Optimizing psychosocial support in prostate cancer patients during active surveillance

Active Surveillance Psychosocial Support (ASPS) Study

A qualitative study reported according to the Consolidated criteria for reporting qualitative research (COREQ). This article will be submitted to the following peer-reviewed journal: Psycho-Oncology.

KM Donachie 5661153
Master Thesis Course
Final
June 28. 2018
Number of words body of text: 3722
Number of words abstract Dutch: 298
Number of words abstract English: 296
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Index

English abstract

Keywords: prostate cancer, active surveillance, psychosocial support.

Optimizing psychosocial support in prostate cancer patients undergoing active surveillance.

Background: Prostate Cancer (PCa) is diagnosed more often. Active Surveillance (AS) is the preferred treatment option in low-risk PCa. During AS patients do not undergo active treatment but remain under close surveillance. Although this is beneficial to both patient and healthcare system, living with untreated disease can cause anxiety and uncertainty. *Aim:* The aim of this study was to identify psychosocial support needs in PCa patients undergoing AS. *Methods:* During this explorative qualitative study, 17 semi-structured interviews were conducted. Fifteen participants underwent AS, one was opting for treatment after recent diagnosis and one underwent active treatment after initial AS. After verbatim transcription, iterative inductive open-coded analysis using NVIVO 10 was performed. *Results:* Seven major themes emerged*: impact of diagnosis, patient-physician relationship, coping strategies, AS challenges, PSA rituals, and practical or emotional support needs*. Most evident was the apparent association between effective coping strategies, disease acceptation, external locus-of-control and positive patient-physician relationships. Ineffective coping strategies, *i.e.* avoidance and denial, seemed to impede stress resilience. Immediate availability of reliable information on disease and treatment after diagnosis contributed to disease acceptation. Lifestyle changes and PSA rituals seemed to provide a sense of disease-control. *Conclusions:* During AS, patients face the burden of frequent medical examinations and living with untreated disease. The specific psychosocial support needs in this group were previously unknown. This research suggests that the negative psychosocial impact of AS can be reduced if caregivers answer the following needs: promote disease acceptation, stimulate adoption of effective coping strategies and encourage meaningful lifestyle changes. *Implications:* The development of a support program addressing these needs should incorporate early-stage reliable and relevant information, assessment of coping strategies, promotion of effective coping strategies and facilitations of health promoting lifestyle changes. Further research should investigate the operational details of this program and its feasibility.

Nederlandse samenvatting

Trefwoorden: prostaatkanker, actief afwachten, psychosociale ondersteuning

Optimaliseren van psychosociale ondersteuning voor prostaatkanker patiënten tijdens actief afwachtend beleid.

Achtergrond: Prostaatkanker (PCa) wordt steeds vaker gediagnosticeerd. Bij laag-risico PCa heeft actief afwachten (AS) de voorkeur. Tijdens AS monitort de uroloog het ziektebeloop en wordt actieve behandeling uitgesteld. AS kan echter leiden tot angst en onzekerheid bij patiënten. *Doel:* Het doel van dit onderzoek is het vaststellen van de psychosociale ondersteuningsbehoeften bij mannen met PCa gedurende AS. *Methode:* Tijdens dit exploratief kwalitatieve onderzoek is er middels 17 semigestructureerd interviews data verzameld bij 15 AS patiënten, 1 patiënt kort na PCa-diagnose en 1 patiënt waarbij actieve behandeling werd ingezet na AS. De getranscribeerde interviews zijn open gecodeerd. Inductieve, iteratieve analyse vond plaats met behulp van NVIVO 10. *Resultaten:* Er zijn 7 thema's geïdentificeerd: *impact van diagnose, relatie met behandelend arts, coping strategieën, AS uitdagingen, PSA rituelen, praktische en emotionele ondersteuningsbehoeften*. Er lijkt een sterke associatie te bestaan tussen effectieve coping, ziekteverwerking, externe controlegerichtheid en een positieve relatie met de behandelend arts. Ineffectieve coping leek de draagkracht van participanten te verminderen. De beschikbaarheid van betrouwbare informatie over ziekte en behandeling direct na diagnose droeg bij aan ziekteverwerking en acceptatie. Leefstijlaanpassingen en PSA rituelen gaven participanten een gevoel van controle over de ziekte. *Conclusie:* PCa-patiënten worden tijdens AS geconfronteerd met terugkerende angst en spanning. Er is weinig bekend over de specifieke ondersteuningsbehoeften van deze patiëntenpopulatie. Deze studie heeft de volgende psychosociale ondersteuningsbehoeften geïdentificeerd: bevordering van ziekteverwerking en acceptatie, aanleren van effectieve coping strategieën en stimuleren van zinvolle leefstijlaanpassingen. *Klinische implicaties:* Het ontwikkelen van een ondersteuningsprogramma met aandacht voor de behoeften van deze patiëntenpopulatie dient zich vooral te richten op vroegtijdige verstrekking van betrouwbare en relevantie informatie, het vaststellen van huidige coping strategieën, de bevordering van effectieve coping en het faciliteren van gezondheid bevorderende leefstijlaanpassingen. Het is noodzakelijk om deze interventies verder te operationaliseren en de haalbaarheid in de praktijk te toetsen.

LIST OF ABBREVIATIONS AND RELEVANT DEFINITIONS

PCa	Prostate Cancer
AS	Active Surveillance, intensive disease monitoring to detect disease progression and delay treatment.
QoL	Quality of life
EC	Dr. E.B. Cornel, urologist specialized in uro-oncology.
IvO	Dr. I.M. van Oort, urologist specialized in uro-oncology.
EW	Mrs. E. Willems, oncology nurse working for the urology department.
AS	Mrs. A. Smits, nurse practitioner specialized in uro-oncology.
JT	Mrs. J. Theunissen, nurse practitioner specialized in uro-oncology.
KD	Mrs. K.M. Donachie, researcher and health science student at Utrecht University
ZGT	Zorg Groep Twente Hengelo, a general hospital in the eastern part of the Netherlands
RUMC	Radboudumc Nijmegen, an academic hospital in the eastern part of the Netherlands
WMO	Medical Research Involving Human Subjects
MREC	Medical Research Ethics Committee
LUTS	Lower Urinary Tract Symptoms
ED	Erectile Dysfunction

