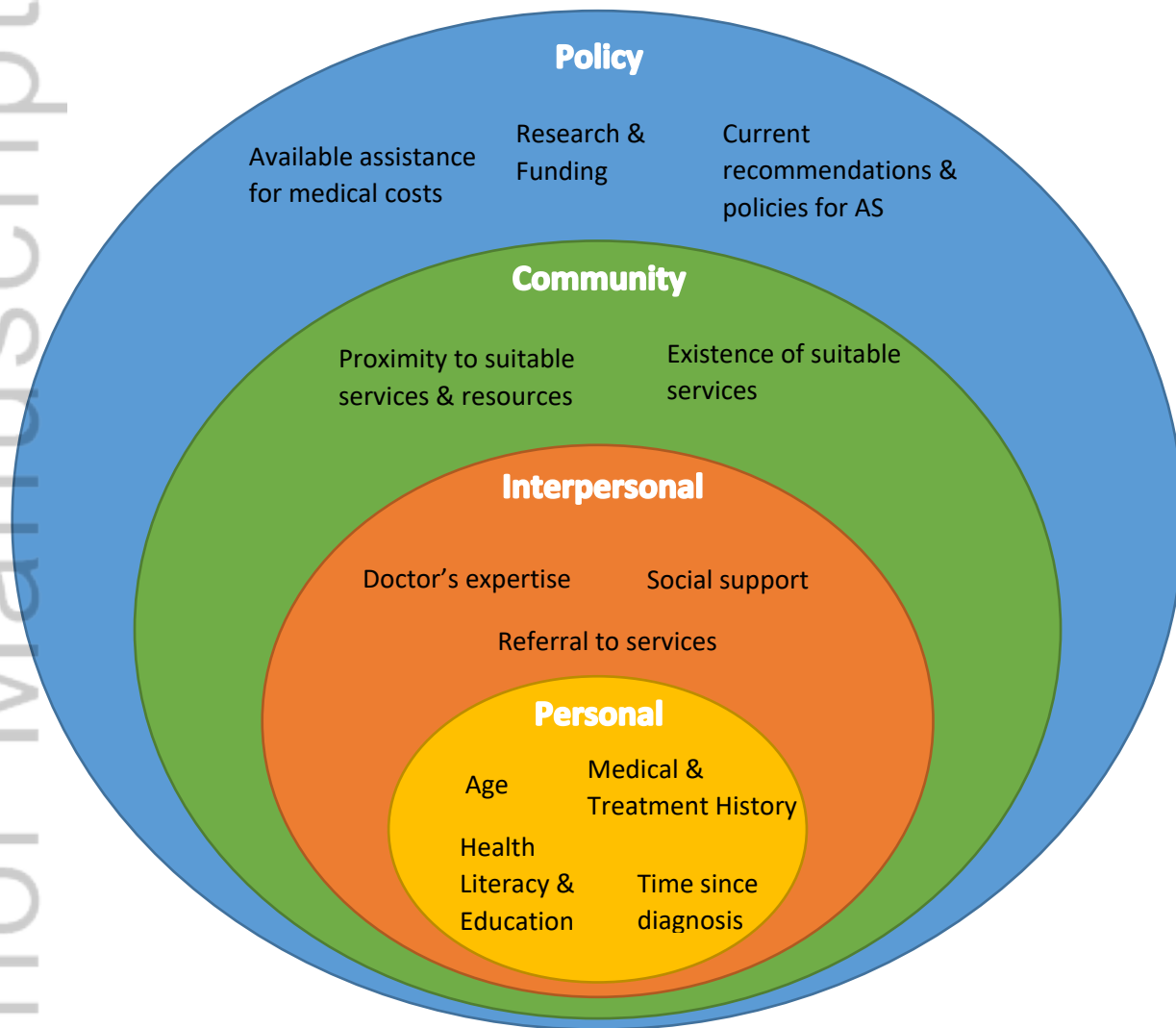


Figure 2. Social-ecological model of the interactive factors which may influence the unmet supportive care needs of men on AS, adapted from Bronfenbrenner⁴⁵.

In this model, the outer level is composed of policy factors, such as current AS recommendations proposed by research and organisations (e.g., PRIAS⁷), research funding from industry, and government bodies that determine what assistance is available for medical costs, and services available with respect to socio-economic status. The community level includes existence of and access to suitable services that address key unmet needs, such as allied health professionals (e.g., psychologists, exercise physiologists), support groups, medical specialists (e.g., prostate cancer nurse), and so on. The interpersonal level comprises of factors which are influenced by our social relationships. For men on AS, this may be their urologists and other medical professionals, and their family/friends. Finally, personal factors may include age, medical history, income, time since diagnosis, education, and other lifestyle or individual factors (e.g., experiencing unrelated significant events). Importantly, these factors can interact to influence each other.



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