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The experiences and unmet supportive care needs of partners of men diagnosed with prostate cancer: a meta-aggregation systematic review.

ROBERTS, C., TOOHEY, K. and PETERSON, C.

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Title: The experiences and unmet supportive care needs of partners of men diagnosed with prostate cancer: A meta-aggregation systematic review

Authors: Cara Roberts, BSc OT; Kellie Toohey, PhD, MCEP, BSc, PG Cert Research, PG Cert Tertiary Ed, AEP; Catherine Paterson, PhD, BA, MSc, PgCert LTA, FHEA, RAN

Author Afflications

Faculty of Health, University of Canberra, Bruce ACT, Australia (Prof Paterson, Dr Toohey and Ms Roberts)

Prehabilitation, Activity, Cancer, Exercise, and Survivorship (PACES) Research Group, University of Canberra, Bruce ACT, Australia Prof Paterson, Dr Toohey and Ms Roberts)

Canberra Health Services & ACT Health, SYNERGY Nursing and Midwifery Research Centre, ACT Health Directorate Level 3, Building 6, Canberra Hospital, Australia (Prof Paterson)

Robert Gordon University, Aberdeen, Scotland, UK (Prof Paterson)

Corresponding Author:

Correspondence: Professor Catherine Paterson, PhD, School of Nursing, Midwifery and Public Health, University of Canberra, Bruce ACT, Australia (Catherine.paterson@canberra.edu.au)

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Catherine Paterson: Conceptualization, Methodology, Validation, Formal analysis, Interpretation, Writing Original draft, Writing –Reviewing & Editing, Supervision.

Kellie Toohey: Data extraction, Methodology, Validation, Formal analysis, Interpretation, Writing – Reviewing & Editing.

Cara Roberts: Conceptualization, Methodology, Validation, Formal analysis, Interpretation, Writing Original draft, Writing –Reviewing & Editing.

Abstract

Background: Partners of men diagnosed with prostate cancer face their own emotional struggles, as they navigate additional caregiver responsibilities, while concurrently adjusting to the diagnosis and coping with greater illness uncertainty for their loved one.

Objective: This qualitative systematic review examined the unmet supportive care needs of partners affected by prostate cancer.

Interventions/Methods: A meta-aggregation was conducted. Four electronic databases were search using key words. The methodology followed the Joanna Brigg's Institute (JBI) for qualitative evidence synthesis. The review process followed a registered priori review protocol and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. Data extraction and quality assessment was conducted in parallel.

Results: 21 publications were included. A total of 239 findings and 32 categories were synthesised into seven domains of unmet needs as experienced by partners. The domains of needs expressed by the participants included: interpersonal/intimacy, physical/daily living, health care service, family-related, psychological/emotional needs, spiritual, and social needs.

Conclusions: There are gaps in clinical service support, despite routine clinical consultation with healthcare professionals. Partner may diminish their social networks to protect their husband at the cost to their own self-preservation and well-being.

Implications for practice: Cancer organisations, policy makers, healthcare care professionals and researchers are slowly making progress to acknowledge the unique support needs of partner affected by cancer. Healthcare professionals should encourage partners to be included in models of prehabilitation access timely support to address informational, intimacy, spiritual and daily living needs support.

Key words: qualitative; systematic reviews; unmet needs; supportive care; partners; spouses; loved ones; prostate cancer.

Introduction

Prostate cancer remains the most frequently diagnosed male cancer in developed countries [1,2]. With advances in disease detection, improved treatment options and reduced mortality rates, more men are surviving beyond their diagnosis. However, men are often confronted with a sequalae of adverse physical and psychological effects which significantly impacts their quality of life in a negative way [3,4]. These morbidities include urinary and bowel incontinence, sexual dysfunction, fatigue and psychological distress [5]. Physical and psychological challenges pose a threat to relational and intimacy experiences for both the man and his partner [6]. Following a prostate cancer diagnosis, the partner is seen as a crucial companion in the cancer care continuum with the partner's support playing an instrumental role in the man's ability to successfully transition from the acute phase of the disease to long-term survivorship [7]. Men tend to rely exclusively on their partner for emotional, practical and medical support, as a result partners are considered valuable communication conduits, actively advocating for the man during the diagnosis and treatment process [8,9]. Partners face their own emotional struggles, as they navigate additional caregiver responsibilities, while concurrently adjusting to the diagnosis and coping with greater illness uncertainty for their loved one [10]. Evidence underscores that partners report lower self-esteem, less social support [11] and they are twice as likely to experience depression and anxiety than the general population [12]. The partner reportedly suffers significantly more distress than the man himself, particularly during the earlier stages of the cancer care continuum [13]. Partners often have to deal with their anxiety and distress privately to minimise the impact of the illness and avoid emotional tension with the man diagnosed with cancer and extended family networks [11]. In an effort to preserve the man's sense of masculinity, partners are reticent to discuss information pertaining to the illness experience, particularly regarding sexual dysfunction [3]. This lack of communication and experience sharing between couples can exacerbate feelings of isolation and distress, which can result in detrimental changes to the spousal bond [14]. Given that dyadic psychological outcomes and quality of life are intrinsically linked to the man's experience of prostate cancer, it would be remiss to neglect the partner in the treatment process [15]. Research to date, has mostly focussed on the needs of the man, with the partner perspective underrepresented in the literature and with a lack of qualitative insight into their experiences [16]. Therefore, it is important to critically appraise existing empirical evidence to understand the unique supportive care needs of the partner of a man diagnosed with prostate cancer. This review will address the following research questions:

- What are the experiences and supportive care needs of partners following a diagnosis of prostate cancer?
- What are the barriers and/or facilitators to seeking and receiving support?

Methods

This systematic review has been reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [17] and was registered on the International Register of Systematic Reviews available from:

https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=190377

Eligibility Criteria

Types of Studies

Inclusion

- Studies that explored the experiences of the intimate partner of men living with a prostate cancer diagnosis.
- Studies that reported findings from both members of the couple were included, providing they reported the partner experience separately.
- Studies published in English.
- All qualitative studies.
- Case studies were considered.

Exclusion

- Quantitative study designs, editorials, conference abstracts, and commentaries.

Types of Participants

Inclusion

- All intimate partners (≥ 18 years) of men living with a prostate cancer diagnosis.
    - Partners refer to those individuals involved in a relationship with the man with prostate cancer.
    - Partners may be of any sex, gender, or sexuality.

Exclusion

- Studies that focussed solely on the man's experience, without exploring the partner perspective.
- Studies involving non-partner caregivers (i.e., other familial or supportive relationships, such as friendships).

Outcomes: Supportive Care Needs Classification

The Supportive Care Needs Framework [18] guided the development of the 'unmet needs' search strategy, which was further refined following careful review of the Supportive Care Needs Survey Partners and Caregivers (SCNS-P&C) [19] and relevant caregiver literature [20-26]. The domains of needs utilised in the search strategy included: health care service needs, information needs, psychological/emotional needs, social needs, spiritual needs, physical/daily living needs, interpersonal/intimacy needs and family related needs. Additional terms were then developed within each of these domains to ensure a comprehensive search was conducted. All citations were managed using EndNote software.

Literature Search

Electronic databases (MEDLINE, CINAHL, PsycINFO and Cochrane) were searched from their date of inception to February 2022, in English language only. Editorials, conference abstracts, and commentaries were excluded. A secondary strategy involved screening the reference lists of retrieved manuscripts for additional relevant studies. Existing reviews were scrutinised for potentially relevant references. The search architecture was created in consultation with an expert research librarian and was modified to suit each database. Three categories of concepts were searched based on the PICo framework [27] (1) prostate cancer; (2) partners or informal caregivers; and (3) experiences or unmet needs. An example of the full electronic search strategy is provided in **Table 1**.

Data Collection and Analysis

Selection of Studies

Following the database searches, all identified citations were uploaded into Covidence systematic review software and the duplicates were removed. The titles and abstracts were screened according to the pre-determined eligibility. The full-text articles were retrieved and carefully assessed against the inclusion and exclusion criteria. All abstracts and full-text screening was cross-checked by two reviewers and any inconsistencies were discussed until a consensus was reached. Any remaining discrepancies were resolved in consultation with a third reviewer.

Data Extraction and Management

The data was independently extracted from the studies using data extraction tools that were developed to capture two levels of information. The first table included the study and sample characteristics (data methods and analysis, country, theoretical model / framework, phenomena of interest, setting, context and culture, partner and relationship characteristics, sample size and description of main results). The second table of data extraction related to the domains of supportive care needs. The data extractions were checked for accuracy by a second author. In the event of missing or incomplete data, the authors of the studies were contacted for additional information.

Assessment of Risk of Bias in Included Studies

Methodological quality of eligible studies was assessed using the Mixed Methods Appraisal Tool (MMAT) [28]. This tool was selected as it allows concomitant appraisal of several study designs however, for this review, only the qualitative checklist was employed. The MMAT consists of two initial screening questions, which determine the empirical status of the studies, along with five additional criteria specific to the study design. Each item was rated against “yes”, “no” and “unclear” as it pertained to the qualitative study criteria. Items that were rated as “unclear” triggered a search for companion papers to provide additional clarification, where required.

Data Synthesis

The Joanne Briggs Institute method of meta-aggregation [29] was used to extract, synthesise, and categorise the data. This three-step approach to thematic analysis initially involved extracting the authors interpretation of the results verbatim and documenting these as findings. Direct illustrative quotes were then used to inform each finding. This afforded an accurate and reliable presentation of results and eliminated the risk of re-interpreting the included studies. Findings and supporting illustrations were assessed for congruence and given a credibility ranking of either 'unequivocal' (clear association between the finding and illustration and not open to challenge), 'credible' (plausible and logically inferred from data however, they are interpretive and open to challenge) or 'not supported' (findings not supported by data) [29]. Unsupported findings were not included in the final synthesis [30]. Following careful and repeated assessment of the compiled data, two or more findings were grouped into categories accompanied by an explanatory statement. Further synthesis of these categories produced overall synthesised findings [29,30].

Findings

A systematic search of the electronic databases yielded a total 2915 records, including CINAHL (n=668), MEDLINE (n=1535), PsycINFO (n=464) and Cochrane (n=248). An additional study was located after manually reviewing the reference lists of included studies. Following the removal of 926 duplicates, the remaining titles and abstracts were assessed against the inclusion criteria. The remaining 88 articles were retrieved in full, and 66 excluded with reasons (see **Figure 1**). A total of 20 studies were included and two publications reported on the same study (a total of 21 publications included). The methodological quality of each study was assessed concurrently with the data extraction process (see **Table 2**). The studies were conducted in a range of countries, including the United Kingdom (5), the United States of America (8), Denmark (3), Norway (1), Australia (2) and Canada (1). All studies reported the partner findings separately but 11 studies interviewing both members of the couple together, and 9 studies focussing exclusively on the partner experience. Most studies recruited partners who identified as female, with only six studies expanding their eligibility criteria to include same sex partners. Of those six studies, two participants included in this review represented the needs of partners in same sex relationships. The sample size of participating partners varied from n=5 to n=113 (total n=380) and the mean age ranged from 32 years to 88 years. Relationship characteristics, such as marital status and length of relationship were inconsistently reported. However, of the available data the length of partnerships varied from less than 5 years to greater than 65 years (see **Table 3** for characteristics of included studies).

Frequency of Unmet Supportive Care Needs

Overall, there was a total of 239 unequivocal or credible findings (see **Supplementary Table 1)** and 32 categories which were synthesized into seven domains of unmet needs experienced by partners, see **Table 4** for an overview of the synthesized findings, and **Figure 2**. The frequency of needs expressed by the participants across the included studies were, interpersonal/intimacy needs (18/22: 82%), physical/daily living needs (14/22: 64%), health care service/comprehensive cancer care needs (12/22: 54%), family-related needs (12/22: 54%), psychological/emotional needs (9/22: 41%), spiritual needs (9/22: 41%) and social needs (5/22: 23%). The facilitators and barriers of support were discussed in (7/22: 32%) of papers.

Experiences of Interpersonal/Intimacy needs

Partners were acutely aware of the risk that sexual dysfunction posed to the man's sense of masculinity [31]. Partners endeavored to lessen the impact and protect the man's dignity by remaining tactful with the personal information they disclosed to others [8] and if necessary, ignoring their own sexual needs [16,32]. Couples with well-established relationship histories identified that their bond was strong enough to withstand any loss of intimacy and they shifted their attention toward sustaining companionship through displays of physical affection and planned 'date nights' [32-43]. Couples admitted to trialing erectile medications and sexual aids to attempt intercourse; however, some partners reported this lacked spontaneity and the interaction became 'too clinical' [8,32,36,38,39,43]. Partners were mindful that resuming sexual activity required a gradual approach and viewed their role as being available when the man was ready to try [40,43]. Partners discussed changes in sexual initiation post-diagnosis. While this was historically the man's role, partners felt compelled to take the lead when they noticed the man struggling with performance [39,41,42]. However, some partners felt embarrassed asking for sex and were hesitant to initiate, as they were concerned it would negatively impact the man's self-esteem [39,42].

A decline in the man's libido following treatment resulted in the couple experiencing different levels of sexual satisfaction [40] and partners reported their sexual needs were no longer being met [39,42]. Partners stated that maintaining intimacy became 'one-sided' [40] particularly when the man was complacent toward his dysfunction [44] or chose not to reciprocate sexual advances [41]. Partners also reported a reduction in the man's expression of verbal and physical affection and without the man's previous sexual responses as evidence of attraction, partners suffered a loss of self-esteem [8,34,39]. Partners no longer knew how to fulfill their sexual role within the relationship, and many opted to forgo sexual activity due to the disparity in pleasure [39,40]. Consequently, most partners experienced grief associated with the loss of emotional and physical intimacy following treatment [5,16,37-39]. Couples who actively tried to maintain sexual activity described immense distress when their attempts reminded them of what they once shared together [5,39]. Younger partners and those in newer relationships placed greater importance on intimacy and many were unable to reconcile losing this dimension of their relationship [33]. Partners expressed the need for psychosexual support to manage sexual dysfunction and relationship anxieties, but options were limited [42]. Partners thought that verbalizing worries about performance would assist in nurturing intimacy [40] however, if the man withdrew emotionally or neglected to include the partner in sexual management decisions, intimacy suffered and partners began to re-evaluate the future of the relationship [5,36,38,43].

Experiences of Physical/Daily Living needs

Partners reported difficulty in managing their own age-related health conditions, as they frequently prioritized the support needs of the man, and often the needs of extended family members [38]. Partners neglected their own self-care to counteract these competing demands and to preserve the physical and emotional resources necessary to fulfill their daily care duties [44]. Partners shared that the men became increasingly reliant on them for emotional and psychological support [8] and as a result, they experienced a shift in dynamic from feeling protected and care for, to shouldering the weight of emotional caretaking within the relationship [36]. Partners stated that they also provided practical support including increased household contributions, proactively seeking disease-related information, participating in the man's medical appointments, and exploring available treatment options [35,45]. Partners were instrumental in fostering the man's support networks and ensuring family members remained apprised of the man's health status [34].

Partners reported that the altruistic prioritisation of the man's needs above their own, along with the added emotional and practical expectations following treatment, resulted in feelings of anxiety, exhaustion, and an inability to cope [5,16,32]. Both individuals in the relationship viewed prostate cancer as a shared challenge. Partners linked themselves to the man's diagnosis by adopting joint terminology with phrases such as "*we are in this together"* [8] and *"when we had treatment"* [35] to describe their experience of living with prostate cancer [43]. This trend extended to other aspects of daily life with partners encouraging healthy lifestyle changes (improved nutrition and exercise) by participating in these alongside the man [32]. However, this 'couple approach' was unique to prostate cancer and partners conceded that they did not receive the same level of reciprocity from the men when facing their own cancer battles [31].

Partners expressed needs about the financial implications of a prostate cancer diagnosis, particularly if the disease was to become terminal [41]. The age and stage of life influenced the level of financial stress. Partners who were balancing employment with care duties expressed guilt when they needed to choose between actively supporting the man during treatments or preserving their household income and health insurance to provide for the family. These partners claimed the diagnosis would have been easier to accept if the couple was older and receiving retirement benefits [35]. Partners of black African and/or Caribbean men reported that delineation of gender roles within their culture prevented open discussion about financial issues and needs and this resulted in partners feeling insecure and uncertain about their family's future [42].

Experiences of Health Care Service/Comprehensive Cancer Care needs

Partners reported that they did not receive enough support, information, and advice from the team of healthcare professionals involved in the man's care [31,42]. Due to the integral role partners play in both the advocacy and care of the man throughout the cancer trajectory, the experience of having their emotional needs ignored exacerbated their distress and left partners feeling like ‘invisible participants’ in the process [8,16,43,46]. Partners desired greater signposting to appropriate services and emphasized the need for referral to help manage their emotional and psychological concerns [5,45]. Partners expressed the importance of clear and consistent communication from healthcare professionals around diagnosis, prognosis, and the man’s continuity of care, so they could adequately prepare for the long-term impacts of prostate cancer on their life and relationship [41,45,46]. Partners wanted more opportunities to ask questions, voice concerns [16] and explore topics such as sexual functioning to prepare for treatment related changes and subsequent sexual recovery [43]. However, partners reported that time pressures and a primary focus on test results during consultations, seldom allowed the chance to do so [41,46]. Partners needed more practical guidance on how to talk to their children about the disease [47] and where to source continence pads and erectile dysfunction aides [48]. Digital literacy was an additional consideration for partners in older couples, who felt they lacked the sufficient skillset to access and navigate the internet to meet their information needs [46]. Without enough information, partners felt their identity was challenged and they were thrust into the role of caregiver instead of companion [31]. Partners proposed that meaningful engagement with healthcare professionals could reduce their feelings of isolation and stress and because prostate cancer was considered to be a ‘couple disease’, partners agreed that it should be treated as such, with their needs being factored into the care provided [16,31,42].

Experiences Family-Related Needs

Some partners reported that the man constrained their communication by instructing them not to speak with family and wider social networks about his diagnosis [5,16]. This isolated partners from valuable support systems and contributed to increased conflict between the couple [45-47]. Partners of black African/Caribbean men experienced communication restriction to a greater degree and stated that disclosing the man’s health information to others would challenge his ego and jeopardize his position as leader of the family [42]. In addition, partners attempted to protect their family from any hurt associated with the diagnosis by remaining silent about their struggles [8,32,44]. This perceived sense of duty to the man and the family was also a driving force behind partners learning about the disease [38,45], advocating for appropriate treatments [36] and encouraging a positive attitude [34]. However, partners described a sense of shame and guilt when their stoicism faltered and they were unable to cope with the emotional weight of caregiving [16,47]. Some stated that when families were aware of the diagnosis and support was not offered [32], the partner's loneliness and exhaustion were amplified [8,44]. Alternatively, the few partners who did receive support from extended family displayed greater levels of emotional wellbeing [32].

Experiences of Psychological / Emotional Needs

Partners reported that living with a prostate cancer diagnosis had taken a serious toll on their emotional wellbeing however, neither the man nor the treating team appreciated the severity of the impact on the partner [42]. The partner's level of anxiety was directly correlated with the extent of the man's distress at diagnosis [8] and partners described a sense of helplessness and impending fear, as if they were on tenterhooks waiting for 'the next thing to happen' [38]. Partners frequently prioritized the man's needs above their own with very few choosing to access professional psychological support [16]. Instead, opting for self-management strategies, such as consciously shifting their focus away from anxiety-provoking thoughts and seeking support from their wider social networks [45]. Suppressing their own emotions and presenting a strong front served a dual purpose for partners; it allowed them to build optimism and resilience to sustain their supportive efforts and it also ensured they could shield the man from additional negativity and hurt [5,8,32]. Although, neglecting their own needs eventually resulted in feelings of isolation which partners equated to 'living in a state of silent suffering' [38]. Partners conveyed fears related to uncertainties around treatment outcomes and possible disease progression [41], the risk of cancer recurrence [8] and the overall impact of prostate cancer on their future prospects [35]. Partners of men on active surveillance were worried about test results and the decisions they may face if the man's status were to change [45]. Partners were especially concerned with the man's potential pain levels and how to best support him through his illness [38]. Partners with extensive caregiver experience acknowledged the burden of long-term care and voiced the importance of re-evaluating their approach to care provision to allow time and space to process their own lived experience [8].