Introduction

Prostate Cancer (PCa) is the most common cancer amongst men in the Netherlands, affecting ~11.000 men annually.[1,2] Although the incidence of PCa increases, the mortality of this disease has not (see fig.1). Low-risk PCa is diagnosed more frequently.[4,5] In order to reduce overtreatment, active surveillance (AS) is the preferred treatment option in low-risk PCa.[6,58] The use of AS varies between different countries and approximately 20-80% of patients with low-risk PCa select AS.[7]

(Insert figure 1)

During AS patients do not undergo active treatment but remain under close surveillance. If disease progression occurs, active curative treatment is initiated. AS has the potential to minimize treatment-related toxicity and complications, reduce overtreatment and health-care costs without compromising survival.[8]

A longitudinal survey by Galbarth et al. suggests there is a greater need for psychosocial support amongst PCa patients undergoing AS compared to patients in active treatment.[15] Recent quantitative studies suggest AS is associated with anxiety and uncertainty caused by living with untreated disease.[9,10] Approximately 10% of patients revise their decision and request active treatment based on anxiety.[11-14]

Results from a prospective cohort study by Parker et al. emphasize the importance of addressing anxiety and uncertainty during AS.[12] His research indicates quality of life (QoL) improves when anxiety and uncertainty are reduced. This may result in increased AS adherence and patient engagement.[13] A literature review conducted in 2007 by Pickles et al. suggests that psychosocial support might reduce anxiety and uncertainty in AS patients.[16]

Custers and Vissers have performed extensive research on psychological and social support in oncological patients. Their findings suggest that nurses might be well suited to provide psychosocial support.[18,19] According to Wade et al., nurse-led care for AS patients is acceptable, accessible and cost effective.[17] Therefore nurse-led psychosocial support in AS patients might be a feasible intervention to reduce anxiety and uncertainty and improve AS adherence.

Since the available evidence is of poor quality and most research does not focus on AS patients specifically, it is unclear what specific problems require support in the AS population.[20-25] Therefore, it is necessary to investigate the specific psychosocial support needs in AS patients and how these should be addressed. To acquire new insights on patient perspectives regarding this sensitive topic, an explorative qualitative research design is justified. [26,30,31]

Aim

The aim of this study was to identify the psychosocial support needs of prostate cancer patients during active surveillance.[27] For this study *needs* were defined as self-defined needs. Therefore participants, and not physician or researcher, established the presence of an existing gap between experienced psychological or social problems and current coping strategies resulting in unmet psychosocial support needs. [28,29]

Methods

Design

A generic explorative qualitative design was selected for this study. From March to May 2018 the researcher conducted 17 semi-structured interviews to identify the psychosocial support needs of PCa patients undergoing AS. Prior to this study little was known on the specific psychosocial support needs of AS patients. Therefore an explorative approach was appropriate.[26,30,31,34] The impact of AS on mental wellbeing cannot be measured very well with quantitative instruments.[33] Talking about psychosocial support needs is difficult and most likely a sensitive topic.[26,32] Therefore semi-structured qualitative interviews were suitable for this explorative study. The interviews provided researchers with a rich insight in patient perspectives and experiences.[31]

Population and domain

To obtain insight in the experience of PCa patients undergoing AS, a sample of 17 participants was selected from a population of patients diagnosed with low-risk PCa at the Zorg Groep Twente (ZGT) hospital in Hengelo or Radboudumc (RUMC) in Nijmegen. Both hospitals are situated in the Netherlands.

This study aimed to achieve theoretical data saturation. It was expected from literature that data collection from ~15-17 participants would achieve data saturation.[26] A maximum variation purposive sample of ~15 patients, diagnosed with low-risk PCa undergoing AS, were included in this study. Participants varied in age, time since diagnosis and educational level. In addition, two deviant cases were also included in this study to obtain valuable information on unmet psychosocial support needs and to challenge emerging patterns.[26,30,31] The first deviant case concerned a participant opting for AS, radical prostatectomy or radiation therapy after a recent diagnosis with low-risk PCa. The second concerned a participant that had discontinued AS and underwent active treatment for non-medical reasons.

Participants were eligible to participate in this study if diagnosed with low-risk PCa and undergoing AS. Follow up took place at the urology department ZGT or RUMC. Participants were proficient in the Dutch or English language, understood the interview questions and adequately expressed feelings and reactions during the interview. Participants were excluded from this study if previously diagnosed with an anxiety disorder, mentally incompetent or legally incapacitated.

Procedures

This study was conducted at two Dutch clinics during a three month period. Two urologists (EC, IvO) applied the in- and exclusion criteria on the PCa patient population. General information about the aim and design of this study was provided to eligible patients by an oncology nurse (EW, AS, JT) both verbally and written. Patients willing to participate were approached by the researcher (KD) for further detailed study information. A 1,5 hour appointment at the participants home or in hospital was scheduled after > 1 week. During this appointment remaining questions were discussed, an informed consent form was signed and KD conducted a semi-structured interview.[48]

The interviews were executed according to a Dutch interview guide and audiotaped (see app. 1). The researcher used detailed field notes to capture thoughts and observations that occurred. After completion of each semi-structured interview the audiotapes were transcribed verbatim.

During the analytical phase attention was paid to rigour, reliability, validity and objectivity. Rigour was increased by verbatim transcription of audio files, the use of NVIVO 10 and inclusion of two deviant cases. Reliability was improved by the use of memo’s to provide a decision trail and by various peer reviews and expert consultations during the analytical phase to discuss methodology and emerging themes. Validity was ensured by returning the interview transcripts to participants for a membercheck. Objectivity was promoted by frequent peer debriefing to achieve reflexivity and critical reflection on own preconceptions. [26,30,31]

Data collection

The 17 semi-structured interviews took place according to a literature based topic list and interview guide (see app. 1).[36-47]

The following sensitizing concepts regarding AS associated problems and coping strategies were identified in the literature prior to this study and shaped the topic list and interview guide.[36-47]

(Insert box 1)

In addition, the demographic data and characteristics of the participants were collected (see app. 2). This included the following variables: age, ethnicity, occupation, education, sexual orientation, marital status, family size, tumour characteristics and time since diagnosis.[32]

Data analysis.

The first step in the analytical process consisted of audiotape transcription. From two interviews an audiotape was not available due to equipment failure. Extensive minutes and fieldnotes were used for further analysis. The transcripts were read and re-read to immerse in the data.[26] NVivo 10 (QRS International, Virginia, USA) software was used to facilitate the coding process. Open coding generated analytical categories by indexing particular phrases and fragments of text. Constant comparison was used to check and compare the data in a category to the rest of the data. Deviant cases were important in this phase to prevent tunnel vision.[30] Sequential analysis used data already gathered and analyzed to shape the ongoing data collection This allowed refining of the interview guide and development of additional categories (see app. 3).

After completion of the coding phase, similar or complementing codes were grouped into themes. Data collection was completed when new cases did not generate new codes or insights (data saturation) and reached after 14 interviews. To understand the larger meaning of the data associations, themes were examined and findings were related to the available scientific literature and research objectives. Participant quotations that reflect themes and findings were selected. Memo's on analytical decisions were written to provide a decision trail.[31] The consolidated criteria for reporting qualitative research checklist (COREQ) were used to report the results.[59]

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki and the Medical Research Involving Human Subjects Act (WMO). Furthermore this study was conducted in compliance with the Data Protection Act and the European Code of Good Administrative behaviour.[50-53] Prior to commencement, the study protocol, patient information and informed consent form were approved by the Medical Research Ethics committee (MREC) of both clinics.

During the interviews the researcher paid continuous attention to the psychological wellbeing of the participant. The researcher offered aftercare to two participants, both declined.

Results

Participants and demographic data

Table 1 shows the demographics and characteristics of all 17 interviewed participants. The majority of participants (n=12) were enrolled from clinic 2. Approx. half of the interviews took place at home, the other half took place at the urology clinic. 1 Interview took place at a university close to clinic 1 upon the patients request. The average interview duration was 0:59 min. All participants were involved in a heterosexual relationship and most (n=16) participants were married. During 11 interviews the spouse was present. All participants were Caucasian and from Dutch decent. Participant age varied between 54-76 with an average of 67 years old. Participants average time since diagnoses was 47 months.

(Insert table 1)

Impact of diagnosis

To determine the presence of psychosocial support needs, insight in the underlying psychological or social problems experienced was obtained/essential. The moment of diagnosis had a big impact on the psychosocial well-being of participants. However, most participants stated that the PCa diagnosis had a transient big impact. Participants described they experienced fear and were confronted with their own vulnerability and mortality immediately after diagnosis. In most cases however, the initial fear experienced, was mostly related to associations with the word ‘cancer’. **(See tab. 2, Q1,Q2)**

Reliable information and education by physician or nurse on disease heterogeneity, mortality risk, morbidity and treatment options enabled participants to process the diagnosis and eliminate the immediate life-threat primarily experienced. **(See tab. 2,Q3)**

Participants elaborated on the long term impact of the diagnosis. Participants that seemed to have accepted their disease, often addressed end-of-life preparations and the implementation of lifestyle changes such as healthy eating and frequent moderate exercise. **(See tab. 2, Q4,Q5)**

Overall the impact of AS was acceptable. AS was valued positively by all participants. Some discomfort was caused by lower urinary tract symptoms (LUTS) or erectile dysfunction (ED). Although questionnaires were used to assess the presence of LUTS and ED, existing problems and potential medical interventions were often not discussed by physicians. **(See tab. 2,Q6)**

Relationship with physician

Participants reported that selection of AS was often advised by their physician. Almost all participants emphasized that trust in their physician was an absolute condition for AS selection. Confidence in the expertise and experience of the physician and an emotional connection seemed to play an important role in gaining trust. In the absence of trust in their physician, doubt and uncertainty arose. **(See tab. 2, Q7,Q8)**

An empathic approach and genuine consideration of the participants interests was highly appreciated. AS seemed less attractive to participants with a strong internal locus-of-control since the disease is primarily managed by the physician. In these participants AS generated a feeling of dependency that was experienced as uncomfortable. **(See tab. 2, Q9)**

Coping strategies

Participants described the use of various effective and ineffective coping strategies. In an early stage effective coping seemed to consist of information seeking behavior, discussing the news with family, friends and peers, seeking the support of family/friends to face anger, fear or grief and preparations for end-of-life scenario's. These coping strategies seemed to be associated with a better acceptation of the disease and a more effective long term coping. **(See tab. 2, Q10,Q11)**

Ineffective coping strategies observed were avoidance, denial, excessive smoking and use of alcohol. Participants with ineffective coping strategies did not appear to completely process or accept their diagnosis. Some preferred to avoid confrontations with their disease, such as peer meetings, hospital visits or discussing the subject with acquaintances. Often the diagnosis was not shared with others, in some occasions close relatives, for instance children or siblings, were not informed. Denial occurred in some instances where participants described not being sick. **(See tab. 2, Q12, Q13)**

Challenges during AS

A considerable negative impact was associated with the necessity to conduct repeat prostate biopsies and monitor tumor blood markers. These medical procedures caused anxiety and uncertainty in a great number of participants. The majority of participants described a latent fear of disease progression, especially the presence of undetected metastases was mentioned. **(See tab. 2,Q14,Q15,Q16)**

PSA rituals

Prostate specific antigen (PSA) is used as a tumor blood marker that is determined every 3-6 months to monitor PCa progression. Awaiting the result of this blood test was a stressful period according to the majority of participants. Some participants described the presence of self-determined and indistinct PSA margins. Increased PSA levels generated uncertainty and anxiety. Sensing loss of control was expressed by some participants. This loss of control was compensated by varying PSA rituals. Two participants mentioned the use of cannabis oil to reduce anxiety and decrease PSA values. A number of participants avoided cycling or ejaculating up to one week prior to PSA testing. Several participants claimed there was a relation between nutritional adjustments and PSA fluctuation. **(See tab. 2, Q17,Q18,Q19)**

Practical support needs

Most participants acknowledged spending a great deal of time in search of new or relevant information regarding their disease. Participants expressed a strong need for information in the first two weeks up to four months after diagnosis. The majority of participants consulted the internet. Some participants conferred with multiple physicians for advice. Several participants contacted peers for additional insights and experiences. The information available online and obtained from peers was often a cause for uncertainty or anxiety. A large disadvantage described by participants was the subjectivity of this information. **(See tab.2, Q20,Q21)**

Availability of reliable, disease specific information was explicitly mentioned as a potential opportunity for improvement. In addition, participants indicated that immersing in information during the first period after diagnosis was helpful in processing and accepting their disease. **(See tab. 2, Q22)**