Experiences of *Spiritual Needs*

Partners reported that faith and spirituality played a vital role in helping them cope with the man's diagnosis and future prognosis [38,42,44]. It also offered connection to community and culture, with many accepting outreach from their church family or finding peace in the practice of ancient ancestral rituals [34]. While they grappled with anxiety and fear related to seeing the man in pain [35], possible disease progression and how they would manage their future alone [8,32,45], partners derived a sense of solace through their belief in a higher power [32,44]. Partners stated that engaging in practices such as prayer and fasting, as a couple, demonstrated mutual support and aided in the management of disease-related side-effects [37]. Partners experienced an increased fondness and admiration for the man, as they moved through the cancer experience and considered their provision of care to be an expression of love [44]. Partners described the illness as an opportunity to find meaning in adversity, enhance their understanding of life, and advance their spiritual growth [32,34,37]. The diagnosis was viewed as a catalyst for appreciating what they had already achieved as a couple but also how they could re-align their priorities moving froward [35]. Partners reported a heightened empathy toward others facing life-altering diagnoses and they felt compelled to connect and share their story with these individuals [34]. By engaging in acts of service, such as running support groups together with the man, partners bolstered their emotional and spiritual wellbeing and were better equipped to integrate the illness into their own lives [37].

Experiences of Social Needs

For the first three months following diagnosis, partners voiced the need to isolate in the home as a couple. Partners considered this a show of solidarity to the man and his support needs, but also recognised self-isolation was a useful tactic to avoid illness related questions they were not yet ready to address with their social networks [44]. The severity of the man's treatment-related side-effects limited the partners ability to leave the house and maintain their social relationships [38]. Over time, the prolonged isolation and lack of social connection led to partners experiencing greater psychological burden [32,44]. Partners reported a need for social and emotional support from a variety of sources including family, friends, health professionals and prostate cancer support groups [31]. Partners sought this connection as a means to normalize their experiences; however, differences in support preferences and communication styles within the couple had the potential to impede the partners opportunity to openly share their experiences with others [31,36].

Facilitators and Barriers to Supportive Care

While some of the above findings reference factors that may enable or impede a partner's access to support, these were relevant to a particular domain of unmet need. Additional facilitators of support include access to Specialist Prostate Cancer Nurses and tailored interventions and/or lifestyle programs. These both fostered greater opportunity for partners to process and share emotions, problem-solve sensitive issues, and build confidence in their ability to actively support the man [8,16,40,41,45,47]. Fear and differing support preferences between the couple were the main barriers to seeking assistance. Some partners limited their exposure to information as a form of self-protection, whereas others wanted to access peer and professional services but felt blocked by the man's reluctance to participate [46].

Discussion

This meta-aggregation set out to identify the experiences of supportive care among intimate partners of men diagnosed with prostate cancer. This systematic review critically appraised existing qualitative studies providing overarching synthesised findings and presented holistic insights as represented through the voices and reports of the partners. This paper provides valuable new insights because the partners self-articulated needs in this review were not influenced or concealed, but representative of their experiences from their perspective alone. These findings add to the existing evidence base because this review was not limited to couples experiences of: a) informational needs [49,50], b) effects of interventions [2], c) advanced cancer [51], d) age [52] or e) constrained by evidence which is clinically outdated by year of publication [3,53,54], but rather explicitly identified the partners experiences through a qualitative individual lens.

This review has highlighted the shared impact of living with a prostate cancer diagnosis. Across the studies there was evidence of gaps in clinical service support, despite routine clinical consultation with healthcare professionals. There is increasing recognition that models of prostate cancer care should be individualised, tailored and sensitive to the unique needs of the couple [10,55]. Service re-design should focus on couple centred consultations and targeted interventions for intimacy, communication and discussion about grief and loss.

It is well recognised that partners experience distress and emotional upset, often to a much higher extent than the man diagnosed with cancer himself requiring social support [2,5,12]. For many, social support is an intuitive term used to describe support received, or perceived, from friends and families within a social network during a difficult time. The Main Effects Model and the Stress Buffering Model are the two dominant theoretical frameworks which link social support to physical and mental well-being in prostate cancer [56]. In brief, the Main Effects Model postulates that people who have high social support (either received or perceived social support) will have improved psychological and physical well-being compared to those with lower support irrespective of the level of stress [57]. Thus, this relationship is hypothesised to be linear. Alternatively, the Stress Buffering Model would assume that social support which is received or perceived by partners is linked to better physical and psychological well-being when they are exposed to stressful situations [58]. Therefore, in the real world setting under conditions of high levels of stress, social support is believed to act as a buffer against the adverse effects of that stressor.

There is a well-recognised movement towards cancer care models of prehabilitation [59,60] and emerging evidence in prostate cancer to address unmet needs and overcome barriers to accessing support [10,61]. Prehabilitation is a model of care used to describe targeted uni- and/or multi-modal interventions after diagnosis, but before cancer treatment, to enhance physical and psychological conditioning of the 'man' to optimise post-treatment recovery. Specifically, prehabilitation prostate cancer interventions have included physical exercise, pelvic floor exercises, erectile dysfunction, cognitive behavioural therapy or general self-management advice for nutrition/diet and alcohol or smoking cessation [10,61]. Importantly, only one study has included the partner in the prehabilitation interventions [10] which provided multimodal self-management support and access to peer social support for both the man diagnosed and the partner. The findings from this study suggested that partners benefited from connecting with others in a similar situation and receiving targeted self-management support that they could use practically and emotionally [10]. Providing up-front support for interpersonal/intimacy, informational, practice daily living needs and spiritual dimensions would be considered appropriate for future prehabilition programmes of supportive care for both the man and his intimate partner.

There are a number of limitations to point out in this prehabilitation study [10] however, namely: 1) this study lacked prospective longitudinal evaluation of the intervention on physical and psychological well-being of the partner, 2) it had small participant numbers (n=19 partners), and 3) this study lacked a control group. Given the concealed unmet needs experienced in solitude by the partner during the first three months, targeted couples prehabilitation models of care holds significant promise but further high-quality prospective intervention trials are needed. Future interventions could be clinically enhanced by multidisciplinary team approaches to capitalise on each healthcare discipline's philosophical, theoretical orientation and clinical strengths to leverage and develop models of holistic health and recovery for the patient and the partner, given the unique insights that this review has provided.

There are several limitations observed throughout the studies included. Most of the study participants represented in this review were from WEIRD (Westernised, Educated, Industrialised, Rich, Democratic) populations [62]. Little is known about the experiences of intimate partners from minority groups, low-to-middle income counties, and those from different cultural and socio-economic backgrounds. Within this systematic review the majority of the included participants were biased in favour heterosexual couples and further research is needed in to the support needs experienced by other gay, bisexual, transgender, queer and intersex (LGBTQI) minority groups [63]. This review has highlighted this gap very clearly, because only two participants represented the needs of partners of men in same sex relationships. Largely, the studies were cross-sectional and further prospective longitudinal designs are recommended to explore how needs might change over time.

Limitations

This qualitative systematic review has many strengths including the clear and specific methodology which followed a registered priori protocol. In addition, to the independent reviewer's contributions throughout the entirety of the systematic review process, the study provided insights across heterogenous study populations in terms of relationship durations, cancer stage and treatments, and ages which strengthens the transferability of the findings. However, within the constraints of the data available in the evidence synthesis, it was not possible to discern differences in the needs of partners across a range of clinical and demographic characteristics which should be a particular focus for future research. Furthermore, given the approach to the JBI meta-aggregation we were not able factor in the inherent underlying qualitative paradigms within the evidence synthesis. The review does not include any participants from low- to middle income countries, and efforts/funding should be targeted to support cancer care in these countries as a future priority [64]. Lastly, this review only included studies published in the English language and therefore by omission valuable insights may have been missed.

Conclusion

This review provides an up-to-date overview of the unmet supportive care needs of partners of men diagnosed with prostate cancer, through their own unique lens. This review has not only confirmed the already well- known psychological impact that a shared prostate cancer diagnosis has but also sheds new insights into their own individual needs. Partners primary focus is to protect and shield their loved one, commonly at the self-sacrificing decrement to their own physical and psychological well-being. Partners experience unmet needs related to interpersonal/intimacy, physical/daily living, health care service, family-related, psychological/emotional, spiritual needs, and social needs.

Implications for Practice

Cancer organisations, policy makers, healthcare care professionals and researchers are slowly making progress to acknowledge the unique support needs of partners affected by cancer. This review provides new clinically important holistic insights into the wide range of needs identified through the perspectives of loved ones of people diagnosed with prostate cancer. Unfortunately, despite clinical follow-up with the man in cancer services, the partner’s individual needs are not well acknowledged with little support provided. As one practical short-term solution healthcare professionals might encourage partners to access social support specifically from cancer support groups to access emotional, information and practical support because of their diminished social networks within three months of a cancer diagnosis.

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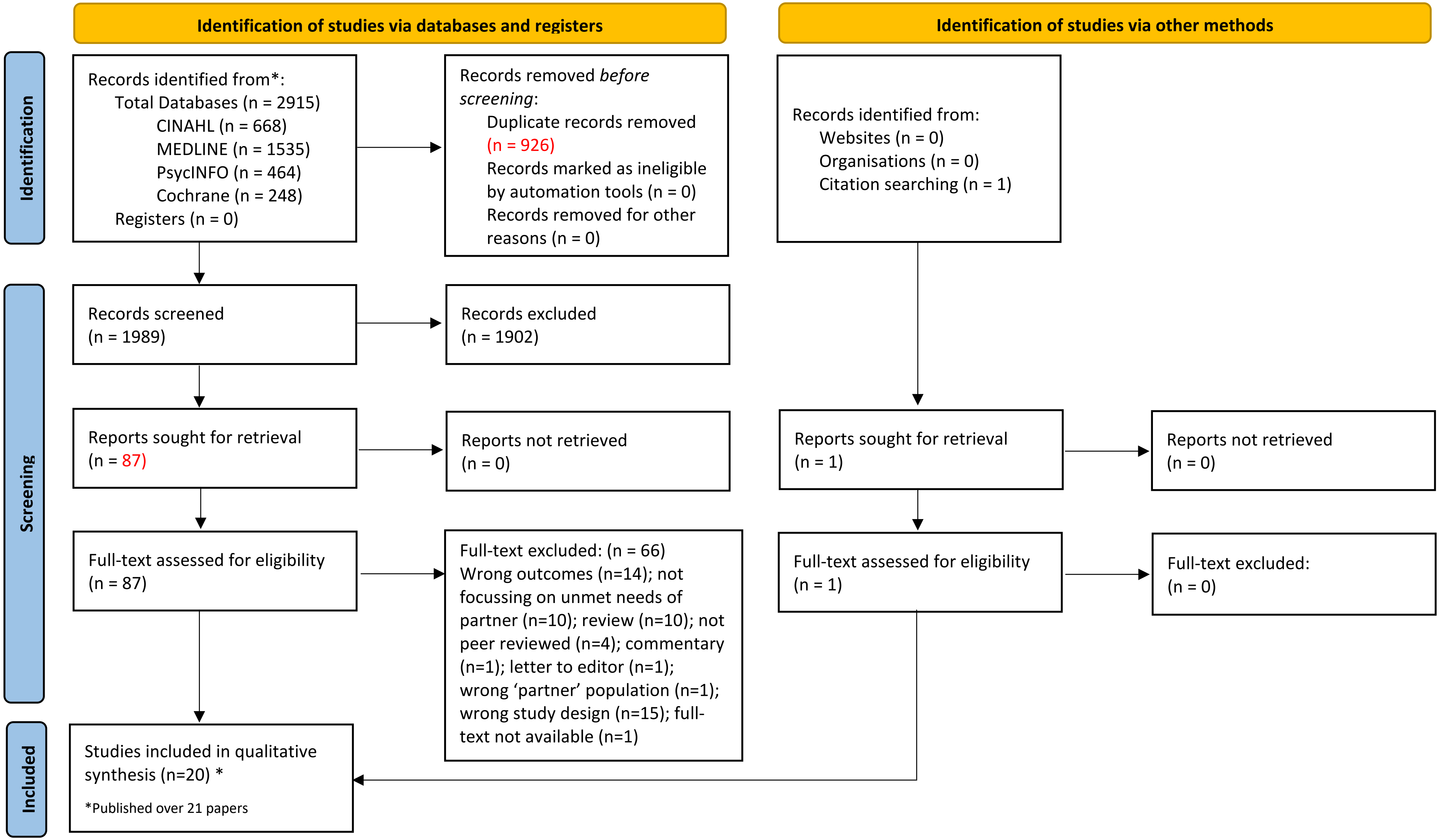
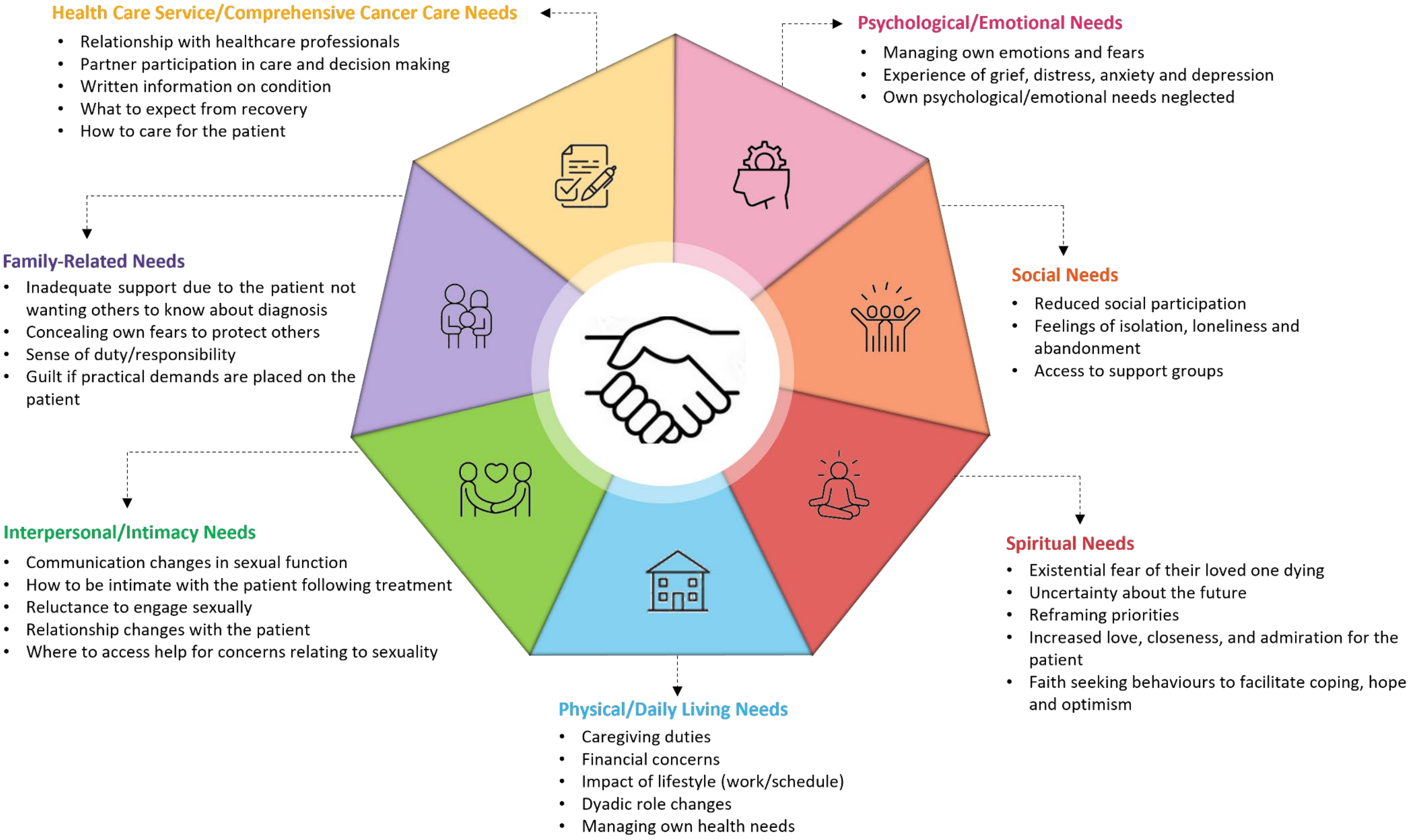


Figure 1. PRISMA 2020 flow diagram



Health Care Service/Comprehensive Cancer Care Needs

- Relationship with healthcare professionals
- Partner participation in care and decision making
- Written information on condition
- What to expect from recovery
- How to care for the patient

Psychological/Emotional Needs

- Managing own emotions and fears
- Experience of grief, distress, anxiety and depression
- Own psychological/emotional needs neglected

Social Needs

- Reduced social participation
- Feelings of isolation, loneliness and abandonment
- Access to support groups

Spiritual Needs

- Existential fear of their loved one dying
- Uncertainty about the future
- Reframing priorities
- Increased love, closeness, and admiration for the patient
- Faith seeking behaviours to facilitate coping, hope and optimism

Physical/Daily Living Needs

- Caregiving duties
- Financial concerns
- Impact of lifestyle (work/schedule)
- Dyadic role changes
- Managing own health needs

Interpersonal/Intimacy Needs

- Communication changes in sexual function
- How to be intimate with the patient following treatment
- Reluctance to engage sexually
- Relationship changes with the patient
- Where to access help for concerns relating to sexuality

Family-Related Needs

- Inadequate support due to the patient not wanting others to know about diagnosis
- Concealing own fears to protect others
- Sense of duty/responsibility
- Guilt if practical demands are placed on the patient

Figure 2. Classification of the domains of supportive care needs (partners/caregivers)

Table 1: Electronic Database Search Terms Used

Electronic Databases	Concepts	Search Terms
CINAHL Medline PsychINFO Cochrane	Prostate Cancer	1. "prostate cancer" OR "prostatic neoplasm*" OR "prostate carcinoma*"
		2. (MH "Prostatic Neoplasms+")
		3. #1 OR #2
	Partners /Spouses	4. spouse* OR partner* OR wife OR wives OR husband* OR couple* OR "significant other*"
		5. "spousal caregiver*" OR "spousal carer*" OR "informal caregiver*" OR "informal carer*" OR "family caregiver*" OR "family carer*"
		6. #4 OR #5
	Experiences / Unmet Needs	7. "lived experience*" OR experience*
		8. physical OR psychological OR psychosocial OR social OR emotion* OR "interperson*" OR practical OR financial OR employment OR "daily-living" OR "housekeeping" OR spiritual* OR existential OR decision* OR communication OR "health care" OR sadness OR fear OR isolat* OR lonel* OR information* OR transition* OR need* OR support*
		9. (MH "Health Services Needs and Demand+")
		10. (MH "Needs Assessment")
		11. #7 OR #8 OR #9 OR #10
		12. #3 AND #6 AND #11
		13. English Language Limiter

Search as conducted in Medline

Table 2: Quality appraisal results of included studies

Qualitative Publications	Item number of check list						
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.
Bamidele et al, 2019 [42]	Y	Y	Y	Y	Y	U	Y
Bamidele et al, 2019 [42]	Y	Y	Y	Y	Y	U	Y
Boehmer & Babayan, 2004 [33]	Y	Y	Y	Y	Y	U	Y
Bruun et al, 2011 [44]	Y	Y	Y	Y	Y	U	U
Dieperink et al, 2016 [47]	Y	Y	Y	Y	Y	U	Y
Ervik et al, 2013 [8]	Y	Y	Y	Y	Y	U	Y
Evertsen et al, 2010 [31]	Y	Y	Y	Y	Y	U	Y
Feltwell et al, 2004 [46]	Y	Y	U	Y	Y	Y	Y
Harden et al, 2006 [35]	Y	Y	U	Y	Y	U	Y
Ka'opua et al, 2005 [34]	Y	Y	Y	Y	Y	Y	Y
Ka'opua et al, 2007 [37]	Y	Y	Y	Y	Y	U	U
Kelly et al, 2015 [43]	Y	Y	U	Y	Y	U	Y
Pinks et al, 2018 [16]	Y	Y	Y	Y	Y	Y	Y
Primeau et al, 2017 [41]	Y	Y	Y	Y	Y	Y	Y
Rossen et al, 2016 [45]	Y	Y	Y	Y	Y	Y	Y
Sanders et al, 2006 [36]	Y	Y	U	Y	U	U	Y
Sinfield et al, 2008 [48]	Y	Y	Y	Y	Y	U	Y
Tanner et al, 2011 [38]	Y	Y	Y	Y	Y	U	Y
Walker et al, 2012 [39]	Y	Y	Y	Y	Y	Y	Y
Williams et al, 2014 [32]	Y	Y	U	Y	U	Y	Y
Wittmann et al, 2014 [40]	Y	Y	Y	Y	Y	U	Y
Wootten et al, 2014 [5]	Y	Y	Y	Y	Y	U	Y

Item number check list key: S1. Are there clear research questions, S2. Do the collected data allow to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question, 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation.