Further examining of this practical support need by the researcher revealed that participants experienced insufficient or inadequate information regarding scientific developments and innovations, available treatment options for PCa, LUTS and ED, recommended lifestyle changes and factors that influence PSA fluctuation. An enclosed website provided by the hospital or recurring theme meetings was the preferred method of information delivery. **(See tab.2, Q23,Q24,Q25)**

Emotional support needs

Although participants did not explicitly describe specific emotional support needs, recurring anxiety and uncertainty occurred in the majority of participants. This resulted in behavioral change and decreased quality of life according to participants. **(See tab. 2, Q26,Q27)**

Some participants appeared to have passed through various stages of mourning and reached a point of disease acceptance. These participants expressed more effective coping strategies. Although uncertainty and anxiety was still experienced in these participants occasionally, the emotional discomfort this caused was openly discussed and the participant allowed the presence of these emotions. **(See tab. 2, Q28,Q29)**

A number of participants did not reach the point of disease acceptance. Most appeared to have stagnated in the denial phase. Ineffective coping strategies, such as excessive drinking or smoking and avoiding confrontation, were observed by participants, their partners or the researcher. Anxiety and uncertainty was experienced by these participants in peaks when scheduled medical examinations took place to monitor disease progression. An effective approach to handle these emotions was absent resulting in avoidance, agitation or substance abuse. **(See tab. 2, Q30,Q31,Q32)**

Integration of findings

After PCa diagnosis and AS initiation, the existence of psychosocial support needs appeared subject to the participants coping strategy. Almost all participants experienced uncertainty and anxiety. Initially these emotions were caused by the PCa diagnosis and in a later stadium by recurring medical examinations, especially PSA testing and prostate biopsies. The ability to cope with these emotions was dependent on the adoption of effective coping strategies after diagnosis. The adoption of a distinct coping strategy seemed dependent on three factors. First, the relationship with and trust in the physician. Second, an internal or external locus-of-control. And third, the ability to accept the disease. Ineffective coping strategies were observed in participants with a strong internal locus-of-control, insufficient trust in the physician or not in acceptance of their disease. Participants with ineffective coping strategies had difficulties expressing their emotions and demonstrated less stress resilience. Participants with a strong internal locus-of-control displayed various PSA rituals. These rituals were intended to affect PSA values to reach self-defined PSA margins. Participants with effective coping strategies expressed the need for reliable and relevant information on low-risk PCa, treatment options, scientific developments, ED, LUTS and recommended lifestyle changes. Although specific emotional support needs were not explicitly described by participants, the researcher did observe negative consequences associated with ineffective coping mechanisms.

(Insert figure 2)

Discussion

This study explored the psychosocial needs of PCa patients during AS. Both practical and emotional support needs were identified during this study. Addressing these needs has the potential to reduce the negative psychosocial impact associated with AS. An important emotional support need identified during this study is the promotion of effective coping strategies. Various effective and ineffective coping strategies were adopted by participants to face the psychosocial burden of living with untreated disease. Ineffective coping strategies, such as avoidance, denial and substance abuse, seemed to impede resilience when faced with stressful situations. In this study, the use of effective coping strategies was associated with a positive patient-physician relationship, external locus-of-control and disease acceptation. An empathic and approachable attitude combined with genuine interest and expertise contributed to a positive physician-patient relationship according to participants. Furthermore, the availability of relevant and reliable information regarding disease characteristics and treatment options immediately after diagnosis was an important condition for satisfactory decision-making and aided in the acceptation process. Shared-decision making was highly valued, especially by patients with a strong internal locus-of-control. The use of a decision-aid might encourage shared decision making and improve effective coping.[72] Participants with a strong internal locus-of-control also expressed the need to receive information on meaningful lifestyle changes and effective ways to influence PSA levels. This contributed to an increased sense of control. An important practical support need identified during this study, was the presence and negative impact of LUTS and ED. These problems were reported by the majority of participants. LUTS and ED required social modifications and decreased the perceived quality of life. The use of validated screening instruments, such as the IPSS-questionnaire for LUTS and IEFF-questionnaire for ED, is common practice. However, an inquisitive and approachable attitude towards sexual functioning and urinary incontinence made it easier for participants to discuss the need for medical interventions with their physician.[71]

Mastris et al. describe in their research that PCa patients' initial relieve of avoiding invasive curative treatment whilst selecting AS is soon replaced by uncertainty and anxiety caused by follow-up.[60] These findings are in accordance with the results from this study. Parker et al. identified a relationship between anxiety, uncertainty and quality of life (QoL) in AS patients.[12] However, multiple studies indicate there is no significant difference in QoL between PCa patients undergoing AS and non-cancer patients.[61-64] This implies an absence of anxiety and uncertainty in this population. This ambiguity between unaffected QoL-scores and decreased subjective well-being in AS patients might be caused by the limited psychometric properties of general QoL-questionnaires in prostate cancer patients.[33,73] The current study asserts the importance of improved psychosocial support during AS. A scoping review performed by Kim et al. indicates that prostate cancer patients who have not received sufficient information on AS reported high rates of stress.[65] The need for information immediately after diagnosis described by participants in this study is similar to these findings. This review also confirms that physician trust is an important factor during AS.[66] Davison and Yanez affirmed the use of information and talking to others as a mechanism to cope with the disease.[67,68] Very little research is available on effective interventions for PCa patients undergoing AS. Kazer investigated an internet-based intervention which did not improve AS acceptation.[69] Wade et al. researched a nurse-led AS clinic in comparison to standard urologists care. However, this nurse-led clinic did not improve psychosocial outcomes.[65] The lack of effective interventions might be due to the knowledge-gap regarding the specific psychosocial support needs in the AS population. This emphasizes the importance of this study.