Three levels of assessment quality scores

🟩 Yes (Y)
🟨 Unclear (U)
🟥 No (N)

Table 3: Characteristics of the Included Studies

Study	Methods for data collection and analysis	Country	Theoretical model / framework	Phenomena of interest	Setting /context / culture	Partner/spouse characteristics, relationship status and sample size	Description of main results
Bamidele et al, 2019 [42] 1 study (2 papers)	***Data Collection:*** Semi-structured interviews. Audio recorded. ***Data Analysis:*** Constructivist grounded theory	United Kingdom	Not reported	The experiences of partners of high risk (1 in 4) Black African (BA) and Black Caribbean (BC) men with CaP remain poorly understood. This study aimed to address this gap by exploring partners' experience and support needs as influenced both by the specific impacts of CaP, treatment side effects and socio-cultural context.	***Setting:*** Interviews occurred face-to face in participants homes or a private office in their workplace (8), skype (2) and telephone (1) ***Context:*** Partners (open to any gender and ethnicity) in a marital or intimate relationship with BA or BC men who had undergone at least 3 months of active treatment for CaP. Part of a larger study focussed on exploring the experiences, psychosocial needs and how best to address them after CaP treatment for both BA and BC men and their partners. *Treatment:* Surgery, Brachy, Surgery + RT, RT + HT, cryotherapy + HT ***Culture:*** BA (3), BC (4), White (4) – all patients were BA or BC men.	***Participants:*** Female partners (41-88yrs) ***Relationship Status:*** Married <20yrs (4), 21-30yrs (2), 31-40yrs (3) and >40yrs (2) ***Sample Size:*** 11 participants interviewed	Six themes identified which were theoretically coded into three broad categories: partner in the passenger seat, caregiving on an isolating journey, and coping as a partner.
Bamidele et al, 2019 [42] 1 study (2 papers)	As above with the addition of 2 x focus groups for HCP to attend	United Kingdom	Not reported	This study explored the psychosocial experiences of BA/BC men with CaP and their partners in the United Kingdom as they lived through the side effects of CaP treatment within their own sociocultural and marital contexts.	***Setting:*** As above ***Context:*** As above. However, this paper included the men's and the healthcare professionals perspective. ***Culture:*** As above.	***Participants:*** As above ***Relationship Status:*** As above ***Sample Size:*** As above	The substantive theory developed was made up of one core category "man in the driving seat" and four related categories from the three data sets: "owning the illness," "navigating the journey through a bumpy terrain," "partner in the passenger seat," and "health care professionals recognising the difference."
Boehmer & Babayan, 2004 [33]	***Data Collection:*** Individual face-to-face interviews (in a few cases telephone interviews. Audiotaped and transcribed. ***Data Analysis:*** Grounded theory	USA	Not reported	To present men's and their female partners' thoughts about erectile dysfunction that may result from treatment. The focus of this analysis was on understanding men's and their female partners' reaction to potentially losing sexual capacity.	***Setting:*** Not reported ***Context:*** Men diagnosed with prostate cancer and their partners (female only) were interviewed separately. Interviews occurred as soon as patients had made their choice but before treatment had commenced. Aside from 2 men with prior history of cancer, this had been their first diagnosis. 13 of 21 men identified their partner as their	***Participants:*** Female partners (average age 55yrs) ***Relationship Status:*** Partnered between 2 years and 43 years (average of 25 years). ***Sample Size:*** 13 participants interviewed (21 men with prostate cancer interviewed).	Among women, a dominant theme was the existence of other relationship dimensions, while being aware about the gravity of his feelings about potency. Both groups were worried about the impact of erectile dysfunction on their relationship. *(Men's perspective consistently included the theme that erectile dysfunction threatened an important aspect of their identity and their reactions to the possibility of losing their sexual capacity due to prostate cancer-related treatment was connected to their current level of sexual function).*

					‘trusted other’ and therefore these were the females included in the analysis. *Treatment:* surgery, Brachytherapy, EBRT ***Culture:*** White (11), African American (2)		
Bruun et al, 2011 [44]	***Data Collection:*** Semi-structured interviews (at two time points), tape recorded and transferred to a program that facilitates analysis of sound data ***Data Analysis:*** Phenomenological hermeneutic framework (Ricoeur’s narratives and interpretation)	Denmark	Not reported	Life with incurable prostate cancer from the perspective of the female partner with the intent of better understanding female partners’ everyday experiences.	***Setting:*** Interviews occurred in homes (4) or at hospital (1). ***Context:*** Partners (female only) of men recently diagnosed with incurable prostate cancer. Interviewed 3 and 10 months after the male partner diagnosis. Patients were not interviewed. *Treatment:* Not reported ***Culture:*** Danish (danish-speaking)	***Participants:*** Female partners (54-73yrs) ***Relationship Status:*** married (4) and cohabitating (1). All had children. ***Sample Size:*** 5 participants interviewed.	One main theme: Coping with life Three subthemes: Aspects of loneliness (imposed and self-inflicted), informal care, and the significance of relationships.
Dieperink et al, 2016 [47]	***Data Collection:*** Participated in 1 of 2 focus groups (male/female split). Semi-structured, recorded, and transcribed verbatim ***Data Analysis:*** Giorgi’s phenomenological approach	Denmark	Not reported	(1) Explore the lived experience of men and their partners living with sexual problems and the impact of this on the marital relationship after radiation therapy and androgen deprivation therapy for prostate cancer. (2) Explore the couple’s experience and the role of a structured rehabilitation program for couple’s after men have undergone radiotherapy with androgen deprivation therapy.	***Setting:*** Rehabilitation Centre Dallund (following a 4-day residential stay) ***Context:*** Prostate cancer survivors and their partners (women only) were interviewed via focus groups at the end of a 4-day residential rehabilitation program. Focus for the rehab program was sexual problems, cohabitation, and intimacy. *Treatment:* All men were treated with ADT (for 6 months – 3 years), all but 1 received RT with curative intent. ***Culture:*** Danish Caucasians	***Participants:*** Female partners (58-74yrs) ***Relationship Status:*** Together for several years with grown up children (7), one elderly couple known each other <5yrs (and had been married before). ***Sample Size:*** 8 couples (therefore 8 women in the partner focus group).	Focus group interviews revealed three themes: negative impact of sexual dysfunction on the relationship; other physical and psychological consequences of late adverse effects; communication issues and partner feelings of frustration Rehabilitation program revealed four themes: importance of peer support; importance of time and space for reflection; improved communication; optimism after rehabilitation.
Ervik et al, 2013 [8]	***Data Collection:*** In-depth interviews, tape recorded and transcribed verbatim ***Data Analysis:*** Phenomenological hermeneutic framework	Norway	Not reported	To explore how the daily life of female spouses is affected by their husband’s prostate cancer	***Setting***: Interviews occurred in spouses’ homes (8) or at University hospital (1) ***Context:*** Spouses (female only) of men receiving potential curative treatment for PCa within the previous 4yrs. Patients were not interviewed. *Treatment:* RP (+/- additional endocrine or radiation therapy); RT alone	***Participants:*** Female spouses (52-68yrs) ***Relationship Status:*** married between 23-48yrs (8) or <5yrs (1) ***Sample Size:*** 9 participants interviewed	Four themes: Strong and optimistic versus vulnerable and overstrained, maintaining a partner’s sense of manhood, being on the sideline, and the need for relationships outside the immediate family.

					Culture: Not reported		
Evertsen et al, 2010 [31]	***Data Collection:*** Focus groups (observed by independent notetaker), audiotaped and transcribed. ***Data Analysis:*** Framework approach	USA	Caring for Patients with Cancer (modification of Kolb model)	To begin to explore the interaction of the female partner with the patient's physicians (primary care and urologist) and her support needs associated with treatment of and recovery from prostate cancer	***Setting:*** Focus groups were conducted at the clinic where the male patients were receiving treatment ***Context:*** Partners (female only) of patients diagnosed with PCa over the past 2yrs. Patients were not interviewed. *Treatment:* Surgical PCa treatment prior to focus groups ***Culture:*** Non-Hispanic/white (12); Black (1); unknown (1)	***Participants:*** Female partners (47-77yrs) ***Relationship Status:*** Married (13) ***Sample Size:*** 14 participants divided into 2 focus groups (7 per group).	Three main themes: more support (validation, information, emotional support), role of physician (transfer of care), partners' relationship changes (support, primary communicator, and caregiver).
Feltwell et al, 2004 [46]	***Data Collection:*** Mini focus group and 8x couple interviews. Audio taped and transcribed in full ***Data Analysis:*** Theme analysed using iterative process	United Kingdom	Not reported	To explore in depth the rich views and experiences of men with prostate cancer and their partners concerning the information-seeking and information-avoiding behaviours of partners	***Setting:*** Focus group – not reported Couple interviews – participants own homes ***Context:*** Men and their partners (female only) were interviewed. Number of months since men's diagnosis ranged from 20-61 months. *Treatment:* HT, watchful waiting, RT. ***Culture:*** White	***Participants:*** Female partners (age range not reported) ***Relationship Status:*** Married ***Sample Size:*** 6 female participants as part of a couple. Mini focus group n = 4 Couple interviews n = 8	Three related themes: Partners information-seeking behaviours, partners information-avoiding behaviours and the conflict between seeking and avoiding information.
Harden et al, 2006 [35]	***Data Collection:*** Semi-structured interview. Tape recorded and transcribed verbatim. ***Data Analysis:*** Preliminary coding and theme development.	USA	Family, Stress, Adjustment, and Adaptation Model (McCubbin)	To examine the experiences of men with prostate cancer and their partners according to their life cycle cohort: 50-64 (late middle age), 65-74 (young-old) and 75-84 (old-old), using a life span developmental perspective.	***Setting:*** Couples were interviewed in their own home, or other location of the couple's preference ***Context:*** Men and partners (female or male) were interviewed together. Three different age groups represented (50-64, 65-74 and 75-84). Partners didn't necessarily fall into the same age category. Attempts made to equally represent different phases of illness in each cohort (1) newly diagnosed with localised disease – 2-4 months following RP or EBRT (2) biochemical recurrence – 1-3 months after having 2 consecutive confirmed rises in PSA levels	***Participants:*** All partners were women (age range of partners not individually reported) ***Relationship Status:*** Married more than 20yrs on average ***Sample Size:*** 15 couples (15 men and 15 partners - 5 men in each age category).	Three general themes emerged: Couples' daily lives, their dyadic and family relationships, and developmental issues.

					(3) advanced phase – 1-3 months after clinical evidence of recurrence or continued progression of disease. *Treatment:* Not reported ***Culture:*** 14 men and 14 women Caucasian. One man and one spouse (2 different couples) were Native American		
Ka’opua et al, 2005[34] 1 Study (2 papers)	***Data Collection:*** 2 waves of semi-structured interviews (at 6-month intervals). Audio taped and transcribed verbatim ***Data Analysis:*** Grounded theory and content analysis	USA	Not reported	This study describes elderly wives of prostate cancer survivors’ perspectives of adaptation to the enduring challenges of prostate cancer survival and considers their experience in the context of ethnicity.	***Setting:*** all but 2 participants were interviewed in their own homes ***Context:*** Elderly Asian/Pacific Islander (API) wives (female only) whose husbands survived five or more years beyond initial diagnosis of prostate cancer. Mean years since diagnosis was 8.3yrs. Patients were not interviewed. *Treatment:* RT, RP, Combination of treatments ***Culture:*** Native Hawaiian (3), Chinese (7), Filipino (3), Japanese (13), White (12) – not included in the analysis	***Participants:*** Elderly API wives (60-86yrs) ***Relationship Status:*** Married >45yrs (22). Others not reported. ***Sample Size:*** 26 participants interviewed (38 initially interviewed however, the 12 white participants were not included in the analysis)	Continuous learning was the most common phenomenon as reflected in four types of adaptive work: involvement in husband’s health, affirmation of the marital bond, normalisation of adversity, and participation in personally meaningful acts.
Ka’opua et al, 2007[37] 1 Study (2 papers)	As above.	USA	Discusses stress-appraisal-coping framework	To identify wives’ challenges at the nexus of long-term prostate cancer survivorship and aging, describe the function of SBR (spiritually based resources) in coping, describe common themes in adaptation among wives using SBR.	***Setting:*** Interviews were conducted in locations convenient to the participants ***Context:*** Wives (female only) of elderly prostate cancer survivors. Mean years since diagnosis 8.5yrs. SBR use was only explored if women initiated the discussion of spirituality or religiosity. Patients were not interviewed Part of a larger survey investigating quality of life among long-term (>5yrs) prostate cancer survivors. *Treatment:* All but one husband received some type of treatment. Either RT, surgery, or both. ***Culture:*** All US citizens - White (8), Japanese (8), Chinese (6), Filipina (3), Native Hawaiian (3)	***Participants:*** Wives (55-86yrs) ***Relationship Status:*** Married but not specifically reported ***Sample Size:*** 28 participants (from the 38 enrolled) who reported SBR use.	Although wives’ spiritual beliefs were rooted in diverse traditions, common themes in SBR use were detected: An embracing spirit was the overarching theme, as characterized by acceptance of change, adversity as opportunity for growth, and proactive coping. SBR facilitated adaptation in four core areas: marriage preservation and couple intimacy, personal growth, and continuous learning, health-related attitudes and behaviours, and community connections.

Kelly et al, 2015 [43]	***Data Collection:*** In-depth interviews. Transcribed in full. ***Data Analysis:*** Coding, categories and overarching themes.	United Kingdom	Not reported	To determine the impact of treatment for prostate cancer on intimacy and sexual expression / relationships from the perspective of couples	***Setting:*** Interviews carried out in participants' homes ***Context:*** Men and partners (same sex couples included) were interviewed either as couples or on their own, depending on preference. Men had completed treatment at least 2yrs prior to minimise short-term treatment effects. *Treatment:* EBRT, Surgery or ADT ***Culture:*** White British (with 44% from minority ethnic backgrounds – Greek, African Caribbean, Chinese, North African, and Filipino)	***Participants:*** Female and male partners (age range of partners not individually reported) ***Relationship Status:*** Not reported ***Sample Size:*** 8 partner participants (6 couples interviewed together; 2 couples interviewed individually).	Four categories: Social influences and language used to describe the loss or recovery of sexual activities, discussing sexual activity with clinicians, the clash of individual versus couple paradigms of prostate cancer recovery, and the re-integration of sexual activities into the relationship.
Pinks et al, 2018 [16]	***Data Collection:*** 3 x 2hr focus groups followed by 2 x 1 hr telephone interviews conducted over 3-month period. Semi-structured interviews recorded and transcribed verbatim. ***Data Analysis:*** Thematic analysis	Australia	This area of research was not bound by theoretical frameworks.	Limited partner research exists. This study aimed to address this gap in the literature by gathering data directly from partners and exploring a deeper understanding of their experiences of prostate cancer survivorship to help inform healthcare service providers.	***Setting:*** not reported ***Context:*** Intimate or married partner (open to both female and male partners) of a man whose initial prostate cancer treatment had been completed at least 12 months prior to the study commencement. Treated for localised prostate cancer. Patients were not interviewed. *Treatment:* RP, RT, HT and other treatments. ***Culture:*** Caucasian	***Participants:*** Female partners (48-88yrs) ***Relationship Status:*** relationships ranged between 3-67yrs. ***Sample Size:*** 16 participants Each focus group (3) comprised of 4-5 participants. Interviews (2) conducted via phone for those unable to attend.	Five salient themes: emotional caregiver burden, not knowing what to expect, suffering in silence, grieving the loss of sex and intimacy, and the invisible victim of prostate cancer.
Primeau et al, 2017 [41]	***Data Collection:*** Exploratory purposive semi-structured interviews. Recorded and transcribed verbatim. ***Data Analysis:*** Framework analysis	United Kingdom	Model of Consultation for Prostate Cancer Care	To explore the experiences of patients with metastatic prostate cancer and their partners/caregivers, as well as the interprofessional team, with a nurse-led multimodality supportive care intervention	***Setting:*** Interviews conducted in participants homes or in a cancer care centre. ***Context:*** Men affected by metastatic PCa, their partners/caregivers (gender not specified) and INT members were all interviewed. Qualitative component of a feasibility RCT comparing standard care to ThriverCare intervention. *Treatment:* ADT ***Culture:*** Not reported	***Participants:*** Partners / caregivers. Gender not specified (62-77yrs) ***Relationship Status:*** Not reported ***Sample Size:*** 7 participants interviewed	*Standard Group:* Themes related to physical, psychological / emotional, intimacy / sexual, patient / clinician communication unmet supportive care needs emerged. *Intervention:* Themes included being listened to by someone who could facilitate emotional expression, provision of individually tailored information and receiving practical help and evidence-based advice for managing the consequences of cancer and its treatment.

Rossen et al, 2016 [45]	***Data Collection:*** Semi-structured interviews (but in all cases the spouses ended up having an open dialogue). Digitally recorded and transcribed verbatim ***Data Analysis:*** Grounded approach through constant comparative analysis	Denmark	Not reported	To explore how the prostate cancer diagnosis and the participation in their partner's behavioural lifestyle intervention influenced the spouse's life and relationship with their partner and how they handled the situation	***Setting:*** Interviewed alone in their own home (7) or at the Danish Cancer Society (1) ***Context:*** Spouses (gender criteria not specified) of men with low risk, early-stage prostate cancer. Patients were not interviewed. The men had completed a 6-month intervention of the Nordic Lifestyle Intervention Study (NILS) an education program on vigorous activity and healthy diet, including high intake of whole-grain rye. Spouses were encouraged to attend all meetings. *Treatment:* Active surveillance ***Culture:*** Danish	***Participants:*** Female spouses (55-68yrs) ***Relationship Status:*** Not reported ***Sample Size:*** 8 participants interviewed	Three main themes (with subthemes): (1) Feeling insecure – lack of information, anxieties (2) Coping – Seeking information, setting information aside, active support, communication (3) Feeling reassured – active support, confidence/hopefulness, communication
Sanders et al, 2006 [36]	***Data Collection:*** focus group (comprised of 3 x 30min segments) ***Data Analysis:*** Not reported	USA	Not reported	Couples (surviving prostate cancer) experiences and concerns regarding intimacy in their relationships	***Setting:*** Not reported ***Context:*** Focus group comprised of couples (partner gender not specified) who were survivors of prostate cancer, with treatment completed in the last 1.5-8yrs. Focus group was divided into 3 segments. To describe experiences (a) as couples (b) individual men and women in concurrent break out groups (c) couples regarding current intimacy and relationship needs. *Treatment:* RP, Proton beam RT +/- EBRT. ***Culture:*** 9 couples reported ethnicity as white.	***Participants:*** Women (38-75yrs) ***Relationship Status:*** Not reported ***Sample Size:*** 10 participants	Findings suggested that men and women think and respond differently to intimacy and relationship challenges that occur as a result of prostate cancer diagnosis, and treatment. Healthcare providers must consider the relationship and intimacy needs that are unique to men, women, and couples.
Sinfield et al, 2008 [48]	***Data Collection:*** Semi-structured interviews. Audio taped and fully transcribed. ***Data Analysis:*** Framework approach (thematic analysis)	United Kingdom	Not reported	To gain an in depth understanding of the experiences of care of men with prostate cancer and their partners	***Setting:*** Interviews conducted in patients' own homes. ***Context:*** Men tested or treated for prostate cancer in the last 6 months and their partners (gender not specified) were interviewed. *Treatment:* newly diagnosed, yet to be treated, active monitoring (no treatment), curative (RP or RT+/- HT), or stabilising treatment (HT)	***Participants:*** Female partners (age range not reported) ***Relationship Status:*** Not reported ***Sample Size:*** 10 participants	Although there was no widespread dissatisfaction with care, patients reported problems throughout care. The two main problems were that throughout care patients' and partners' information needs were often not identified or met, and patients' preferred role in decision-making about testing and treatment was not explored.

					Culture: White (8), Afro-Caribbean (1), South Asian (1)		
Tanner et al, 2011[38]	***Data Collection:*** 2 x open ended questions on 2 x longitudinal surveys. ***Data Analysis:*** Content/descriptive analysis (grouped into categories according to similarity of content)	USA	Not reported	To understand the effects of prostate cancer on the female partners of prostate cancer patients	***Setting:*** Surveys sent out to participants homes ***Context:*** Part of larger longitudinal study over 8 years. Men, who were survivors of prostate cancer and their partners (female only) completed surveys bi-annually for the first 1.5yrs and then annually. 2 open ended questions were embedded in the surveys to collect female partners perspective. *Treatment:* not reported ***Culture:*** white (87%). No further data reported.	***Participants:*** Female partners (average age 65yrs) ***Relationship Status:*** not reported. ***Sample Size:*** 113 women (364 women enrolled in larger study.)	Three overarching themes: coping with life in the face of cancer, encountering difficult emotions related to partner's illness and, learning to live with relationship changes
Walker et al, 2012[39]	***Data Collection:*** Unstructured open-ended interviews. Audio-recorded and transcribed verbatim ***Data Analysis:*** Grounded theory	Canada	Not reported	To describe the sexual struggles that couples encounter when attempting to adapt sexually to ADT	***Setting:*** Not reported ***Context:*** Men and their intimate partners (female only) were interviewed as couples. Men had been on ADT for a minimum of 3 months and were not currently receiving other treatments. Time since diagnosis (8mo-15yrs), time on ADT (4mo-3yrs). *Treatment:* ADT only ***Culture:*** Not reported	***Participants:*** Female partners (32-82yrs) ***Relationship Status:*** married 1mo-60yrs (16), dating 1-5yrs (2) ***Sample Size:*** 18 heterosexual couples (therefore 18 female partners)	Three categories of sexual struggle were identified: Adjusting to changes to sexual relationship (changes to sex, fatigue, and absence of sex) Nonmutuality (expressing affection, connection/withdrawal, willingness to engage sexually, initiation of sex, his libido, experience of pleasure, and her libido Attitudes and perceptions (doubt, grief, decreased self-esteem, and negative attitudes towards sex.
Williams et al, 2014[32]	***Data Collection:*** In-depth, semi-structured telephone interviews at three time points (average time between baseline and T3 was 10 months). Audio recorded and transcribed verbatim. ***Data Analysis:*** Coding, categories and overarching themes.	USA	Not reported	To describe the experiences of low-income Latina's longitudinally as their husbands recovered from radical prostatectomy for prostate cancer, as well as to develop a framework for understanding the strategies they used when caring for their husbands and coping with his illness and its side effects.	***Setting:*** Telephone interviews ***Context:*** Men and partners (gender not specified) were recruited from a longitudinal survey. Interviews with patients and partners were conducted separately (in Spanish). Only partner results reported in this paper. Patients had a radical prostatectomy within the previous 6 months. *Treatment:* RP ***Culture:*** Latino (Mexico, Central America, and South	***Participants:*** Female partners (36-63yrs) ***Relationship Status:*** Not reported ***Sample Size:*** Recruited 28 (10 lost to follow-up at T2 and 10 lost to follow-up at T3) = 8.	Found an overarching process of normalisation across all time points, with some themes: Working against normality - feelings and changes that that challenged women's feelings of normality. Working toward normality - women's efforts and outside influences working toward that sense of normality.

					America). Had lived in US between 1 and 40yrs.		
Wittmann et al, 2014 [40]	***Data Collection:*** Interviews. Digitally recorded and transcribed verbatim ***Data Analysis:*** Grounded theory iterative process	USA	Grief theory (biopsychosocial)	Partner sexual function has been viewed as a factor in men's erectile function recovery after prostatectomy for prostate cancer. However, patients' and partners' perceptions on the role of the partner in couples' sexual recovery has not been studied. We wanted to understand those perceptions and to see whether their perceptions were congruent.	***Setting:*** Interviews conducted in a midwestern academic cancer centre ***Context:*** Men and their partners (open to male or female) were interviewed separately. 9 Men had ED, 6 female partners were post-menopausal, and the male partner had post-prostatectomy ED. Mean time since surgery was 14.3 months for men (13.6 months for partners) *Treatment:* Surgery for localised PCa. One patient required additional RT. ***Culture:*** Not reported	***Participants:*** Male and female partners (mean age 58.3yrs). ***Relationship Status:*** Relationships averaged 30-years in length. ***Sample Size:*** 9 participants (7 females as part of a couple, 1 x male as part of a couple and 1 x female partner alone).	Three related themes emerged: Couples' perceptions of the overall sexual recovery of the couple at the time of the study, patients' perception of the importance of the partners' emotional and logistical support as well as interest in sex, and partners' desire to be fully supportive of the men but finding their role complicated and sometimes difficult to fulfil.
Wootten et al, 2014 [5]	***Data Collection:*** Semi-structured Focus groups recorded and transcribed verbatim. One structured individual interview ***Data Analysis:*** Thematic analysis	Australia	Not reported	To explore the experiences of partners of men diagnosed and/or treated for CaP to better understand the impact of CaP on the partner.	***Setting:*** not reported ***Context:*** Partners (male or female) of men diagnosed and/or treated for PCa 6mo-3yrs prior to study commencement. Patients were not interviewed. *Treatment:* RP only, RT only or combined (+/- hormone therapy). 3 still under active investigation. ***Culture:*** Not reported	***Participants:*** Female partners (43-76yrs) ***Relationship Status:*** Intimate spouse or partner ***Sample Size:*** 27 participants. Including 6 focus groups (4-5 participants in each) and 1 telephone interview	6 main themes: Influence of a man's response to prostate cancer on the partner; need to be involved in treatment and medical decision making; supporting a man who is experiencing a loss of masculinity; degree of congruence between each partners coping response; constrained communication and changed roles and increased practical management.

Table 4. Overview of synthesised findings

Total	Label	Category	Synthesised Finding
Papers: 12 *Findings:* 39 *Categories:* 4	F1, F60, F61, F62, F64, F146, F239	More support from healthcare professionals	**Health care service/comprehensive cancer care needs:** Partners were disappointed in the level of support and communication they received from healthcare professionals. Lack of consideration in treatment and follow-up visits left partners feeling excluded and ignored, despite their strong involvement in the man's ongoing care. Beyond the diagnosis, partners believed they were left to manage without enough resources, information, and practical guidance to adequately prepare them to support the man throughout the cancer trajectory. The uncertainty regarding continuity of care resulted in feelings of worry as partner's adjusted to an unfamiliar dynamic as caregiver instead of companion.
	F57, F75, F76, F78, F114, F115, F116, F117, F127, F128, F138, F147, F148, F169, F240	Insufficient communication in consultations	
	F38, F39, F59, F77, F118, F119, F130	Disempowered and neglected	
	F2, F33, F58, F63, F65, F79, F129, F170, F171, 241	Lack of information and resources led to unpreparedness	
Papers: 9 *Findings:* 22 *Categories:* 4	F3, F42, F131	The psychological impact on partners was not recognised	**Psychological/emotional needs:** Partners reported that both the men and healthcare professionals failed to recognise the impact that prostate cancer had on their psychological wellbeing. Partners initially experienced a range of negative emotions and struggled to balance these with the needs of the man. While these anxieties diminished over time, partners expressed nagging worries about test results, treatments, and possible cancer recurrences. Many partners attempted to conceal their own emotions in an effort to protect the man however, this increased their anxiety and isolation.
	F40, F41, F150, F151, F152, F153, F172, F174, F176	Managing their own anxieties	
	F81, F139, F149, F175, F213	Cancer-related fears	
	F43, F173, F214, F242, F243	Suppressing their own emotions	
Papers: 5 *Findings:* 7 Categories: 2	F21, F22, F177, F215	Isolated in the home	**Social needs:** While isolating at home was viewed as a show of support to the man, the partners desire to socially engage increased over time. Partners also sought to normalise their experience through connection with others in a similar situation. Without adequate support, partners suffered greater psychological burden.
	F66, F67, F158	Normalising the experience	
Papers: 9 *Findings:* 31 *Categories:* 5	F4, F24, F101, F105, F107, F178, F179, F181, F217	Spiritual connection facilitated coping	**Spiritual needs:** Faith was instrumental in helping partners cope with the man's cancer diagnosis. It was a source of comfort, community, and cultural connectedness, that strengthened with time. Partners also experienced increased closeness and love within the relationship, as a result of the care they provided for the man. Partners were able to find meaning in their experience of cancer through their spirituality and used this to enhance their understanding of life and re-evaluate their priorities. They also engaged in acts of service and felt that helping others was important for their own wellbeing. Partners recognised that illness was part of life however, they described constant worry about their husband dying and what would happen in the future.
	F23, F44, F46	Increased closeness	
	F45, F82, F109, F154, F180, F216	Thoughts about the future	
	F83, F84, F94, F95, F104, F106, F108, F218	Finding meaning in the illness	

	F92, F93, F100, F102, F103	Giving hope to others through acts of service	

Total	Label	Category	Synthesised Finding
Papers: 14 *Findings:* 27 *Categories:* 6	F27, F182, F219	Dealing with their own health challenges	**Physical/daily living needs:** The roles within the dyad shifted as partners assumed greater responsibility in the provision of both emotional and practical support. This increased physical and psychological dependence resulted in additional care burden and neglected self-care, particularly for those partners trying to manage their own ill-health alongside the man's needs. While some partners attempted to integrate the illness seamlessly into their everyday lives, others found that the increased time dedicated to care duties contributed to a strained relationship with their loved one. Partners were concerned about the financial implications of a prostate cancer diagnosis, especially if the disease was to become terminal. They felt torn between their desire to actively support the man during treatment and the financial pressures to continue earning an income and maintaining their health insurance coverage. Partners viewed prostate cancer as a shared challenge, using joint terms when discussing the illness. They encouraged healthy lifestyle changes and participated in these changes together with the man. However, it was noted that this approach was not reciprocated when navigating their own disease process.
	F25, F26, F28, F68, F70, F85, F140	Integrating the illness into everyday life	
	F48, F132, F159, F160	Becoming the emotional caretakers in the relationship	
	F71, F96, F155, F244	Taking the lead to manage practical responsibilities	
	F47, F69, F120, F88, F220	A shared challenge	
	F5, F86, F87, F141	Financial implications of the disease	
Papers: 18 *Findings:* 87 *Categories:* 8	F7, F15, F19, F89, F91, F97, F110, F142, F162, F165, F185, F189, F190, F191, F197, F198, F199	Affirming the couple bond	**Interpersonal/intimacy needs:** In light of treatment related sexual dysfunction, partners shifted their focus toward affirming the couple bond as a means to maintain intimacy. However, without intercourse as an indicator of attraction, partners suffered a loss of self-esteem. Partners reported that communication differences surrounding sexual issues resulted in reduced levels of physical and emotional intimacy and left some partners questioning the future of their relationship. Partners attempted to protect the man's sense of masculinity by avoiding disclosure of intimate issues with others and physically withdrawing from the relationship to reduce the impact of sexual dysfunction on the man. Regardless of whether a sexual relationship could be maintained, partners were unable to avoid grief associated with absent or altered sexual relationships. Partners in newer relationships struggled to reconcile the loss more so than those with long relationship histories. Partners had to take the lead to initiate sexual activity and were uncomfortable with the imbalance in sexual satisfaction following treatment. Partners were mindful that resuming sexual activity was a gradual process and they facilitated this process by being available to the man. Attempts to improve the man's sexual function led to lack of spontaneity and as a result, some partners preferred intimate activities that promoted pleasure without intercourse.
	F52, F161, F200, F201, F210, F212	Lack of affection impacted self-esteem	
	F13, F14, F20, F34, F112, F124, F164, F187, F188, F202, F224, F225, F233, F245, F247	Communication and relationship challenges	
	F49, F53, F72, F98, F134, F222	Protecting the man's sense of masculinity	
	F16, F90, F111, F133, F166, F183, F184, F211, F221, F231, F246, F248	Grieving the loss of intimacy	
	F6, F203, F204, F234	A shift in who was responsible for initiating intimacy	
	F113, F121, F192, F205, F206, F207, F208, F209, F230, F237	An imbalance in the sexual experience	
	F17, F18, F50, F51, F122, F123, F125, F163, F186, F194, F195, F196, F223, F232, F235, F236, F238	Restoring the sexual relationship	

Total	Label	Category	Synthesised Finding
Papers: 12 *Findings:* 26 *Categories:* 3	F8, F9, F10, F11, F12, F35, F80, F136, F156, F249	Constrained communication	**Family-related needs:** At times, partners felt that the man excluded them from important decisions and was selective about how much information they shared. Partners also reported that the man stipulated whether or not they were able to discuss their diagnosis with others. This, along with feeling a sense of duty to shelter family from the negative impact of the diagnosis meant partners had less access to support systems when required. The inability to share the burden with others affected their capacity to cope and left partners feeling alone in their experience.
	F31, F56, F99, F135, F157, F167, F168, F193	A sense of duty	
	F29, F30, F36, F54, F55, F226, F227, F228	Protecting the family	
Papers: 7 *Findings:* 10 *Categories:* 2	F32, F37, F126, F137, F143, F144, F145, F229	Facilitators of support	**Facilitators and barriers:** Tailored support through specialist prostate cancer nurses, support groups and/or lifestyle interventions facilitated emotional openness and improved coping in partners who had access to these services. However, some partners avoided seeking support due to fear of what the information may contain or as a result of different support preferences to the man.
	F73, F74	Barriers to seeking support	

Supplementary Table 1: Overview of primary findings

Author: Bamidele et al, 2019 (1 study, 2 papers) – women's perspective

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Felt unrecognised and excluded from their husbands newly diagnosed cancer journey. This was mostly attributed to the men not sharing their concerns about their CaP illness with their partner and also lack of information from HCPs to specifically address partners' needs.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS1
Narratives from some women showed that although they accompanied their husband to his clinical appointments, they were minimally involved in conversations that took place.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS2
Only a few of the women reported being actively engaged e.g. scheduling their husband's appointments, taking notes for them during consultations and helping the men to search for information online when asked.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS3
Women's perceptions were also that HCPs showed limited awareness and interest in partners' experiences and needs. This seemed to compound the women's distress as they were further pushed towards a peripheral position.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS4
The women suggested that HCPs specifically engaging and supporting partners of CaP patients could facilitate coping by reducing isolation and uncertainty and also help sensitise men towards the unmet needs of their partners.	"…I think if we have an avenue, perhaps as you have come, for the person to talk to the two of us so as to extract this type of conversation, because when you are in a situation you want to see that pain from your own point of view alone, it might not have occurred to him that this woman that is taking care of him has some emotional needs as well, has some needs that are not being met as well, if it comes from an outsider, it will be very effective because if it comes from me, he will say you this woman you have come again, you are always complaining and whining, but if someone else says it, if a counsellor or psychologist says that in the presence of both couple I think it will be very helpful…"	Health Care Service / Comprehensive Cancer Care Needs	U			F1
The women described how they were psychologically affected in terms of feeling shocked at their husbands CaP diagnosis; worried about the potential consequences of the disease on their individual marital and family lives; having uncertainties around recovery outcomes and processes; and lacked information on how best to support themselves and their husbands through the disease trajectory.	"…I was very worried, but I did not show it to him at the time because he needed a supportive person… I wasn't sure how it will affect him being a man because, you are not really told about that sort of thing…I think information is important and especially if you know some people em especially women if they are younger, if they do have quite a good sexual relationship with their husband, how it will affect their relationship, you know because nobody really tells you anything like that, you are not really supported with that…" (pg. 1092)	Health Care Service / Comprehensive Cancer Care Needs	U			F2

The psychological and emotional impact of the CaP on partners was not recognised by the men or HCPs. For example, a participant expressed disappointment at her husband's exclusive focus on his illness without showing much insight or acknowledging how the CaP had significantly affected her as his partner.	"…he was acting as if he was the only one who had been through the diagnosis…I could argue my stress has been more, I used to say to him, we have both been very very stressed and he said well you do not know what you are talking about, I do not think he ever, I do not think he ever grasped the level of stress I was under the whole time…" (pg. 1092)	Psychological / Emotional Needs	U			F3
Faith played a central role in helping them cope with their psychological and emotional concerns. They prayed to God that their husband would not die from the CaP and drew strength from believing their prayers were answered.	"…because I was reassured that he would be ok, he would be fine and through prayers... having prayers… we believe er, I believed in healing…" (pg. 1092)	Spiritual Needs	U			F4
Felt insecure about the possible economic impact on them and their wider family if their husband died from his CaP illness	"…I was obviously very worried because I knew then he had to have operation, I knew then that would affect us, because in many respect not just as a man but he is a very active, strong person, he is also the main breadwinner, you know he's also head of the family…he was always the strong male of the family, you know, so it was how it would affect everybody else and that was quite you know, worrying for me…" (pg. 1092)	Physical / Daily Living Needs	U			F5
Husbands had always taken the lead in the sexual relationship and women felt reluctant to initiate sex and change this routine, as they felt their husband's personal self-esteem could be affected. Current lack of psychosexual support was also a source of concern.	"…and I think because we had a very straightforward sexual relationship which was based on penetration and mutual satisfaction, neither of us was particularly skilled in any other kind of play really, I find that I am actually very anxious, because he is not getting an erection very quickly, maybe he is not finding me attractive or I am not doing what I should be doing I feel that I have not got the skills to help him, so that makes me extremely anxious, I guess anxious is not good for your libido but yea I am struggling with that…" (pg. 1092)	Intimacy / Interpersonal Needs	C			F6
Older women (over 65yrs) reiterated that couples staying with each other in good and bad times is culturally ideal within BA and BC marriages.	"…well in the Caribbean to be quite honest, you just stick together, so I guess it's the same thing there as it would be here you know, you just have to stick together, support each other... that's it…" (pg. 1092)	Intimacy / Interpersonal Needs	U			F7
Partners expressed feelings of exclusion as husbands took sole ownership of their CaP and exercised as autonomous right to steer treatment and recovery decisions whilst wives assumed a background supporting role.	"…he had pretty much made his decision before he came to me, he had already made his decision, he very much owned the illness and did not want to share, I will say did not want to share the burden…" (pg. 1092)	Family Related Needs	U			F8
Concerns were heightened where the man had not prepared a will prior to his diagnosis and they (women) perceived the subject as too sensitive to discuss	"…how long will he have to live, for instance the issue of will, what is going to happen to me, in African set up, you dare not mention it to your husband at that time, because it would mean you are thinking ah ah so that was the major one but with an English person they are free to talk about it, they can seek help, but I have not been able to, with him you dare not, so I was, I felt boxed in" (pg. 1092)	Family Related Needs	U			F9
Many women reported they were only given information as much as their husband was willing to share.	"…I would prefer, my husband to be more interactive, more communicative than he is, something is poking you then talk to me about it but I tend to be the one that has to draw out everything … I guess any problems will be on his side because he tends to hold his feelings back… (long pause), it hurts…" (pg. 1092)	Family Related Needs	U			F10

Some women explained that their husband's controlling attitude towards their illness mirrors the men's position as the head of the family and natural leaders in their nuclear and extended family settings.	"…I do not think African men, I do not think they like being told because, culturally it's like they tell people what to do, they do not like being told so …" (pg. 1092)	Family Related Needs	U			F11
Although they actively provided moral and practical support for their husband, they themselves had limited support due to their husband's reluctance to disclose the CaP diagnosis among wider members of their social network. This constrained the women's access to the much-needed support for themselves and increased their feelings of isolation. CaP threatened their husband's cultural identity as a BA/BC man. Where husbands did allow some disclosure, it was limited to immediate family members, employers, close friends, and church pastors – women described the support from these avenues as excellent.	"…he did put an embargo on me discussing it with my friends… because my natural instinct would have been to discuss it, I think it was so sensitive to him, you know to his identity really, he did not want me to be talking about it with them so I really had to take it inwards, there wasn't anybody to talk to about it…" (pg. 1092)	Family Related Needs	U			F12
The women expressed that their unconditional love and loyalty towards their husband made them feel obliged to prioritise his wellbeing over their own psychological and emotional needs.	Not reported	Family Related Needs			NS	NS5
Author: Bamidele et al, 2019 (1 study, 2 papers) – Men and women perspective (#2633)						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Women further expressed disappointment at the lack of professional support focused on partners within the current health care.	Not reported	Health Care Service / Comprehensive Cancer Needs			NS	NS6
Women's psychological and emotional distress was also attributed to their feelings of financial insecurity if their husband died from the CaP	Not reported	Physical / Daily Living Needs			NS	NS7
The women were distressed by their husbands' lack of recognition for the psychological impact the CaP experience had on them as partners. Some women said their husbands autonomously took decisions on how they wanted to deal with their sexual problems without consulting with them.	"… so without letting me know, he bought erm Viagra tablets a couple of times …" (pg. 1716)	Interpersonal / Intimacy needs	U			F13
Women's psychological and emotional distress was also attributed to their feelings of financial insecurity if their husband died from the CaP, lack of couple-focused psychosexual support, and especially communication barriers with their husband regarding how treatment-related sexual dysfunction was impacting on their marital intimacy.	"… I felt the burden because I am somebody that talks … you know women we talk … it's a form of healing and letting everything out, but he doesn't, the impact was the quietness, you know that he was always quiet … I don't know what is on your mind … you know the relationship wasn't that great … the sexual aspect of things went out of the window … so yea that's the main issue now because it's not easy … I ask myself is it going to be like this forever? Or is it going to correct itself? … emotionally I feel that there's something missing, and sort of when am I going to get that back… you feel a bit frustrated sometimes." (pg. 1716)	Interpersonal / Intimacy needs	U			F14
Author: Boehmer & Babayan, 2004						