An important limitation of this study is the lack of investigator triangulation.[26] However peer-review on emerging themes did take place. A second limitation of this study was the limited experience of the researcher with qualitative methods. However expert consultation took place regularly. It is possible that a selection bias was introduced into this study. Participants with ineffective coping strategies may have a tendency to avoid confrontation with their disease, therefore their willingness to participate in this study might be limited. In addition, all participants were either married or in a long-term relationship. The psychosocial support needs of single patients might not be correctly reflected by this study. Although a relationship between major themes emerged from the data during this study, a theoretical or conceptual framework was not established. The relationship between themes was identified during the last data analysis phase and therefore the conceptual framework was not sufficiently challenged by comparison to deviant cases and ongoing data. A grounded theory approach is necessary to confirm the findings from this study and create a conceptual framework for AS associated psychosocial problems.[26,30,31] An important strength of this study was the enrollment of two diverse clinics and the inclusion of deviant cases. Furthermore tunnel vision was limited by conducting a member check with participants and peer debriefing.[30]

The results from this study may contribute to improved care for PCa patients undergoing AS and a decrease of the psychosocial burden they experience. On the short-term this study has generated specific recommendations for clinical practice. In the long-term, the findings from this research may contribute to the development of a psychosocial support program for PCa patients undergoing AS. This program should consist of the following components: early stage information on disease characteristics and treatment options, increasing patient-physician trust, promotion of disease acceptation, identifying ineffective coping strategies and introduction of effective coping strategies. Further research on the development of this program, the specific interventions and its feasibility is required.[70]

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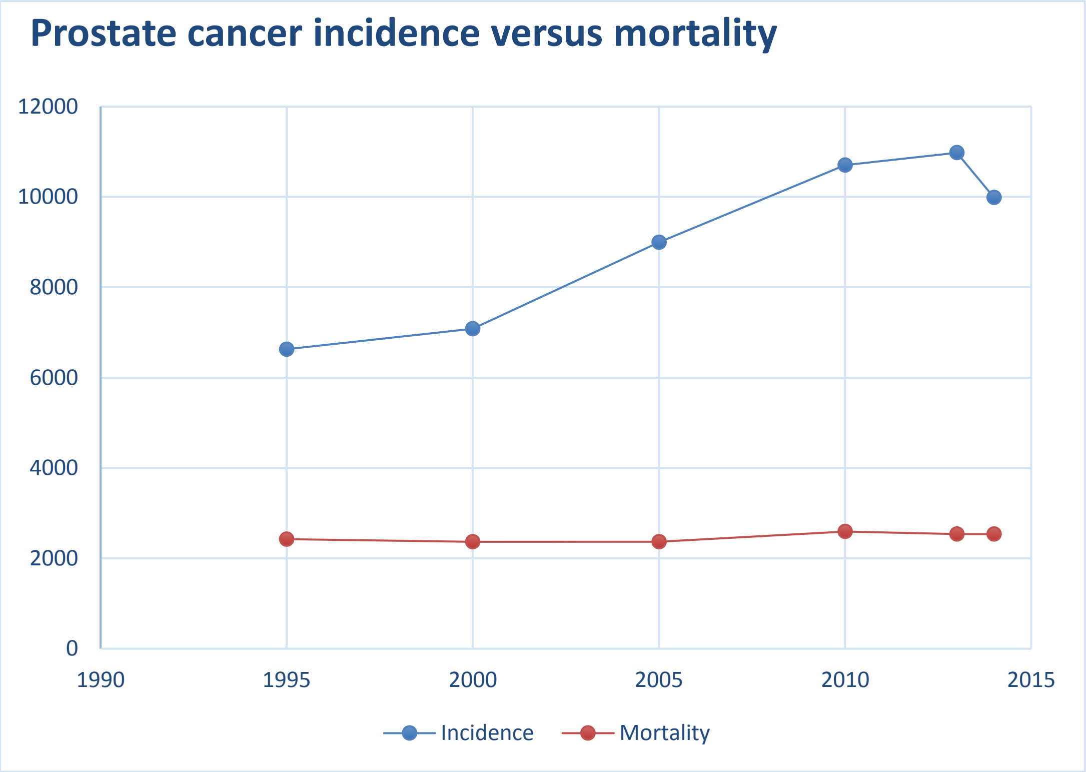
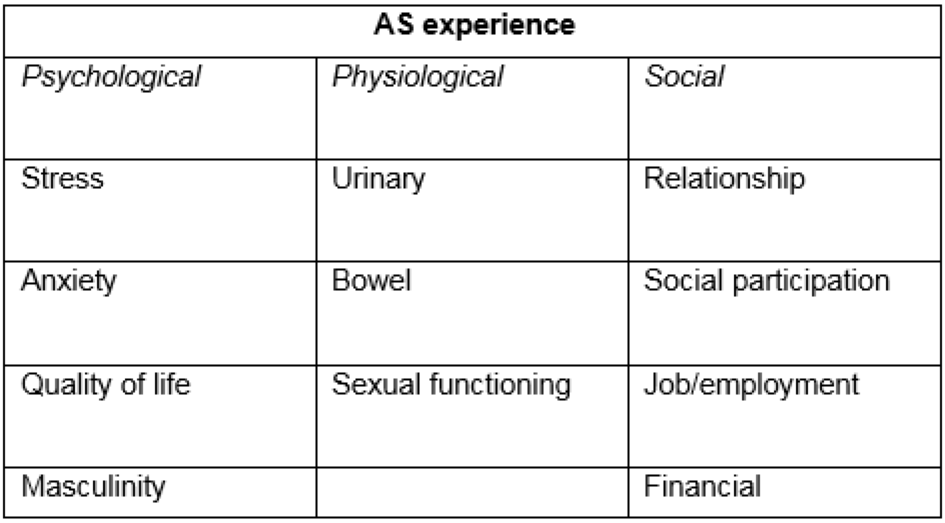
Tables and figures

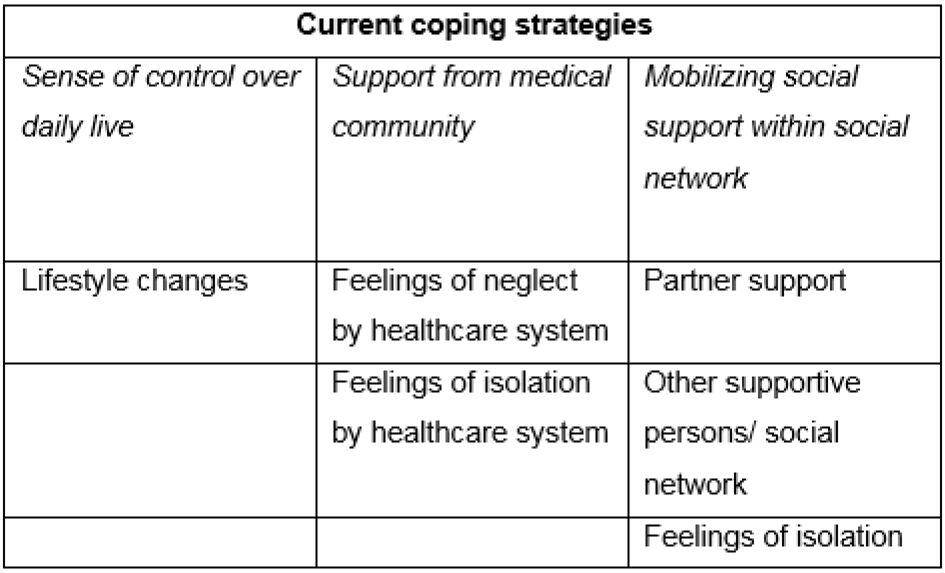
Figure 1. Prostate cancer incidence versus mortality[3]