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Women emphasized that after so many years together sex does not have the importance it once had and that their love for each other was able to sustain this loss.	"He feels he has to be able to satisfy me as a man, and that kind of stuff. And we've had long conversations about that. And I think he's okay with that now. I think he's okay with that. And I don't know why he thinks that anyway. It must be a man thing. It's a boy thing. That they feel they have to do that… I don't know why he feels that way. Because our relationship is - I mean, we're soul mates. I mean, we've been together for 22 years. It's such a tight relationship we have. I mean, to me, for him to even think that bothers me - but he doesn't think that as like I'll leave him or anything like that. He thinks of it as it's his job. It's part of his job in this relationship to do that. You know, just part of it all. It's like, ''Well, it's not.'' You know? It was at one point. I mean, I think if he were 32 and this happened, then it might be a real big problem. But you know, it's not." (pg. 843)	Interpersonal / Intimacy Needs	U			F15
Being together for a shorter amount of time or being at a younger age did make a difference in reacting to the possibility of losing the capacity for intercourse.	"It has a significant impact, I think, particularly for us because we're just sort of starting out a relationship. Again, if you were invested with 25 years of a shared life, and you had your children, and you had a life built together, and your sexuality was a dimension of that but certainly, you had lots of other dimensions that you could hold onto, I think it's very different than if you're just starting out a relationship, and you're still trying to find your way within the relationship, and also look at whether it's a lasting relationship or not." (pg. 843)	Interpersonal / Intimacy Needs	U			F16
Another women described that her partner's already existing erectile dysfunction prior to treatment put a strain on their relationship. Erectile dysfunction caused by prostate cancer treatment would deprive of her of any hope for a remedy and instead would make erectile dysfunction permanent and irreversible.	Not reported	Interpersonal / Intimacy Needs			NS	NS8
They insisted that there would be a sex life after treatment. However, only the rare man or woman mentioned that their sex life would be sustained through adjusting their sexual practices.	"The impotence is a higher percentage, but it's still not definite. And there are other things that you can do to take care of it. My feeling is with a loving relationship. That's the most important. I want him to be healthy. I think that's the most important. It would be different if we were terribly vain or he didn't have a nice, comfortable relationship with me, but we do… And I think we can be creative. Who knows, we might even come up with something new and exciting [laughter]." (pg. 844)	Interpersonal / Intimacy Needs	U			F17
Couples who had already dealt with erectile dysfunction prior to his prostate cancer diagnosis assumed that they would return more or less to the level of sexual function that was known to them.	"He's already used the Viagra. Before, of course. And it's quite an interesting medication, I must say. It worked very well. So I figure, if his health is good, it probably will work again. I mean, he's not 30 anymore, but if they've got medication that will do the job, fine. There doesn't seem to be any downside to it, at least, none that I know of." (pg. 844)	Interpersonal / Intimacy Needs	U			F18
Women foresaw complete acceptance of their partners	"If he's impotent, he's still my husband. That doesn't make him not my husband. When you take the vow you said for better or for worse. So if the worse comes, he's still my husband." (pg. 845)	Interpersonal / Intimacy Needs	U			F19

Women stressed that the loss of their husband's sexual function was not that important to them personally but worried about how his dealing with it affected their relationship.	"He knows that [impotence] that's not that important to me. In the scope of things that's not that important. He knows that. But how he reacts to it when it actually happens I don't know. We'll have to wait and see." (pg. 845)	Interpersonal / Intimacy Needs	U			F20
Author: Bruun et al, 2011						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Thoughts and experiences about the illness and the associated silence are believed to affect both the social and psychological situation. Silence about the illness from everyone around and the accompanying imposed loneliness seems to affect daily life to such a degree that exhaustion can develop in the attempt to cope with life.	Not reported	Psychological / Emotional Needs			NS	NS9
Even though self-inflicted loneliness could be of positive significance, the study also showed that one's own needs were disregarded, perhaps out of a sense of duty to support the male partner.	Not reported	Social Needs			NS	NS10
An apparent isolation in the home – an isolation that can be the couple's strategy to avoid daily questions about the illness and its consequences. In this physical and social isolation, self-inflicted loneliness can be one way to support the male partner.	"We stay more or less at home on our own." (pg. 296)	Social Needs		C		F21
Isolation in the home can be experienced over time as a further burden on top of the male partner's illness. The wish to get out and be among other people, and that the need for social company and conversation becomes stronger over time.	"I don't like being here (at home); I need to be out where there are other people." (pg. 296)	Social Needs	U			F22
Love between the partners was the foundation for and an important dimension of having the strength to cope with life. The strength found in love is not considered to lessen over time but is more obvious.	*Three months* - "A tenderness between us, it's like we look after one another a lot." (pg. 296) *Ten months* - "We really look after each other a lot; we've always done so, but recently, it's perhaps been a bit more obvious." (pg. 297)	Spiritual Needs	U			F23
For some female partners, faith in God contributes to a foundation of peace in life in relation to the illness. Faith did not become less significant over the period; on the contrary, it was strengthened.	"It (faith) helps us, especially because we believe in life after death, we have somewhere to take our anxiety and our joy and our whole life...it means one takes it all more calmly." (pg. 297) *Ten months* - "I pray to God whenever there's anything..." (pg. 297)	Spiritual Needs	U			F24
Informal care has changed over time from needing to be constantly available to providing care in the usual sense where warmth and closeness are expressed.	"It's about care, but hardly at all about duty (care burden)." (pg. 296)	Physical/Daily Living Needs	U			F25
An attempt is made to live with the illness in everyday life, so it is invisible and dominates as little as possible. This approach ignores the illness and is believed to be a tool to control the	"We don't let it have too much influence on our daily lives... we're both agreed on that, so we do what we usually do." (pg. 296)	Physical / Daily Living Needs		C		F26

consequences of the illness and thereby a way of managing to live with it.						
There was an imbalance between looking after oneself and looking after others. The capacity for self-care is weakened because the need to look after others overshadows the recognition of one’s own needs.	“I’m the type to put myself last and make sure everyone else is okay.” (pg. 296)	Physical / Daily Living Needs	U			F27
Informal caregiving takes up a lot of time in daily life. The first few months of the illness, there is little time for anything apart from a range of duties in connection with the partner’s illness.	“I spend all my time on caring for my husband.” (p. 296)	Physical / Daily Living Needs	U			F28
The female partner experienced the man’s silence as a discomforting factor in their joint daily life that contributed to the couple isolating themselves from each other. The female partner found herself alone with her thoughts and feelings, which intruded on her in connection with the partner’s illness.	Not reported	Interpersonal / Intimacy Needs			NS	NS11
A culture and value system where it is meaningful to help and support each other. This shows natural care and concern, where there are no boundaries to prevent assisting and supporting the family.	“We can go (to the family) if we need help.” (pg. 297) “But if there’s anything, no matter how small...I know I can just ring my son and daughter-in-law.” (pg. 297)	Family Related Needs	U			F29
This experience of loneliness seems to become worse if the family and the social network pretend the illness does not exist and do not talk about it.	“People really don’t want to hear about the illness and especially not the children.” (pg. 296)	Family Related Needs	U			F30
A dilemma was experienced with regard to care for the family in that their own needs were put aside. The need is expressed here as a will or a duty to provide care and thereby ensure others are looked after.	“I have always wanted to help others.” (pg. 296)	Family Related Needs		C		F31
The need or duty to provide care for the family is considered to be completely fundamental, and the duty of care is never questioned for the partner and family in the course of the illness.	Not reported	Family Related Needs			NS	NS12
Author: Dieperink et al, 2016						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
The possibility of exchanging stories seemed to reduce the participants’ feelings of loneliness and stigmatization. Normalisation was obtained by telling individualized but similar stories about disease, late effects, and marital problems. All participants’ appreciated the facts of not knowing any of the other couples beforehand.	Not reported	Facilitator			NS	NS13
The women claimed that the residential stay allowed the time and space to work with problems. They enhanced the importance that the staff saw the spouses as individual but	“You should not overrule the significance of being away from everything, with nature and a lovely place to be, and to be in it, in another way, than if you are sitting in a coincidental conference room”. (pg. 26)	Facilitator		C		F32

connected persons and the sessions provided room for both laughter and tears.						
The diverse information from different health professionals at the hospital confused the couples. They were usually satisfied with the information about the treatment, but they wanted more information and guidance about the impact on their everyday life as a couple and as a family, and e.g., how to talk with their grown-up boys about the risk of prostate cancer.	"They (health professionals) still have a lot to learn about giving information". (pg. 25)	Health Care Service / Comprehensive Cancer Care Needs		C		F33
Before treatment, all men were told that their sexual function would decline, but several of them could not believe it until it really happened. Some of the women felt neglected when the physicians directed the information about sex only towards the men.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS14
The majority of both men and women experienced that the sexual decline involving erectile dysfunction and a lack of libido slowly had caused a distance between them as couples, although none of them wanted this to happen.	"It was shocking to learn, that we wasn't able to maintain the intimacy, although we had agreed to maintain it, as the sexual ability disappeared. It surprised us, and it leaked out just quietly – not by one day to the other, and maybe therefore we didn't realize it before it was too late." (pg. 24)	Interpersonal / Intimacy Needs	U			F34
Both men and women emphasized the psychological changes as the most significant, and some of the men claimed the new experience of a quick temper. This caused bickering and rows between the spouses.	"When we came here, I was almost going into panic, because last week it went crazy in our house. We were both very aware that we can't live like this anymore. We couldn't find any tools to go further." (pg. 25)	Family Related Needs	U			F35
The women felt they had to be strong in order to comfort and support the partner, and to spare the rest of the family. All these tasks caused some of the women to forget taking care of themselves.	"I am always asked how my husband is doing, but in one year, no one has asked me how I am." (pg. 25)	Family Related Needs		C		F36

Author: Ervik et al, 2013

Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Talking to other wives in support groups for spouses was especially valuable for those who had attended learning and coping seminars or seminars at the rehabilitation centres. The context of these seminars provided room for greater openness about their inner feelings.	''I was amazed that I was able to talk so much about our relationship… We were in an environment where the leader of the group was very straightforward with her questions... About marital relations, many cried. They were afraid of being alone it became so natural to talk about *everything.''	Facilitator	U			F37
Although the spouses played an active role in providing care, they simultaneously felt relegated to the sideline. Particularly encounters with healthcare providers at the hospital during treatment and at follow-up visits.	''I did talk with physicians and nurses… but clearly, they are busy and engaged with the patients, and then you move to the side line.'' (pg. E11)	Health Care Service / Comprehensive Cancer Care Needs	U			F38
The experience of being ignored was difficult for spouses because of their strong involvement in their husbands' illness experiences.	''In the hospital, the patient is the focus; it feels a bit hard when I do so much.'' (pg. E11)	Health Care Service / Comprehensive Cancer Care Needs	U			F39

Many of the spouses voiced anxiety about information being withheld by their partners, and they emphasized the importance of having the same information as their husbands for managing their own well-being and for helping their partners. Therefore, encounters with healthcare providers were seen as an important arena for gaining information. The spouses were often responsible for taking the initiative to obtain information. When taking the initiative themselves, however, the spouses experienced the encounters as satisfactory and important.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS15
Healthcare workers provided information about technical remedies, such as syringes or medication to promote erections, but at home, couples had to find ways to manage the situation themselves.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS16
The spouses felt caught in a situation where they had to balance supporting their husbands' needs with managing their own anxiety.	‘‘Regardless of whether it is cancer or another serious illness, it is very hard to be the next of kin, and perhaps few understand how hard it is when serious illness strikes I am the next of kin, and I am supposed to be strong. Sometimes it is difficult’’ (pg. E10)	Psychological / Emotional Needs	U			F40
The anxiety diminished for most spouses after the first few months. The strain of being supportive continued, however, and a feeling of exhaustion grew for those who had lived with the illness for years.	"It is hard to be the one who has to listen and reassure all the time. It is a difficult situation for me as well." (pg. E10)	Psychological / Emotional Needs	U			F41
Those with the longest experiences gave voice to a growing need to focus on their own feelings and experiences. Some wondered if their strong involvement in their husbands' experiences and methods for dealing with the illness were accompanied by a risk of ignoring their own needs.	‘‘I was extremely afraid of hurting XX, and I was afraid of hurting myself as well. I was so focused on him that, in a way, I forgot myself. In retrospect, I have cried very little (tearful).’’ (pg. E12)	Psychological / Emotional Needs	U			F42
Many spouses felt that they had to suppress their own feelings to maintain the effort of being supportive over time. They emphasized the need to be positive and remain in good spirits.	‘‘being strong and calm.’’ / ‘‘not being hysterical.’’ (pg. E10) ‘‘I have to stay positive; there is no use in collapsing. I can collapse for a while but not stay that way; you have to face it; it will not disappear.’’ (pg. E10)	Psychological / Emotional Needs	U			F43
Spouses described the provision of practical help as something that brought them closer to their husbands as a couple and something that they did out of love for their partners.	"I had to help him take care of the wound (change the dressing after surgery). We are very open with each other and have no inhibitions. I think that it is very positive to work together on those issues, to help each other… Nobody knows what old age brings; we have to help each other. We just have to." (pg. E10)	Spiritual Needs	U			F44
Focusing on themselves was an emotional experience when talking about the impact of the illness on daily life and their thoughts about the future.	"I am used to taking care of myself when dealing with practical issues… sometimes, I find things to be difficult emotionally. Obviously, one is always anxious and afraid of being alone… one is used to being two; thus, everything becomes different the day one is by oneself." (pg. E11)	Spiritual Needs	U			F45

Many spouses felt that their husbands’ illness had brought them closer as a couple.	“…After being married for many years, partners often take each other for granted… The illness brought us close together, we felt more on the same wavelength.” (pg. E12)	Spiritual Needs	U			F46
Although the experience was difficult, the spouses all felt that it was important to be able to support their husbands, whom they loved and cared for, and some felt that the illness experience provided an opportunity to appreciate the good things in life and to live their lives differently.	Not reported	Spiritual Needs			NS	NS17
The husbands’ illness was frequently referred to as a shared challenge for the couple.	“we are in this together.” (pg. E10) “we will make it.” (pg. E10)	Physical / Daily Living Needs	U			F47
Most spouses felt that their husbands became more dependent on them and that many husbands therefore required ample psychological support in daily life.	‘‘He has become more dependent on me being with him and on us doing things together. I do not know if he feels unsafe in a way… so I do have to go with him (to a learning and coping seminar).’’ (pg. E10)	Physical / Daily Living Needs	U			F48
Many spouses described their efforts to reassure their husbands that their sexual problems were something that they faced together and that they both had to be patient. For one woman, it became especially important to convince her husband that his altered sexual performance would not result in her breaking off the marriage.	“I tried not to hurt him but to reassure him that he means as much to me today as before, as a lover and also for the person he is.” (pg. E10)	Interpersonal / Intimacy Needs	U			F49
In dealing with sexuality issues, some spouses made jokes to try to relax the situation, and one woman bought literature with sensual content for inspiration. Other spouses had accepted a life without intercourse. They dealt with the situation by focusing on their own age and facets of sexuality other than intercourse.	“After menopause, I lost interest (in sex) … we are very close… and that nearness means a lot to me.” (pg. E10)	Interpersonal / Intimacy Needs	U			F50
Sexual dysfunction was experienced as difficult for both partners, and therefore, they felt especially relieved when they were able to have intercourse.	“Tablets enhanced the desire, but it is artificial; the naturalness was lost, and it felt unpleasant. It was great when we managed without any remedies and other influences, a great moment.” (pg. E10-E11)	Interpersonal / Intimacy Needs	U			F51
Some felt it to be difficult and hurtful when their husbands did not express sexual desire.	“After a while, I felt something was missing because of his lack of desire, more than I would have imagined… It was tough to hear him compare embracing me with hugging a trunk.” (pg. E11)	Interpersonal / Intimacy Needs	U			F52
The spouses did not want to expose their husbands’ situation to others, especially when dealing with intimate issues.	“(I was) letting my husband down.” (pg. E11)	Interpersonal / Intimacy Needs		C		F53
They did not wish to excessively worry or involve their children, and they did not wish to expose their husbands’ problems to others. Professional healthcare providers with expertise in prostate cancer and peers were preferred.	“Actually, it would have been acceptable to be able to speak with someone you do not need to relate to on a daily basis, someone who is not involved with your own family” (pg. E12)	Family Related Needs	U			F54
Although they understood why the men were the centres of attention and support from family and friends, they reflected on their own situations as the ones standing by.	“Only one person has asked me how we are doing; everybody asks how everything is with him.” (pg. E11)	Family Related Needs	U			F55

Encounters with people in public were described as potentially difficult, both when the husbands did not want to tell others that they had prostate cancer and when they were open about their illness. Some spouses felt that it was particularly difficult to hide their own feelings when meeting people they knew, and they encouraged their husbands to be more open toward others to make the situation easier for them as spouses.	Not reported	Family Related Needs			NS	NS18
Other spouses described a more passive approach to their support and justified this approach by noting that their husbands were calm about the situation.	"…(I) have not accompanied him anywhere because he deals so well with the situation himself... Maybe he sometimes may have wanted me to go with him (to the hospital), but I have been more - 'Ok if I do not have to accompany you, I have work to do" (pg. E10)	Family Related Needs	U			F56
Author: Evertsen et al, 2010						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
They did not know what questions to ask which left them unprepared. They relied on the primary care physician and urologist to tell them what they needed to know, both the good and the bad.	"Maybe they don't tell us these {bad} things because they don't want us... to put ideas in our head." (pg. 2-3) "I think the men need to be told upfront...they need to come out and say...this can be a real problem. This is what's going to happen." (pg. 3) "Is he {husband} the unusual one, or is he not the usual one?" (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F57
Some of the women suggested that they needed doctors, both the urologist and primary care physician, to be honest and give "more practical information" about how difficult and long the recovery is going to be.	"It's all trial and error… if you could share that information that would be helpful." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs		C		F58
Some of the participants said that the doctors ''were very respectful'' in regard to any questions that they would have but ''not really worried about me {emotionally} at all.''	"He {primary care doctor} would ask 'how are you doing' and you would say 'fine' and that's it. They don't ask any more questions… I am not saying he doesn't take the time to talk to me, but he talks about the issue that I'm in there for." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F59
Many of the women said that they tried to seek comfort from their own primary care providers but were disappointed with the lack of information and support they received.	"I have never talk with my family physician...I was never asked how I felt." (pg. 3) "...they {treating doctors} were not really worried about me at all. And I guess I wasn't surprised with that. I think actually... now that you've asked that question, I think I would have been very surprised if they had been worried about me. I just didn't... I mean, that never occurred to me. So that's an interesting question." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F60
One woman noted that she was frustrated by the lack of ongoing support for her husband after surgery from his primary care physician and urologist. She said that she would bring her husband into the clinic with numerous symptoms and was told to wait and see what happens.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS19
A few participants noted that they received more information and support from the primary care doctor than the urologist.	"He'll sit there with you...ask you about the family, everything. He'll say 'well, and how are you' and I have a bit of a habit of saying 'I'm	Health Care Service / Comprehensive Cancer Care Needs	U			F61