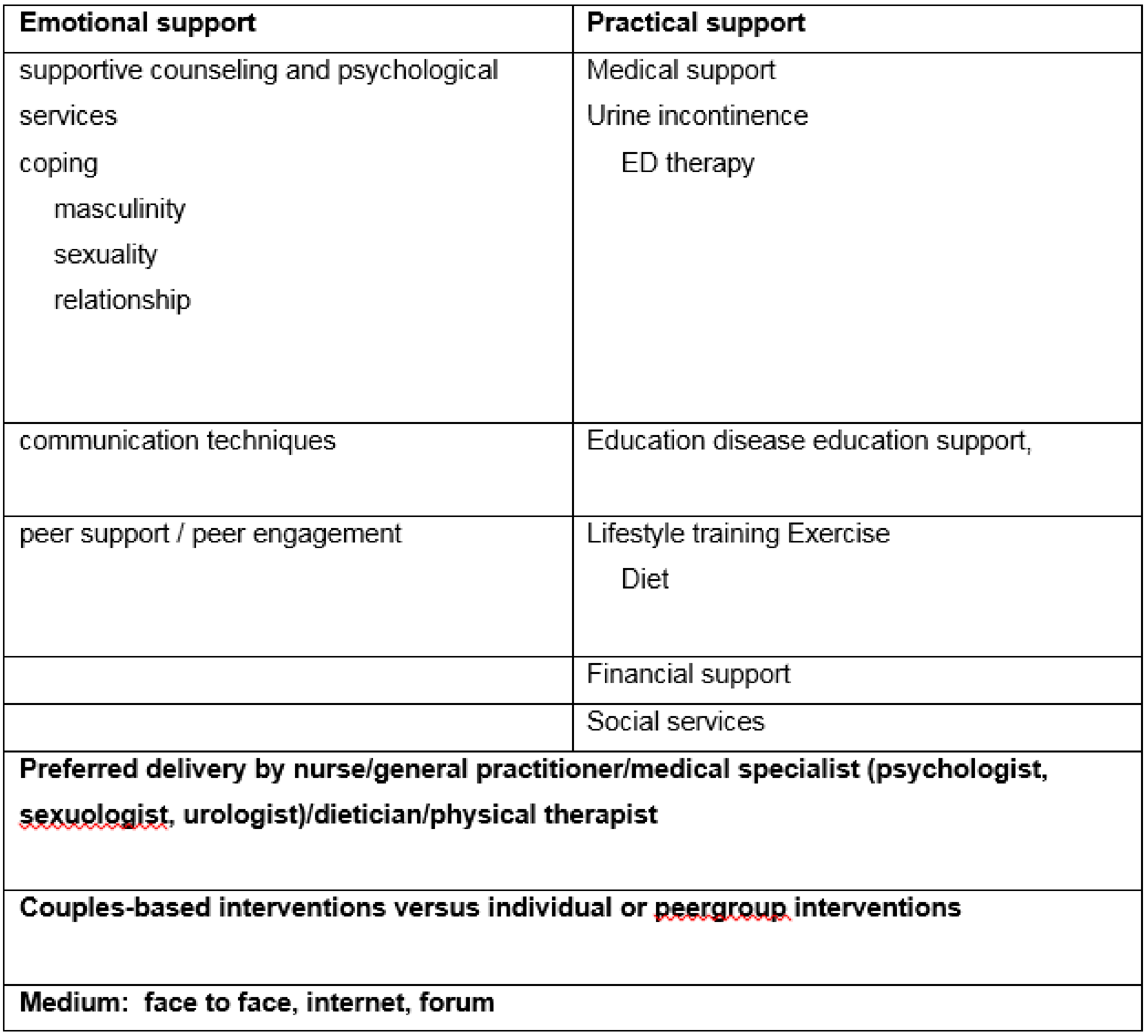
Box 1. Literature based topic list



AS experience		
Psychological	*Physiological*	*Social*
Stress	Urinary	Relationship
Anxiety	Bowel	Social participation
Quality of life	Sexual functioning	Job/employment
Masculinity		Financial



Current coping strategies		
Sense of control over daily live	*Support from medical community*	*Mobilizing social support within social network*
Lifestyle changes	Feelings of neglect by healthcare system	Partner support
	Feelings of isolation by healthcare system	Other supportive persons/ social network
		Feelings of isolation



Emotional support	**Practical support**
supportive counseling and psychological services coping masculinity sexuality relationship	Medical support Urine incontinence ED therapy
communication techniques	Education disease education support,
peer support / peer engagement	Lifestyle training Exercise Diet
	Financial support
	Social services
Preferred delivery by nurse/general practitioner/medical specialist (psychologist, sexuologist, urologist)/dietician/physical therapist	
Couples-based interventions versus individual or peergroup interventions	
Medium: face to face, internet, forum	

Box 2. Operationalized demographic variables

Variable	**Operationalized**
Age	in years
Ethnicity	Dutch Turkish Indonesian Moroccan Surinamese Antillean Other
Occupation	Technical, IT, scientific Professional, managerial Health care Industrial Office, clerical ,administrative
Education	Less than high school High school graduate Some college Associates degree Bachelor’s degree Master’s degree Prof/doctorate degree
Sexual Orientation	Heterosexual Homosexual
Marital status	Single Unmarried (with unregistered partner) Married/registered partner Widower
Family size	in numbers
Tumour characteristics	In stage and grade
Time since diagnosis	In months