	OK' {Doctor says,} 'What do you mean by OK? Why don't you tell me what...why it isn't fine." (pg. 3) ".... He answered all the questions that we both asked, and we both had our list of questions and he would get them from both of us. You know, both of us would come at him with different types of questions, and we both felt very confident with the doctor." (pg. 3) "...we went in and we saw the primary care physician at that point and talked with him about the various options. So he was very helpful, very supportive. Obviously has some opinions but talked through all of the options, pros and cons, before we actually made the decision." (pg. 3)					
One woman noted that her partner was disappointed that his primary care physician did not visit him in the hospital after surgery.	"His primary care just never came by to see him...he didn't stop by because he couldn't bill me." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F62
General discussion emerged during the focus groups regarding inconsistencies in who should be providing follow-up, whether the urologist or primary care physician. One woman suggested that a team approach to the treatment and follow-up of prostate cancer could ease some of the burden on the patient and their family members.	"...they were on their own until the next appointment." (pg. 3) "...once you're done seeing the urologist, you're still going back to your primary doctor. And if there are problems with one, the primary doctor needs to know about that. For further treatment down the line". (pg. 3) "If I have a question I would call the {urologist}. Those would be the first ones I would pick to phone and call." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs		C		F63
Two participants suggested the addition of a visiting nurse to help by answering questions and assisting with care-giving duties.	"relieve a little stress." (pg. 4)	Health Care Service / Comprehensive Cancer Care Needs		C		F64
All participants believed they did not receive enough information and were thrown into an unfamiliar role as a caregiver instead of a companion.	"The wife in something like this is very much involved," (pg. 2) "this diagnosis affects the wife as well." (pg. 2)	Health Care Service / Comprehensive Cancer Care Needs		C		F65
In addition to more information, the female partners identified a strong need for emotional support from family, friends and others going through the same diagnosis. It was important for them to feel like what they were going through was normal.	''When you find this out {diagnosis} you need to talk to somebody and that somebody's just not there.'' (pg. 3)	Social Needs	U			F66
Participants emphasised the need for additional support.	"why isn't there a group for me to go to?" (pg. 2)	Social Needs	U			F67
Discussion of shared experiences through support groups was mentioned by many of the women as important for both the patient and their partner to feel like what they were going through was normal.	Not reported.	Social Needs			NS	NS20
The lack of information and increased time serving as a caregiver rather than a couple caused increased stress for the female partner and at times took a significant toll on the	"You just don't know where they're going to be from day to day. Cause one day they're one way, and the next day they're in a different mood and the next day... this is bothering them and that was where I	Physical / Daily Living Needs		C		F68

couple's relationship causing increasing tension and even arguing.	wasn't prepared. I just...I knew we had to get through but I think you go through that big trauma period and then you hit a point where you go, 'okay, now we've got that sort of under control. We're not sure where we're going with it yet but it's kind of under control,' and that's when things sometimes get out of control. And you're their back at home, and they're going through all these different things emotionally. Well you're sucked into all that stuff. I mean, you don't know from day to day how they're going to handle it." (pg. 4) "We are still trying to figure it all out. It was a big change for both of us." (pg. 4)					
The couple's relationship during the diagnosis and treatment seemed to shift from the male patient attending doctor's appointments alone to the couples attending appointments together. One of the women lamented this relationship change when describing her partner's use of the words "we" and "us" to describe his illness. However, she noted a difference in classification when faced with her own illness. A number of women expanded on this statement.	"when I had breast cancer, it wasn't 'our' breast cancer. It was my breast cancer." (pg. 4) "From the very beginning of the process, we always did it together and I think it was just assumed... the two of us assumed that we would do it together." (pg. 4)	Physical / Daily Living Needs	U			F69
Several women noted that physical changes during treatment and recovery caused changes to their relationship.	"But everything's still not quite the same because now you're told you'll heal up, but when you have major surgery, your whole body goes through a change. And he seemed to like… he got moody, and, you know, crabby, and so I just kind of went 'OK' cause you know… I don't know what to do". (pg. 4) "After two weeks my husband couldn't even get out of bed because of the pain... the discomfort... I mean I wasn't prepared for that." (pg. 4)	Physical / Daily Living Needs	U			F70
The physical effects of the diagnosis decreased the men's activity levels leaving the wife to take on more duties around the house.	"There's so much that's affecting their masculinity...." (pg. 4) "This is sixteen months later, we only go places where he can be near a restroom because he always feels like he has to go." (pg. 4)	Physical / Daily Living Needs		C		F71
One of the women said that her husband felt a "loss of manhood" due to a decrease of sexual function as well as the innate instinct to provide for his family during this time.	"a woman can't know what it's like mentally to a man not to be able to have sex and still have the desire." (pg. 4) "A man in his fifties...ending your sex life as you knew it, it's a big step. Especially with my husband, it was a big...a big blow to his ego and our sex life stopped as we knew it." (pg. 4)	Interpersonal / Intimacy Needs		C		F72
Author: Feltwell et al, 2004						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
One partner explained that although she wanted to talk to other women whose partners had prostate cancer when her husband was first diagnosed with the disease, she did not want to get information from other women at the time of the interview, because she thought it would be too frightening.	"I don't feel the need to at the moment [talk to other partners]. At the time [around diagnosis] I felt as though I wanted to know something or talk to somebody who had had the experience . . . in some ways you know people who've had it… and that's why sometimes people don't want to know because err… it's frightening." (pg. 182)	Barrier	U			F73

One partner explained how she once wanted to ring a help-line to get some prostate cancer information but did not ring because her husband did not want her to.	"I did once see a helpline for prostate cancer sufferers and there was a number, and there was also a local number actually and I was going to phone but my husband said… But my husband didn't want it." (pg. 183)	Barrier	U			F74
Some partners actively sought information about prostate cancer from a variety of sources and providers, including healthcare professionals. One partner explained how she sought information about her husband's condition by asking his consultant questions.	"I go in [to see the consultant] with him [husband] because I question him [consultant]. I question Dr X." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F75
Some partners suggested that they had to actively seek information in order to get their information needs met. One partner explained that she would not have been told any information about her husband's condition by his consultant if she had not actively sought information from him by asking questions.	"You wouldn't get to know anything [if you don't ask for the information]. Yes, I do the same with my own doctor if I want to know I ask her straight out. I think it pays you, go in and ask what you want to know." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F76
Some partners failed to seek information because they felt disempowered and lacked confidence in seeking information. One partner explained how she felt unable to seek information from her husband's consultant because she did not feel included in the patient–physician consultation.	"Now, like the lady, she asks, now I don't because Mr. X, he's completely looking at Rupert [husband], not me, he is talking to Rupert… so I don't say nothing, 'cause I'm not the type to push forward, although you want to know." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F77
Partners failed to seek information from consultants because they felt that their time was pressured within the consultation. One partner explained that she would like to have talked openly with the consultant but the idea that he was a busy man stopped her from pursuing questioning him.	"We're not wimps… we want to know the facts, but by the same rule you are very conscious that they are very busy people and you can't sit and have a chat, you don't feel that you can open up for a chat like this." (pg. 183)	Health Care Service / Comprehensive Cancer Care Needs	U			F78
Partners failed to seek information from sources like leaflets because they were not aware of the existence of such materials. Other partners avoided seeking information from sources such as the Internet because they felt they were too old.	"Oh, I don't use it." (pg. 183) "I wouldn't know where to start." (pg. 183)	Health Care Service / Comprehensive Cancer Care Needs		C		F79
One partner explained how she and her husband avoided talking about prostate cancer in order to get back to normal, but sometimes found it difficult to gauge when she should talk about the disease with her husband.	"We haven't got an ostrich attitude to it but I find it difficult to know when it's right to talk about it." (pg. 182)	Family Related Needs	U			F80
Author: Harden et al, 2006						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
(Young-old developmental stage): Many in the group expressed a nagging worry about their future together. One wife said that they frequently talked about their situation in the middle of the night, discussing treatment situations and modifying plans. Another wife said she worried about his status.	''I faced my own breast cancer (a survivor) and that doesn't bother me. It's something I live with. But I'm having a much harder time with his. I worry. I worry all the time (she cries).'' (pg. 373)	Psychological / Emotional Needs		C		F81

(Young-old developmental stage): Another wife hated seeing her husband in pain but felt his overall attitude toward the cancer helped her to cope with the situation. (Worry seemed to be a constant companion of wives in the young-old group.)	‘‘I don’t like the idea that our lives are going to end or we are going to be separated. And a lot of times, I start feeling sorry for myself, not for him but for me, to be by myself.’’ (pg. 373)	Spiritual Needs		C		F82
(Late middle age developmental stage): A diagnosis of cancer caused couples to re-evaluate their priorities. It helped them realign their priorities to more meaningful goals for them.	“What has hit me the most is realizing the importance of the small things and doing those things. We don’t take it for granted at all.” (pg. 372)	Spiritual Needs	U			F83
(Young-old developmental stage): Frequently commented that they had a good life. They had been able to do the things they had planned. Felt comfortable with their accomplishment.	‘‘We have said many times that we have been blessed. We have a wonderful family. We have gone together and been married for over fifty years. We just feel very blessed that the Lord has given us these wonderful kids and grandkids. He (her husband) has said many times, ‘If I die tomorrow, I will have lived a wonderful life’. And that is really how I feel too.’’ (pg. 373)	Spiritual Needs	U			F84
(Late middle age developmental stage): Household plans frequently had to be postponed related to a lack of energy. Wives expressed the need to be constantly vigilant, monitoring their husband’s status and using that as a determinant of activities for the day. Wives spoke longingly of activities they used to enjoy together.	“It slowed him down; for example, he can’t do some of the outdoor things he likes to do. In some ways, we just kind of adapt what we are doing.” (pg. 371)	Physical / Daily Living Needs	U			F85
Two wives who were currently active in the work force expressed distress and guilt because they could not be present with their husband at all doctor’s visits and treatments. This was a source of great concern for wives.	‘‘I couldn’t be there for all his treatments because I had to work, and I felt bad because I wasn’t there supporting him all the time… we discussed it and the best thing for me to do was to work and not lose my job, because if I lose my work, I lose our insurance and possibly our house. So, it was important for me to work, but it was hard. I just had to be strong and keep things going.’’ (pg. 371)	Physical / Daily Living Needs	U			F86
Would have been easier to accept their diagnosis if they were older.	‘‘We would have had at least enough time to work to retire. So, at best we would have had medical care. I don’t have any. There is no retirement benefit.’’ (pg. 373)	Physical / Daily Living Needs	U			F87
(Old-old development al stage): When couples in this age group discussed living with prostate cancer, both husbands and wives discussed it as a couple’s disease. Wives were often proactive in looking for new treatment options and discussing them with the doctor.	‘‘we decided’’… ‘‘when we had treatment,’’… ‘‘we accepted it.’’ (pg. 374)	Physical / Daily Living Needs		C		F88
(Late middle age developmental stage): [related to: men no longer getting sexual reminders and now need to think more about showing affection] His wife said she felt left out at first, but after discussing her feelings with her husband they were able to adjust.	Not reported	Interpersonal / Intimacy Needs			NS	NS21
(Late middle age developmental stage): [related to: hormone therapy causing impotence] His wife explained the changes they made:	“We do a lot of hugging. We just spend a lot of time together. So it has basically not been a hard thing for me. But he feels bad that he is not meeting my needs. I think men have an idea that to meet your emotional needs it means sex. Well, actually that is a very small part.	Interpersonal / Intimacy Needs		C		F89

	So, it was a hard thing for me to get across to him that I'm doing very well." (pg. 372)					
(Young-old developmental stage): Although some of the couples discussed changes in their normal intimacy patterns, they did not express distress related to these changes. One wife said she thinks about the changes in their sexual activity.	"It seems strange that we have the lack of sexual activity now because we weren't like that before. But I'm accepting it; he's accepting it and we're okay with it. He tells me, 'I'm going to be 72 years old, what else do you expect?" (pg. 373)	Interpersonal / Intimacy Needs	U			F90
(Old-old developmental stage): Although intimacy seemed important in this age group, this group raised less concern than what was voiced in the younger age groups.	"We don't even talk about it or think about it. We're together all the time." (pg. 374)	Interpersonal / Intimacy Needs	U			F91

Author: Ka'opua et al, 2005 (1 study / 2 papers)

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Giving hope to the sick through the sharing of their experience with prostate cancer offered couples opportunities to integrate illness experiences into the larger fabric of their lives.	"This is my husband, a kind hearted person who gives of himself to others. When we go to the doctor, we "talk story" with other patients. If they're really sick, we encourage them. When we give hope, we get hope back." (pg. 151)	Spiritual Needs	U			F92
Women in the study said that they participated in spiritual, health promoting, and charitable activities from which they derived a sense of purpose and a context for examining the meaning of cancer, aging, and adversity in their lives. More often than not these were activities that wives shared with their husbands.	"We're active in the support group. It's important to help others and a way we practice our faith." (pg. 151)	Spiritual Needs		C		F93
Across the trajectory of their husbands' illness and survival, women relied on various types of spirituality and religion to understand the meaning of change in their lives and thus were able to adopt a flexible, yet proactive, approach that allowed for continuous adaptation to life's adversity.	"My husband was very depressed. Chi classes helped us be positive and learn from life. When bad things happen, you try to see the lesson in it for you." (pg. 151) "His cancer made me more resourceful… I learned to pray and meditate on all the things that were stressful." (pg. 151)	Spiritual Needs	U			F94
Women reported that they continued to learn through coping with challenges related to their husband's cancer, as well as with other experiences of illness and aging.	"Through my husband's cancer, other experiences, even his death — I've come to understand that changes don't have to define our lives. We can adjust and go through it." (pg. 149)	Spiritual Needs	U			F95
Women helped their husbands navigate the medical system. They reported accompanying their husbands to medical appointments and treatments, discussing treatment options with their husband and other family members, and providing or facilitating social support.	"We rode the bus to the city for radiation, a trip that took the whole day. I go with him because he's limited in talking English and I help answer questions… then I know what is going on." (pg. 149) "The doctor said that my husband had two treatment choices. We came home and had a family *pule* [prayer] about what to do. We talked as a family and then made the decision." (pg. 150) "Japanese men have a *samurai* streak—they're private with feelings. It was difficult for him to go to support group, so we both went. Sometimes I put my head down and didn't look at the men who were talking because what they were saying seemed so personal and I didn't want them to be embarrassed." (pg. 150)	Physical / Daily Living Needs	U			F96

Women worked to affirm the couple bond, especially in light of changes associated with treatment side effects.	"The doctor asked if sex is important to us. He explain to us that my husband will be 'half man, not full man.' When we come home, I say to my husband: 'don't worry. I have strong independence.' I would be lying if I said it is not a problem. We went still sleep in separate rooms." (pg. 150) "Permanent impotence, a treatment side effect! But we've had 45 nearly perfect years together and sex is like the frosting on the cake. Too many marriages have gone under the rocks because of impotence. The main thing is the cake. From the beginning we decided we have our cake" (pg. 150) "The only thing that separates married people is death. I do my best so that he can use his life in old age" (pg. 150)	Interpersonal / Intimacy Needs	U			F97
With respect for their husbands' dignity and self-esteem, the wives learned to reframe their husbands' changes as part of the normal aging process and thus approached sensitive discussions about changes in sexual intimacy. Humour was used sometimes to initiate such discussions.	"I joke with him 'if you had to get cancer, why this one' because we both know the prognosis… and we laugh… joking is one way to recognize what's going on and deal with it." (pg. 150)	Interpersonal / Intimacy Needs	U			F98
Almost all the couples who wanted to restore their sexual intimacy found an acceptable solution, including use of medication to help husbands have an erection, oral sex, more kissing, and caressing. They also found alternative ways to express intimacy without sexuality. Affirmation of the marital bond was expressed through shared activities seen by the wives as romantic, spiritual, playful, or companion-like.	Not reported	Interpersonal / Intimacy Needs			NS	NS22
In the face of daily deficits and physical disabilities, the wives encouraged their partners to keep a positive attitude.	"When he is downcast, I comfort him and remind him there will be a time when all suffering will end, so take heart. God will provide. Enjoy what we have!" (pg. 150)	Family Related Needs	U			F99
Author: Ka'opua et al, 2007 (1 study / 2 papers)						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Although cognitively prepared by health care providers to anticipate treatment side effects, wives felt that they were not offered guidance or suggestions to help cope with the husband's impotence and incontinence as threats to emotional and sexual intimacy.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS23
Developing and sustaining community connections through meaningful participation in spiritual communities and secular groups reinforced spiritual learning and provided opportunities to give and receive social support.	Not reported	Spiritual Needs			NS	NS24
The majority of women participated in service activities that specifically provided succour and healing to others, such as providing Healing Touch services to cancer patients, sharing	Not reported	Spiritual Needs			NS	NS25

knowledge of Chinese herbal medicines, and reaching out to newly diagnosed patients.						
Across diverse traditions, engaging in service to others reflected the belief that caring for others was integral to personal well-being.	“Honouring the sacred in everyday life.” (pg. 35) “Commitment to we – not I” (pg. 35)	Spiritual Needs		C		F100
Service often preceded cancer diagnosis, and in long-term survival, continuing participation in service activities helped women maintain a semblance of normalcy in the face of changing conditions.	Not reported	Spiritual Needs			NS	NS26
Notably, some wives said that their experiences as the spouse of a cancer patient / survivor motivated them to help others cope with cancer. During the period of long-term survival, women engaged in activities that included coordination of cancer support groups convened in either conventional health care or spiritually based settings, providing Healing Touch program therapy to cancer patients, and sharing information about complementary and alternative medicine believed to reduce cancer risk and alleviate distress.	Not reported	Spiritual Needs			NS	NS27
Through service to others, women affirmed their spiritual connection, nurtured a sense of purpose across the trajectory of survival and adaptation, and furthered the integration of their own experience with cancer.	Not reported	Spiritual Needs			NS	NS28
Not reported (Community connections and meaningful Participation)	My church community is an extended family. When my body was weary, the bishop visited and sent others to help.” (pg. 34)	Spiritual Needs		C		F101
Not reported (Community connections and meaningful Participation)	“Because of my experience I wanted to comfort others. I got certified to do Healing Touch with cancer patients.” (pg. 34)	Spiritual Needs		C		F102
Not reported (Community connections and meaningful Participation)	“My husband and I run a prostate cancer support group. This is how we take our faith out into life.” (pg. 34)	Spiritual Needs		C		F103
In the process of adapting to such challenges, women became keenly aware of life’s ephemeral nature, which punctuated a search for purpose and positive meaning in adversity. In this search women relied on spiritual beliefs and practices to cope with changes and attain a quality of life congruent with valued life priorities.	“Religion and spirituality have a lot to do with coping. You have to believe in something that’s greater than yourself otherwise life seems hopeless.” (pg. 32)	Spiritual Needs	U			F104
Two of them practiced family rituals that were termed as “ancestral reverence” or “ancestor worship” (that is, going to grave sites with offerings to ensure ancestors’ comfort in the afterlife, praying to ancestors) and stressed that these spiritual practices offered them a sense of comfort and cultural continuity.	“In traditional Chinese culture we believe that the ancestors watch over us from the life beyond and appear at times of despair to give that extra strength to accept things that can’t be changed.” (pg. 32)	Spiritual Needs	U			F105
A minority of women said that they were “spiritual but not religious.” For these women, spirituality was derived from a	“Feel the awesome power of the universe, see my trials and tribulations from a bigger perspective, and be inspired to go on.”	Spiritual Needs	U			F106

more personal system of beliefs and practices. The sacred source was described as a “guiding light,” “the source of all good,” or “nature.”	(pg. 33)					
The sanctity of the marriage was frequently referenced. Prayer or meditation and inspirational readings offered women optimism and motivated affirmation of the marital bond as a “covenant” between God and both members of the couple, as “God’s gift,” and as a challenge of resolving “spiritual brokenness.”	Not reported	Spiritual Needs			NS	NS29
In some cases, couples used SBR together, and such shared experiences provided both partners with an opportunity for introspection, empathic communication, and mutual social support. For example, one couple used prayer, inspirational reading, and fasting to deal with the husband’s incontinence and related social anxiety.	“These [practices] help us to concentrate our minds to the problem. Through consciously working to be closer to our Heavenly Father, we believe that we can better understand and support each other.” (pg. 35)	Spiritual Needs	U			F107
Spiritual stagnation was avoided through discovery of life’s lessons, and crises generally were embraced as opportunities for enhanced understanding.	“How you look at your life is a choice. Each day you can choose to be holy [by] showing love and compassion, learning to appreciate whatever life brings with a grateful openness.” (pg. 35)	Spiritual Needs	U			F108
Beliefs related to acceptance of illness, aging, dying, and death as part of life; human choice or active will; and collaboration with the sacred source were all cited. From the premise of these beliefs, women accommodated physical disabilities and deficits, tried different solutions (for example, new medications, complementary and alternative treatments) for palliation and healing, and modified lifestyles (for example, dietary habits, exercise practices) to reduce disease risk or control existing medical conditions. In the majority of cases, a proactive attitude of wellness promotion and health maintenance was expressed.	Not reported	Spiritual Needs			NS	NS30
Not reported (Health-focused attitudes and behaviours)	“We accept that aging and death are part of life. We know we’re going to have physical problems as we get older—so, we work to prepare spiritually, emotionally, physically.” (pg. 34)	Spiritual Needs		C		F109
Several women stated that sexual intercourse could not be restored because of treatment - related impotence; in most cases, wives learned to appreciate that their husband was alive, focused on helping their husband stay healthy through lifestyle modifications, and found closeness through deepening the marital friendship or spiritual relationship.	“Our relationship is different, but he’s still my guy. We’re good friends. We pray together every night, holding hands. It’s hard to stay angry with each other when you do that.” (pg. 33)	Interpersonal / Intimacy Needs	U			F110
Reservation of the marriage was a key focus of women’s adaptive work and in most cases involved the cultivation of couple intimacy. Characteristic actions included affirmation of the marital bond, efforts to understand problems from the husband’s perspective, and finding new ways to share intimacy.	Not reported	Interpersonal / Intimacy Needs			NS	NS31