Table 1. Characteristics participants

PARTICIPANT	CLINIC	LOCATION INTERVIEW	DURATION INTERVIEW	PARTNER PRESENT	TIME SINCE DIAGNOSIS	AGE	EDUCATION
P1	1	Hospital	1:10	No	36 months	76	MSc
P2	1	Hospital	1:09	Yes	48 months	68	BSc
P3	1	Home	0:47	No	12 months	55	Some college
P4	1	Home	0:57	Yes	48 months	65	BSc
P5	1	University	0:37	No	< 1 month (13 days)	69	MSc
P6	2	Home	1:01	Yes	7 months	66	MSc
P7	2	Hospital	0:59	No	114 months	71	Some college
P8	2	Hospital	0:50	No	27 months	65	BSc
P9	2	Home	1:08	No	120 months	68	BSc
P10	2	Hospital	1:13	No	24 months	67	Associates degree
P11	2	Hospital	1:15	Yes	20 months	73	Associates degree
P12	2	Home	0:23	Yes	48 months	68	Associates degree
P13	2	Home	0:44	No	117 months	73	Associates degree
P14	2	Home	1:01	No	12 months	69	MSc
P15	2	Home	0:54	Yes	50 months	54	BSc
P16	2	Hospital	1:30	No	84 months	63	Associates degree
P17	2	Hospital	1:05	No	36 months	64	MSc

Figure 2. Model of AS coping and support needs

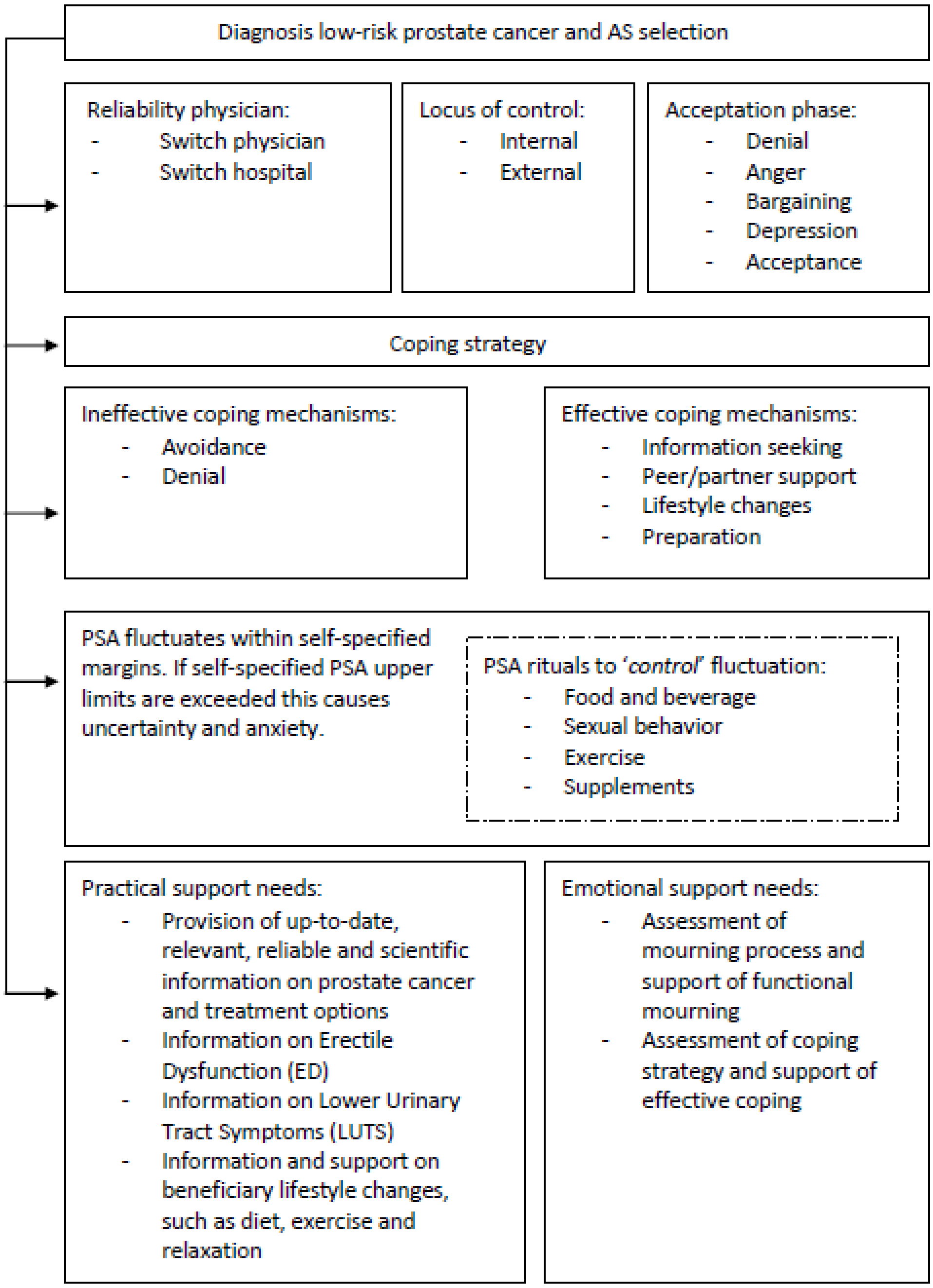


Table 2. Quotations

Quote #:	Quotation:	Participant:
Q1	*” I was scared, to be very honest, it scared me, yes.”*	**P4**
Q2	*“But that one word, that one word, it is prostate…. cancer.”*	**P11**
Q3	*“Well uh.. then he explained it to me, he said.. you are not going to die because of prostate cancer. Maybe you will die with prostate cancer, but not because of prostate cancer. That last sentence did it for me…”*	**P10**
Q4	*” [..] It is not just the technical stuff, it is also the insurance, the bank details. Who is our accountant? I have written everything down, 8 sheets of paper, everything is on there.”*	**P7**
Q5	*” [..] I try to live healthy and uh.. I quit smoking some time ago. Recently I stopped drinking. What else can one do? I eat a varied diet, I exercise.“*	**P9**
Q6	*”Well uh… when I think about it, I think about urinating, that has become more difficult, and all the little problems surrounding that. It’s not, that I am especially bothered by prostate cancer, that is not a very big deal [..] “*	**P13**
Q7	*“With this urologist, I thought… I don’t know, if I google I probably know as much as you do..[..] Well, I thought, I have to get out of here as soon as possible.”*	**P2**
Q8	*“If you do not have trust in someone, it is very difficult to make such a decision. My doctor is my confidential advisor. I need to be able to trust him.”*	**P6**
Q9	*“Everyone can tell me.. you will live to be 95 with this disease, but on the other hand, in my mind I think.. that cancer is still in my body. I start thinking and reading and at a certain point I know what I am talking about. [..] And then someone can tell me, damn it, in our eyes it is not, you don’t have to worry, but…”*	**P10**
Q10	*“Yes, it was very difficult. On the one hand there is something in your body. You have to think about the pro’s and con’s. My wife will tell you, we needed, I needed about 14 days to get to a certain point.”*	**P10**
Q11	*“There is nothing you can do to prevent it.. And I think, eh… if.. when you are ready.. Well, I have had a great life. If I die, I have*	**P14**