Women reported efforts to understand their husband's experience of treatment and survival, sought to reinforce the husband's sense of masculinity, and nurtured the marital bond through modified sexual practices (e.g. caressing, oral sex, baths) and other nonsexual means (e.g. shared social activities).	Not reported	Interpersonal / Intimacy Needs			NS	NS32
Not reported (Preservation of marriage/couple intimacy)	"Losing our sexual relationship was hard. I talked to God daily asking for help to find other ways to be close to my husband." (pg. 34)	Interpersonal / Intimacy Needs		C		F111
Not reported (Preservation of marriage/couple intimacy)	"Marriage is a covenant relationship a sacred promise made to each other and with God. In keeping this promise comes the working out of problems in marriage." (pg. 34)	Interpersonal / Intimacy Needs		C		F112
Not reported (Preservation of marriage/couple intimacy)	"It's important not to feel deprived in your marriage. That's an erosion of God's gift. Find out why you feel deprived. Correct it. Amen." (pg. 34)	Interpersonal / Intimacy Needs		C		F113
Author: Kelly et al, 2015						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Health care professionals in outpatient clinics had communicated their understanding of the expected pattern of sexual recovery of patients and their partners.	"We found … (the nurse practitioner) very good and explained about sex life. Her information helped a lot." (pg. 134)	Health Care Service / Comprehensive Cancer Care Needs	U			F114
Talking about sex and intimacy was an important topic, requiring a senior clinician to give the topic the gravitas it deserved.	"I think you have to have a doctor or a nurse or somebody who's in a senior position who is quite sympathetic and knows how to be able to sit down and talk to a couple, because I think that's very important really, you know it's no good like the couple going in and seeing the consultant or the doctor or the nurse and they're just flippant with them, they don't explain things." (pg. 134)	Health Care Service / Comprehensive Cancer Care Needs	U			F115
The majority of this sample did not feel that clinicians had discussed sexual functioning well and reported that such concerns were not always appropriate to share with friends / family.	"Unconsciously, I was really scared. I wish I'd had somebody like you (the researcher), what I would call a professional that's, because it's not something that you can talk about to close friends because, it's too intimate". (pg. 135)	Health Care Service / Comprehensive Cancer Care Needs	U			F116
There were also examples where the private impact had probably not been appreciated by health professionals. One of the members of the two gay couples who took part spoke of how his partner had become 'very fat after the hormone therapy' and his partner does not now ejaculate.	"This was very hard to come to terms with, a fattish old man." (pg. 135) "Joint ejaculation had been very important to us, now he says I'm coming, I'm coming! but there's no visible signs." (pg. 135)	Health Care Service / Comprehensive Cancer Care Needs	U			F117
The man also spoke of feeling guilty at finding his partner unattractive since hormone therapy but had felt unable to discuss this—certainly not with a health professional.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS33
Learning had been experiential rather than anything given to the couple as an information package associated with the treatment choices.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS34

Partners often reported feeling excluded from the events relating to the cancer and its impact.	"I would have liked, just once in a while, for the consultant to say, "How is your wife getting on? I really feel out of it and the fact was of course, I was affected." (pg. 136)	Health Care Service / Comprehensive Cancer Care Needs	U			F118
Partners were rarely asked during clinics about their own needs in relation to the effects of the diagnosis and treatment outcomes. They were rarely made to feel they had a genuine contribution to make to the medical consultation.	*Interviewer:* "Did they ask you, questions in terms of you know, were you okay?" *Partner:* "No they never did, they were very nice but I think the… medical establishment in general is still rather formal." *Interviewer:* "There's no guidance, for same sex couples?" *Partner:* "No, that's right, and that really would have been helpful." (pg. 136)	Health Care Service / Comprehensive Cancer Care Needs		C		F119
It was noteworthy that women would often speak of the problem in joint terms rather than just the mans'.	"we had a small, fairly flaccid penis" (pg. 133)	Physical / Daily Living Needs	U			F120
One partner, who found it difficult to express her frustration at her husband's ED, and his complacency towards it.	"I'm dying… of thirst… of food" (pg. 133) "A little cuddle? No! I'm starving." (pg. 133)	Interpersonal / Intimacy Needs		C		F121
Partner's understood the gradual process involved in resuming sexual expression after prostate cancer treatment.	"Rome wasn't built in a day" (pg. 133)	Interpersonal / Intimacy Needs		C		F122
[Expectation of resuming full sexual activity as soon as practicable] Partners expressed the belief in taking things at a more steady pace.	"He was too anxious to try to please me and nothing would happen at all and I would say, 'Don't be silly, you wait and see another couple of months will be fine and give it time and don't jump the gun too quick. You know, you're not ready yet'. After a while it was fine. I think it was a natural reaction." (pg. 134)	Interpersonal / Intimacy Needs	U			F123
Some couples told the interviewer that they had not talked with each other about sexual concerns either before or after treatment.	"No, we didn't actually. I was very patient, because I think you have to be like that, you can't just like click your fingers and everything's going to come back to normal because it's a big operation and he was very ill and it's just basically, if you love somebody enough it's just, you just must sort of have patience and wait and then everything is fine." (pg. 136)	Interpersonal / Intimacy Needs		C		F124
Couples discovered that although penetrative sex may not be possible, other forms of intimacy and sexual activity were still available, and again the issue of orgasm without full EF was mentioned.	"One thing that I picked up on, which I thought was quite extraordinary was that you can have an orgasm with a flaccid penis." (pg. 136)	Interpersonal / Intimacy Needs	U			F125

Author: Pinks et al, 2018						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
The focus group process had provided an opportunity to talk about things that they would not have discussed in any other context.	“We do talk to a certain degree but it’s not quite the same… I just feel better for being in this group and having an opportunity to talk about things that I’ve kept bottled up. Some of the things I’ve said here this morning I wouldn’t say to anyone else.” (pg. 56)	Facilitator	U			F126
Younger participants sought support from healthcare teams and were happier to share the responsibility of care for their partner.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS35
Participants described how important it was to have information and someone to talk to before treatment, when they did not know what questions to ask or what to expect and was when their anxiety was high.	“I got really angry and frustrated at the lack of information. You need to know at the beginning what sort of changes will happen, especially in your sexual life…this type of information is not something you can put in a brochure, you need to be able to talk to someone, sexual counselling or someone who can help you figure out what you need to do and how to prepare for what’s going to happen.” (pg. 54)	Health Care Service / Comprehensive Cancer Care Needs	U			F127
Their interactions with healthcare professionals focused only on treatment choices and that the implications had not been fully explained to them. Medical teams were only focused on curing the cancer and were reluctant to discuss the impact of sexual dysfunction on their quality of life.	“The doctors certainly didn’t give us any help on the sexual side of things, they never mentioned it, basically it felt like they were saying “I’m here to cure the cancer I’m not here to help you with anything else.” I believe the medical profession has got this mindset that once they have treated the cancer then they think that you don’t need to worry about anything else.” (pg. 54-55)	Health Care Service / Comprehensive Cancer Care Needs	U			F128
Some participants said they felt they were left to deal with it on their own and were just given a “bag of information to take home and read” when they wanted support and information to help prepare for changes in their relationship. Participants described having a sense of helplessness and uncertainty that had left them feeling distressed.	“I Felt absolutely useless, I really wanted to do something to help my husband, but I didn’t know where to turn as there wasn’t any information for the wives… I just needed someone to talk to, I remember going off and just crying as I didn’t know what to do to help him.” (pg. 55)	Health Care Service / Comprehensive Cancer Care Needs	U			F129
Many reported they did not have an opportunity to express their concerns with the specialist and said they were made to feel that their needs were not important. Participants agreed that prostate cancer was actually a couple’s disease and that the impact on partners should also be considered.	“He only spoke to my husband about what he thought or was worried about, it was as if I wasn’t there. The urologist didn’t consider the fact that he was treating the partner of somebody else… I think this is a really important issue because it’s the kind of cancer that affected both of us. I think doctors really need to treat the couple rather than the man.” (pg. 57)	Health Care Service / Comprehensive Cancer Care Needs	U			F130
Few had sought help from counsellors, whilst most didn’t know where to obtain support. Many participants felt that their partners were so consumed in their own illness that they had no awareness of what they were going through, or the needs they may have.	“He was so focused on what was happening with him that he hadn’t thought about was happening to me… I felt so alone, I just wanted to escape to somewhere where I wasn’t thinking about it…I just needed some respite, but nobody seemed to care.” (pg. 57)	Psychological / Emotional Needs	U			F131
The experience of emotional caregiving had started to take its tole to the point where they were struggling to cope.	“I didn’t know how to cope with his moods, he has always been the support for me and I was trying to support him, but I felt absolutely useless… I know it’s been very hard for him to mentally readjust to the whole thing but I’m really struggling, I don’t know what to do, I’ve tried everything.” (pg. 54)	Physical / Daily Living Needs	U			F132

Some participants shared how erectile dysfunction had left their husbands feeling less of a man because they could not perform sexually. This resulted in many men withdrawing from the relationship which left participants grieving a loss of intimacy both physically and emotionally.	"If I'm being honest, I'm missing that intimacy … as far as he was concerned the sexual side of our relationship was finished and that didn't seem to bother him, but it upset me … He just withdrew totally from the relationship…it didn't seem to matter to him what I wanted or needed…now it feels like we are just acquaintances rather than husband and wife." (pg. 56)	Interpersonal / Intimacy Needs	U			F133
Some who had had an active sexual life prior to treatment, expressed feeling more distressed by the sexual dysfunction in their relationship. These participants described exploring new intimacy options as a couple, even those who relied on what was familiar before the cancer diagnosis were willing to encourage their partner and take the lead, which they said they had not done before.	Not reported	Interpersonal / Intimacy Needs			NS	NS36
Some partners, who had been married for a long time explained that sex had not been part of their relationship for several years, thus, finding satisfaction in companionship.	Not reported	Interpersonal / Intimacy Needs			NS	NS37
Most women admitted that they simply withdrew from the physical side of the relationship as well in an attempt to cope with their loss and protect their partner from his.	"There was definite withdrawal on my side, in fact it was all my side…I didn't want to put him in that position and remind him of his sexual issues… making him feel inadequate, I didn't want him to think that I thought he was less of a man." (pg. 56)	Interpersonal / Intimacy Needs	U			F134
All the participants agreed that intimacy was important to them and that they would have benefitted from support to help them adjust to the intimacy changes in their relationship.	Not reported	Interpersonal / Intimacy Needs			NS	NS38
Participants felt a sense of responsibility to be the sole provider of emotional support and encouragement to try to help their partner cope.	"It was almost like once his sexuality had gone, he wanted to die, he gave up. He has been suffering from depression for quite a few years now, I try to cheer him up and encourage him to do things…to get involved just so he had other things in his life, but he won't. His life just revolves around me…I've had to be his backbone, it's so exhausting". (pg. 53)	Family Related Needs	U			F135
Older participants struggled alone as best they could, describing a sense of duty and stoicism to take on the caregiver responsibility. These women expressed feeling an expectation that it was their role to look after their husband when he was ill and that they felt they should be happy that their partner was alive. This perspective had left them feeling a sense of guilt and shame when they were unable to cope.	Not reported	Family Related Needs			NS	NS39
Most participants shared how they were constrained by their partners, and how their partners were unwilling to talk about their issues.	"Communication is a big issue for us. I've said, "unless we know what each other's thinking we can't help each other," but he's very private… also he didn't really want anyone else to know about this… I've had to respect his wishes, but it has left me with no one to talk to." (pg. 55)	Family Related Needs	U			F136
Some younger participants described how they had taken the lead to ensure important issues were discussed.	Not reported	Family Related Needs			NS	NS40

Other women who had always been able to discuss issues with their partner prior to prostate cancer continued to talk openly during survivorship.	Not reported	Family Related Needs			NS	NS41
Many older partners found it harder to talk and described how they came from an era where men did not talk about their feelings and the intimate side of their relationship was not discussed.	Not reported	Family Related Needs			NS	NS42
All participants agreed that they needed help in being able to vocalize some of their feelings, so they did not have to suffer in silence. Even those in close relationships admitted they held back on discussing some things that they felt would upset their partner.	Not reported	Family Related Needs			NS	NS43
Author: Primeau et al, 2017						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Participants felt they were given time to share emotional concerns with Prostate Cancer Support Nurse (PCSN).	"[The specialist nurse] answered my questions when I asked about what hot spots [were], and she explains it to you in detail and you understand what she is saying. Since we have come into contact with the specialist nurse, we have been able to ask her things, because she sits and listens to you and asks you questions." (pg. E246)	Facilitator	U			F137
They lacked clinical information on diagnosis. Did not fully understand the information or implications for treatment.	"[The clinician] said it was prostate cancer, and [my husband] had hot spots. But they never explained to us what the hot spots were and where they were." (pg. E246)	Health Care Service / Comprehensive Cancer Care Needs	U			F138
They expressed uncertainty about treatment and progression of cancer. They were unsure of how often the extent of metastases would be assessed and how their care team would monitor their condition.	"Is it going to spread more? And how would they know, other than asking [the specialist nurse] if he could have a scan to see if it was spreading?" (pg. E245)	Psychological / Emotional Needs	U			F139
The main physical needs were related to managing the long-term side effects of ADT.	"I would have liked some advice on how to cope with this tiredness" (pg. E245)	Physical / Daily Living Needs	U			F140
Couples spoke of financial implications and consequences of man living with a palliative cancer diagnosis.	"I mean, I gave up my work. I was due to retire, but I gave up my work earlier… I would have probably carried on working as I was not due state pension until now, but I do get an occupational pension as well. I took the decision to be the carer. But I just felt that I was not giving my best to my job, and so I felt it was time to stop." (pg. E245)	Physical / Daily Living Needs	U			F141
Most couples were comforted they still had each other, seemed to appreciate continued companionship, and accepted the adjustment in their intimacy. However, change in sexual function had a major negative impact on some couples' quality of life, which was a struggle to adjust to.	"You weigh it all up, I would rather have [patient 150/1]. I would rather have companionship and [patient 150/1] than a sex life, you know, life changes and priorities, you know. Rather companionship, I just put up with it." (pg. E246)	Interpersonal / Intimacy Needs	U			F142
Author: Rossen et al, 2016						

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Spouses all mentioned that their partners participating in the lifestyle intervention helped them cope because they knew their husbands were doing something.	"I was happy that he participated in the lifestyle intervention. Really happy about it. I relaxed more because I knew something was being done." (pg. E5)	Facilitator	U			F143
At this stage of their husband's disease, most women did not feel that they had to supress their own needs (e.g., their need for information or to communicate with others for support). This is due to their ability to initiate satisfactory coping action and the information received through NILS that has led them to believe their husbands are not ill at this stage. One of them talked about needing to have a little more patience with her husband in their everyday life.	"Greater patience in our everyday lives. All the little things. I don't know if I am better at it, but I'm aware of it if he doesn't have as much patience as he had otherwise." (pg. E7) "I don't think there is a difference, not now. There is no big difference. Because I don't feel he is sick anymore." (pg. E7)	Facilitator		C		F144
The framework of active surveillance and the behavioural lifestyle intervention fostered confidence in spouses to embrace supportive role toward their husbands.	"I felt very safe with my husband going to check-ups. I rely a lot on professional knowledge and the scientific values. I think the knowledge we have gotten from the doctor, and the NILS team has been really good. And we have been able to ask questions." (pg. E6) "Because you feel you can do something with your diet and exercise - even though there are no guarantees that it will work but being able to do something. Not just sitting around like a victim. I think that's the reason we don't really consider him a cancer patient." (pg. E6) "It was like, when you were in a project, you relaxed because you knew he was under surveillance, and he went through it all. Nothing left to chance there." (pg. E6)	Facilitator	U			F145
One of the spouses felt that she would have benefitted from extra support in the form of consultations with a doctor or psychologist about her anxieties. This woman did not feel she could talk to anyone in her social network.	"That would have been good. Getting to know, 'Missus, your husband is in a very early disease stage. Don't worry so much.'" (pg. E6)	Health Care Service / Comprehensive Cancer Care Needs		C		F146
Several of the spouses reported feeling anxious and frustrated with what they considered to be insufficient information about the situation provided by health professionals at the time of their husband's diagnosis.	"How were we to know what a disease stage means? We just knew it was cancer. I was sure that my husband was going to die." (pg. E4) "There was a really bad follow-up on what it means to get a prostate value (PSA) that requires some sort of treatment or surveillance." (pg. E5)	Health Care Service / Comprehensive Cancer Care Needs	U			F147
They also pointed out that receiving information from doctors or seeking it themselves had helped them a great deal.	"I think you get a whole lot of information, and I think that is really nice. A lot of things that you didn't know. I think that's what you do when you get a disease." (pg. E5)	Health Care Service / Comprehensive Cancer Care Needs	U			F148
All spouses talked about worries while waiting for test results.	"But it's really tough. It's wonderful when he has just had the test and gets told that it hasn't increased a lot. Then it's great for about a month. But then you start to worry, what about next time? And what if it has increased, what then? Do we choose the operation or what?'' (pg. E5)	Psychological / Emotional Needs	U			F149

While spouses acknowledged issues that caused them to worry and feel anxious, they also described how they tried not to focus on worrisome issues so as to avoid overly disrupting their everyday life activities.	“You have to be careful not to dwell on it. You have to remember to keep it where you can say, ‘‘Now we are setting it aside.’’ It can easily rear its head again, if something happens, but you also have to set it aside. You have to be careful not to focus on it all the time because then I think you could get some weird thoughts.” (pg. E5) “I think I am good at keeping a lid on it. We shouldn’t think about it all the time. And I don’t. It’s there, but it’s not what you go around thinking about.” (pg. E5) “I once had a very good psychologist who gave me some tools to say, ‘‘Okay, there is a worry. On a scale from 1 to 10. How big is that worry’’? A very, very rational approach. And then to say, ‘‘Okay there is a worry and it is there. Don’t sweep it under the carpet, it is there. It is there but you have to set it aside.’’ Then you can take up that worry if the PSA values go up, for example.” (pg. E5) “He knows I don’t think of him as a cancer patient. I get a little…, when he gets a letter where it says ‘‘cancer patient,’’ I think, ‘‘He is not a patient yet.’’ You are not a patient until you are sick.” (pg. E5)	Psychological / Emotional Needs	U			F150
Most spouses did not feel a need at this stage to receive extra support through consultations with a psychologist or support groups with other women (lifestyle intervention project is a reason for this).	“Maybe if it progresses and starts to be a threat in another way than it feels today.” (pg. E6) “I think that I haven’t had that great a need to talk about it and that I haven’t had so much focus on this disease thing because he has been so good at taking advantage of these things [exercise and rye]. I believe it has made a huge difference.” (pg. E6)	Psychological / Emotional Needs	U			F151
In general, the spouses used their social network and communicated with their husband, children, family, friends, or coworkers about their husbands diagnosis and their own anxieties.	“If I’m worried, I’m very bad at hiding it. And if I’m hiding it, I’m sure the people around me, including my husband, notice that I’m feeling bad. So, it’s better to put it into words, maybe they’re sad words, but you know what, I’m thinking about this, and it worries me. But I think, I put it into words, and when it’s said, it’s much easier. Maybe it’s hard and maybe there is no solution, but saying it out loud, I think that’s important.” (pg. E6)	Psychological / Emotional Needs	U			F152
Immediately after the diagnosis, some found it hard to talk about it, but this got easier over time.	“I thought sometimes at work, ‘‘You have to get some work done now.’’ My thoughts were all over the place. The further I came along, the easier it was to talk about it.” (pg. E6)	Psychological / Emotional Needs	U			F153
Most had sporadic anxieties about their situation. They worried about the progression of the disease, their husband dying, and what was going to happen in the future.	“It’s there, but I don’t think about it all the time. It always comes to the surface at some point when you lie awake and can’t sleep. That’s how it is for me, I think. But I don’t think it is taking over our lives. It comes when it comes. Sometimes, some sort of event starts something that makes you think about it.” (pg. E5)	Spiritual Needs		C		F154
Most spouses actively supported partners with regard to practical concerns in relation to diagnosis. They helped them seek information and accompanied them to doctors’ appointments. Some even arranged doctors’ appointments for them.	“I have been with him every time there has been something. That has been good, because then you know what it’s all about.” (pg. E6)	Physical / Daily Living Needs	U			F155