	to accept it […]”	
Q12	*“ I haven’t told family or acquaintances, I didn’t share it. [..] I have a large family but I haven’t told my brothers or sisters.”*	**P11**
Q13	*“ I think that, that is my control. I know there is nothing wrong with me. To say it flatly.. I am not sick. That’s it.”*	**P15**
Q14	*“It.. it.. it is such an ambiguous feeling. Anything can happen. If you did not have this disease, you would not think about it. [..] What if you do have metastases in your bones, well that means the end.”*	**P2**
Q15	*“It has a big impact. You don’t get closure. That is it. If you had an operation, there would be some check-up and then it’s done. This is not.”*	**P6**
Q16	*“ Yeah, it is the anxiety again.. what are the results going to be.”*	**P13**
Q17	*“It went up. I used my diet and close attention to do all sorts of things to bring it down. But it still went up. That disappointed me.”*	**P4**
Q18	*“ Well, normally it is 6,7-7, 6,9 around that level.”*	**P9**
Q19	*“Since this spring my PSA went up 1 point. [..] that makes me think. It concerns me.”*	**P12**
Q20	*“hmmm.. well we uh.. we looked up a lot of information. [..] You find all sorts of information about prostate cancer. [..] In that uncertainty you start looking, as a patient you shouldn’t.”*	**P2**
Q21	*“I know that there are mostly disaster scenario’s found online.[..] Those forums have an emotional character.”*	**P15**
Q22	*“I talked about it a lot. I looked up a lot of information that first week. I had to ‘ruminate’. It helped me to process [..]”*	**P16**
Q23	*“Just tips, point me in the right direction. Where can you.. what can you.. together. What should you do, what shouldn’t..[..] Food, lifestyle, that stuff. “*	**P4**
Q24	*“ I mean, the open information, it is so contradictory. What should I believe?”*	**P8**
Q25	*“ Especially in the first six months. You want to know everything, what can happen, what are the treatments options., all that..[..] You want to become your own expert”*	**P10**
Q26	*“It is never away, it never leaves my mind. You know it is there. The anxiety is less, especially in the beginning the thought*	**P10**

	scared me a lot.”	
Q27	*“ If it happens to you, it is uncomfortable. Yeah, well, you are relieved but always scared”*	**P12**
Q28	*“I try to live with it. I talk about it among other things.”*	**P3**
Q29	*“Yes, that.. exchanging experiences, that helped me.”*	**P4**
Q30	*“During that time I faced a lot of problems. And it caused me to drink a lot”*	**P8**
Q31	*“No, when you get more involved.. [..] you are confronted, it makes you think about it, worry.”*	**P14**
Q32	*”I’m scared that, if I start with interventions, it would make me more aware of my cancer, it would cause anxiety.”*	**P16**

Appendix

Appendix I: Dutch interview guide

Fase I

Kunt u mij vertellen wat het met u deed toen u te horen kreeg dat u prostaatkanker had?

Er werd u gevraagd een keuze te maken voor een behandeling, hoe ging dat bij u?

Hoe vond u het om een keuze te maken?

Wat heeft u doen kiezen voor AS.

Welke voordelen verwachtte u?

Welke nadelen verwachtte u?

Hoe heeft u AS tot nu toe ervaren?

Op welke wijze heeft AS uw lichamelijke welzijn beïnvloed?

Op welke wijze heeft AS uw sociale welzijn beïnvloed?

Wat heeft AS voor uw emotionele welzijn betekent?

Hoe ervaart u de ondersteuning vanuit uw partner?

Hoe ervaart u de ondersteuning vanuit uw omgeving?

Hoe ervaart u de ondersteuning vanuit huisarts en ziekenhuis?

Sommige mannen ervaren een verlies van controle over lijf, leven en ziekte tijdens AS, hoe is dat voor u?

Welke negatieve gevolgen heeft AS (problemen) voor u gehad?

Hoe bent u daar mee omgegaan?

Fase II

Op welke wijze zouden wij u tijdens AS beter kunnen ondersteunen?

Welke emotionele ondersteuning zouden wij u kunnen bieden?

Welke praktische ondersteuning zouden wij u kunnen bieden?

Wie zou er het meest geschikt zijn om u deze ondersteuning te bieden?

Zou deze ondersteuning aan u alleen, aan u en uw partner of aan een groep geboden moeten worden?

Zou deze ondersteuning middels bijeenkomsten, via internet of een ander medium geboden moeten worden?

Appendix 2: Operationalized demographic data collection form

Variable	**Operationalized**
Age	in years
Ethnicity	○ Dutch ○ Turkish ○ Indonesian ○ Moroccan ○ Surinamese ○ Antillean ○ Other
Occupation	○ Technical, IT, scientific ○ Professional, managerial ○ Health care ○ Industrial ○ Office, clerical ,administrative
Education	○ Less than high school ○ High school graduate ○ Some college ○ Associates degree ○ Bachelor's degree ○ Master's degree ○ Prof/doctorate degree
Sexual Orientation	○ Heterosexual ○ Homosexual
Marital status	○ Single ○ Unmarried (with unregistered partner) ○ Married/registered partner ○ Widower
Family size	in numbers
Tumour characteristics	In stage and grade
Time since diagnosis	In months

Appendix 3. Alterations to interview guide based on sequential data analysis

Phase 1 Questions	Phase 2 Questions	Phase 3 Questions
Impact diagnosis	Impact diagnosis	Physician reliability
AS selection	Role physician in AS selection	Influence of AS on emotional, social and physical wellbeing
Expected (dis)advantages of AS	Experienced (dis)advantages of AS	Experienced anxiety and uncertainty
Experienced (dis)advantages of AS	Experience with peer support	AS associated problems
Influence of AS on emotional, social and physical wellbeing	Disease and PSA control	Coping strategies
Experienced support from partner, peers and professionals	AS associated problems	Disease and PSA control
Masculinity and disease control	Coping strategies	PSA rituals