One spouse did not talk to anyone about her anxieties.	"I don't talk to anyone about it. Not even my husband. He knows that I speculate a lot about it. He knows that I don't sleep that well at night; I feel a bit like we must talk as little as possible about it. You don't start to say, ''Oh I feel so bad, I am so afraid there is something wrong with my husband and I sleep so badly at night.'' I just don't do that. I don't do that. There are maybe a few I mention to that I don't sleep very well at night because I can't stop speculating, and then they say, ''You have got to stop with that.'' (pg. E6)	Family Related Needs	U			F156
Several of them actively supported their husbands in their lifestyle intervention. They did not see it as a nuisance, and some even took it up as a hobby	"Sometimes we all eat rye, but we have other things on the table as well because the other family members don't always want to eat rye pasta. But it's not a problem." (pg. E5) "I have never got as much exercise as I have since my husband joined this project. It gives me energy. I have gotten several friends to exercise as well. So it has been really positive being a part of this. I make sure he gets exercise. Sometimes he comes home and says, ''I don't feel like it today, I am tired, do I have to go?'' Then I say to him, ''You have to.'' (pg. E5)	Family Related Needs	U			F157

Author: Sanders et al, 2006						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Couples did agree that receiving individualised information and personal coaching from healthcare providers would be more useful than being provided with a list of resources to contact. Thus tailoring the method of delivering information about prostate cancer survivorship in a manner that uniquely meets the needs of men and women, as well as their needs as couples is important.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS44
Women stated that they wanted to participate in support groups with other women.	Not reported	Social Needs			NS	NS45
Another woman commented that she wanted to talk about sexual issues and the loss of sexual desire with other women without men in the room.	Not reported	Social Needs			NS	NS46
Not reported (Comments demonstrating differences between men’s and women’s perspectives on communication, intimacy, and relationships).	“I mean, us women really enjoy getting together. We can communicate really well and share, you know, but men may not be comfortable with that.” (pg. 506)	Social Needs		C		F158
Women reported feeling that their roles changed from being protected and cared for to a more active role of emotional caretaking.	“Now, all of a sudden, I’m protecting him and taking care of him.” (pg. 505) “having to build up his ego” (pg. 505) “I started working on my husband from the day we found out he had cancer, working on his ego” (pg. 505)	Physical / Daily Living Needs	U			F159
Not reported. (women’s perspectives on communication, intimacy, and relationships).	“Our roles are changing. He used to be my protector; now, all of a sudden, I’m protecting him and taking care of him, and it’s kinda odd.” (pg. 506)	Physical / Daily Living Needs		C		F160
Women also reported that sex was different since treatment and that they felt unattractive and not wanted.	“I don’t feel like a woman anymore: He doesn’t have a reaction.” (pg. 505)	Interpersonal / Intimacy Needs	U			F161
The women talked about wanting to show warmth and affection in other ways.	“It’s being more overtly warm and loving towards him; I pat him on the butt, pour his coffee, hug him on the forehead.” (pg. 505)	Interpersonal / Intimacy Needs	U			F162
The women spoke of a loss of affection from the men because the men feared it might lead to the expectation of sexual performance.	Not reported	Interpersonal / Intimacy Needs			NS	NS47
Women reported a lack of romance in their intimate lives and frustration at the lack of available sexual information.	Not reported	Interpersonal / Intimacy Needs			NS	NS48
They felt that sex had become too clinical between them and their partners. For example, too much preparation and planning were involved, which contributed to a lack of spontaneity.	“You don’t always want to be the initiator.” (pg. 505)	Interpersonal / Intimacy Needs		C		F163

Not reported. (women's perspectives on communication, intimacy, and relationships).	"I think that was such a giant aspect of what we all go through… If we had just talked about sex." (pg. 506)	Interpersonal / Intimacy Needs		C		F164
Not reported. (women's perspectives on communication, intimacy, and relationships).	"we should remember you are never too old to have a date night… it just means enjoying each other… it doesn't have to be the full thing." (pg. 506)	Interpersonal / Intimacy Needs		C		F165
Not reported. (women's perspectives on communication, intimacy, and relationships).	"It made us different as a couple… The sex has to be different… and I decided to make me feel like him… less sexual." (pg. 506)	Interpersonal / Intimacy Needs		C		F166
The women believed they had to be active as women and had to work learning what they could about the disease and how best to proceed.	Not reported	Family Related Needs			NS	NS49
Not reported. (women's perspectives on communication, intimacy, and relationships).	"As women, we buck up and take care of business… walking of being genuinely concerned… but not breaking out and making him unduly alarmed." (pg. 506)	Family Related Needs		C		F167
Not reported. (women's perspectives on communication, intimacy, and relationships).	"I don't think he would have done anything about it. It was like denial… They didn't want to do any surgery, but I insisted something should be done." (pg. 156)	Family Related Needs		C		F168
Author: Sinfield et al, 2008						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
They also confirmed that the urology nurse specialist provided an important source of information.	Not reported.	Facilitator			NS	NS50
Partners often encouraged the patient to go to their family physician with their symptoms but did not attend the appointment themselves. Consequently, their understanding of the situation was often limited by the extent of the family physician's explanation and the ability of the patient to remember and report what had been said. Neither they nor the patient understood the reason for referral.	"I had never heard of a PSA test um obviously I read up about it afterward and I know a little bit about it now but at the time I didn't know that's how a diagnosis, you know one of the ways of diagnosing." (pg. 94)	Health Care Service / Comprehensive Cancer Care Needs		C		F169
Partners usually accompanied the patients when they attended the hospital for further tests even though they had not been invited or encouraged to do so by the family physician or the hospital. They were pleased that they had attended the hospital to support the patient and reported positive experiences (e.g. the hospital facilities and their treatment by staff), as well as negative ones (e.g. unclear what was happening and felt ignored or excluded during explanations).	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS51
Partners felt that it was important that they were invited to attend the appointment with the specialist because having heard what was said first hand, they found it easier to take part in subsequent discussions.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS52

Partners were keen to support the patient, by accompanying them and asking questions about issues that the patient was unlikely to raise.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS53
Some felt that their concerns were not taken seriously or that they were perceived as trouble, as the specialist gave the impression that they did not wish to be questioned.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS54
Partners sometimes had to take initiative to be included in consultations and, where they reported they had their own information and support needs, these were not met in the consultation.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS55
Partners sometimes has to take initiative to be included in consultations and, where they reported they had their own information and support needs, these were not met in the consultation.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS56
Partners echoed the importance of being clear about practical arrangements for dealing with side-effects of treatment (e.g. where to get supplies of continence pads, erectile dysfunction)."	"Erm I think one thing that I didn't have at that stage which might have been helpful is to have a one to one with somebody just on my own cos I don't think that ever happened." (pg. 94)	Health Care Service / Comprehensive Cancer Care Needs		C		F170
Partners identified the provision of written information as useful.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS57
One partner reported that she made regular contact with a charity to build a supportive relationship. Many of the partners referred positively to their experience of attending a support group and the access they had to the urology nurse specialist at these meetings.	Not reported	Social Needs			NS	NS58
Other unmet needs included practical support with shopping and support for themselves.	Not reported	Physical / Daily Living Needs			NS	NS59
The monitoring of patients was re-assuring for their partners, some of whom took a leading role, developing a better understanding of the process and requesting tests on behalf of the patient.	Not reported	Family Related Needs			NS	NS60

Author: Tanner et al, 2011

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
They reported feeling secure with and completely confident in the medical care their partner received and had faith that their partner's cancer would be cured.	"great time" (pg. 155) "wonderful experience" (pg. 155)	Health Care Service / Comprehensive Cancer Care		C		F171
Female partners reported feeling helpless, sad, violated, scared, and "waiting for the next thing to happen."	"I often feel as if I'm sitting on a block of ice that is slowly melting, and when it melts my husband's cancer will be back—if it ever really was gone." (pg. 155)	Psychological / Emotional Needs	U			F172

Many talked about living in a state of silent suffering, watching as their partners suffered, and refraining from sharing their own experiences in an attempt to not hurt their partner’s feelings.	“More and more we are tied together as the husband’s health deteriorates and he becomes more dependent on his wife. A wife suffers silently as she watches a beloved husband lose his health and gradually his independence. I don’t suppose there is much of a way to gauge that kind of pain. It is of the hearth. It definitely saps the pep out of a girl.” (pg. 155-156)	Psychological / Emotional Needs	U			F173
Not reported (Emotions)	“I detest cancer. I watched it slowly consume my mother. The fact that my husband is now fighting it makes me feel old and vulnerable.” (pg. 156)	Psychological / Emotional Needs		C		F174
Not reported (Emotions)	“I worry about my husband, with his PSA going up. What can we do for him, to help him? How bad his pain will be if there is medicine that could help him.” (p. 156)	Psychological / Emotional Needs		C		F175
Not reported (Emotions)	“For some reason I don’t feel as angry as I did—life is just too short to waste it on negative stuff.” (pg. 156)	Psychological / Emotional Needs		C		F176
Outside relationships became harder to maintain as a partner’s illness limited the ability to continue usual socializing activities.	Not reported	Social Needs			NS	NS61
Women discussed how their lives were totally changed by their partner’s illness or treatment. They reported being unable to maintain their usual couple activities because of their partner’s mental or physical limitations and how things such as travel and socialization with friends were inhibited by their partner’s health problems.	Not reported	Social Needs			NS	NS62
Not reported (Treatment-related issues)	“My husband has a lot of body pain which keeps us from social activities as a couple. . .” (pg. 156)	Social Needs		C		F177
Many women also reported that, overall, they were happy. This viewpoint was maintained in spite of reporting on the additional workload, insecurity about the future, and emotional stress brought on by their husband’s condition. In addition, spirituality, prayer, and being thankful were main threads running through these women’s responses, and many women connected their happiness to their relationship with God.	Not reported	Spiritual Needs			NS	NS63
Not reported (God/spirituality)	“The church is the center of our world.” (pg. 156)	Spiritual Needs		C		F178
Not reported (God/spirituality)	“Because of our connection with God, we are both doing the best we can for our health and putting our trust in God.” (pg. 156)	Spiritual Needs		C		F179
Not reported (God/spirituality)	“I worry every day about losing him but thank God for every day we have together.” (pg. 156)	Spiritual Needs		C		F180
Not reported (God/spirituality)	“I . . . am praying that everything will be all right.” (pg. 156)	Spiritual Needs		C		F181

Frequently, women reported coping with acute health problems or surgeries or dealing with chronic health conditions of their own, and some discussed how they found themselves reliant on their ill partner for care.	"He makes most of the decisions and helps me to take the medicines I need." (pg. 155) "He deals with all the nasty stuff I hand out while I'm in pain". (pg. 155)	Physical / Daily Living Needs	U			F182
Some shared how they found themselves struggling to care for other ill family members or deal with the death of loved ones in the face of their own or their partner's health challenges.	Not reported	Physical / Daily Living Needs			NS	NS64
Women also discussed the need to deal with other life stressors such as being forced to learn new household skills ranging from managing for the family finances to dealing with household repairs.	Not reported	Physical / Daily Living Needs			NS	NS65
Many women recognized the need to maintain life balance by actively striving to continue their regular activities in spite of these lifestyle challenges. This included continuing both leisure activities (eg, belly dancing, lunching with friends) and activities of daily living (eg, getting one's hair done, going to work).	Not reported	Physical / Daily Living Needs			NS	NS66
Humour and patience were helpful tools women used to deal with the physical and personality changes they observed in their partner, as was the focus on fighting the cancer together, and on self-care activities such as dietary changes, new exercise programs, and complementary and alternative therapies.	Not reported	Physical / Daily Living Needs			NS	NS67
Frequently, women reported mourning the loss of a sexual relationship with their partner.	"I do miss my partner's automatic sexual responses as there has always been a terrific chemistry between us as well as tremendous goodwill. We both mourn this loss." (pg. 156-157) "One of the things that is missing in our life is sex. I miss the closeness and good feelings I always felt." (pg. 157)	Interpersonal / Intimacy Needs	U			F183
Women shared feelings of disbelief that this had happened to them, their acceptance of their new reality, their search for alternatives to sexual relations, and an increased focus on intimacy. They also reported a desire to confirm their experiences with others.	"It would be interesting to find out if other people have become impotent." (pg. 157)	Interpersonal / Intimacy Needs	U			F184
Some shared that their partner's diagnosis affected their philosophy of life and that their focus had become more attuned to living an intentional high-quality, love-filled life while enjoying the time they had left together. Others reported living in a state of limbo as they awaited some future event that would indicate a return to "normal."	"We are so looking to that time when we can resume our lovemaking and have a normal life." (pg. 157)	Interpersonal / Intimacy Needs		C		F185
The majority also reported changes in their sex lives ranging from minor inconveniences during sex to complete lack of sexual relations, and most attempts to improve their partner's sexual functioning were unsatisfactory.	"The sex sucks!" (pg. 157) "It's like living with a best friend now." (pg. 157)	Interpersonal / Intimacy Needs	U			F186

	"I have a hard time believing that the radiation and/or cancer can cause this disinterest in me." (pg. 157)					
Some women attributed these sexual changes to advancing age and did not perceive it as a problem, whereas others reported that the lack of a sexual relationship was driving them apart and that they felt as if they were losing touch as time went on.	Not reported	Interpersonal / Intimacy Needs			NS	NS68
Some women reported re-evaluating their relationship in light of the changes experienced in their partners.	"I do not know my husband anymore. He has become a different person. I have to think about my future: to continue like this or be done. Which is worse?" (pg. 157)	Interpersonal / Intimacy Needs	U			F187
They reported feeling betrayed by their spouse's lack of sharing and were reluctant to risk increasing their partner's suffering by talking about personal experiences with them.	"He refuses to discuss his lack of sexual performance or seek medical help. I feel unloved, undesirable, and useless. When I try to discuss this, he feels sorry for himself, ignores or gets angry, and blames me or gets mean." (pg. 157)	Interpersonal / Intimacy Needs	U			F188
Women acknowledged that how they and their partners deal with each other and how they take care of themselves are both important.	"My husband will never be the same person. I believe he gets very frustrated because he can't perform sexually… There is nothing I can do anymore. I already tried to be the perfect wife. It doesn't work anymore… I decided to fill my life with many activities… to help me with it and not to get ill. I take one day at a time, and I love to look after myself. He is what he is, and I have to let him be what he wants to be." (pg. 158)	Interpersonal / Intimacy Needs	U			F189
Not reported (Marriage/children)	"After just celebrating 60 years of marriage, we find we pretty much know what each other is thinking or what we'd like to do." (pg. 156)	Interpersonal / Intimacy Needs		C		F190
Not reported (Relationship issues)	"My husband's cancer has had an impact on our relationship and philosophies of life. It has been the catalyst that smoothes out the bumps in the road of life. What is important has changed and how we live our life every day has become much more positive. The little annoyances of life seem much less important and planning and maintaining a high quality of a love-filled life has become very important." (pg. 156)	Interpersonal / Intimacy Needs		C		F191
Not reported (Sexual issues)	"Even with the use of Viagra, at times it's not possible to have intercourse. This is very hard for both of us since a great marriage must have intimacy in order to survive. He has been so good to see to it that I am satisfied but even then desire for sex has left him. This has been a big adjustment for me because he was always so virile and so easily aroused. I was slower and not as interested in sex as he was, for years. Now it seems the roles have switched; I crave the intimacy that sex brings, and his interest just is not there. He could live without sex!" (pg. 156)	Interpersonal / Intimacy Needs		C		F192
Not reported (Coping)	"I spend time each day doing nutritional research on what studies have been helpful in defeating cancer in lab experiments, realizing that this may not apply to humans but looking for every possible edge to help him defeat the cancer." (pg. 156)	Family Related Needs		C		F193
Author: Walker et al, 2012						

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
The nature of sexual and intimate experiences had to be renegotiated. Often this process included changing the goal of the sexual encounter from orgasm to experiencing other pleasurable sensations.	"We [now] like having nice dinners, we like having a nice bottle of wine. I still like to somehow get involved sexually, even though it doesn't involve intercourse." (pg. 454)	Interpersonal / Intimacy	U			F194
For some this intimacy could not be adequately replicated in any other way. To stop having sex would mean to stop being intimately and emotionally connected. Maintaining sex, despite changes, was the best way for them to maintain intimacy.	"I think it's a part of who you are, to share this with your partner, and maintain it, as best as you can." (pg. 456)	Interpersonal / Intimacy		C		F195
Some were attempting to use oral erectile medications, erectile aids, or toys to restore sexual activities. These methods were appreciated.	"I always touch him when he's touching me. Even if he doesn't get an erection; I still need to feel him. Even though we're playing with a toy, I don't find it enjoyable unless I fantasize that it's actually him." (pg. 456)	Interpersonal / Intimacy	U			F196
Another partner shared how she appreciated being able to focus on touch and physical affection without it always having to turn into something entirely sexual.	"I love the cuddling; I love the touch. I would actually say that that's one of the gifts at this time: there hasn't been the sexual urgency with the reduced testosterone." (pg. 457)	Interpersonal / Intimacy	U			F197
Replacing sex with another valued intimate activity seemed to be a common strategy that allowed them to maintain relational intimacy.	"We can't do this [sex] anymore, but let's find something that we can do to replace that. We try to always have something planned to look forward to, like a little holiday, or going out to a dinner theatre, live music, or something like that. That maybe replaces some of those other activities, but still we get a lot of pleasure and enjoyment out of it." (pg. 457)	Interpersonal / Intimacy	U			F198
A strategy was to consider that sex was no longer a priority (age did not influence this).	"The reason it didn't really affect us that much is because there are other parts to the relationship. That's just one little part of it, and we were able to bypass it." (pg. 457)	Interpersonal / Intimacy	U			F199
Partners often expressed that their relationships had suffered from a loss of expressed affection. Partners usually continued to exhibit affection in the same way they always had, whereas displays of affection became less common from the patient. Without intercourse as a clear indication of attraction – doubt feelings.	"When he does do things to show me, he loves me, it's because I've had to get angry about it. If he just took the initiative on his own, without having to be told." (pg. 457)	Interpersonal / Intimacy	U			F200
Not all reported that ceasing intercourse was accompanied by fewer expressions of affection.	"I was relieved that he still wanted to cuddle, kiss, and tell me he loves me. I thought that if the libido was gone, that all that good stuff would be gone. But it wasn't, so that was great." (pg. 458)	Interpersonal / Intimacy	U			F201
Partners felt a sense of isolation and the imbalance in connection became a significant challenge that affected sense of intimacy. To avoid isolation, the women tended to facilitate conversation, and were particularly persistent in making a conscious effort to engage their partner in discussion.	"I spent a lot of time really trying to get an understanding of what's going on for him, so that I can look back and understand. So that next time it comes up, maybe we cannot go into the same ugly places." (pg. 458)	Interpersonal / Intimacy	U			F202

They indicated that they were embarrassed to have to “ask” for sex, and struggled with the thought that, if they had to ask him to participate, he must view sexual activity as a chore.	“When he does help me out [sexually], I almost feel like I’ve had to ask him, because we’ve had to resort to using a toy now, and I almost feel like I’m being selfish. And I’m worried about us using a toy, like how does that make him feel?” (pg. 459)	Interpersonal / Intimacy	U			F203
Successfully maintaining sex was associated with a shift in who was responsible for initiation.	“I took over the role of initiator, which has been wonderfully freeing for both of us. It has added richness to our intimacy and allowed him “off the hook” to start what he has no inclination for.” (pg. 459)	Interpersonal / Intimacy	U			F204
Several women reported that they felt they were putting in more “effort” than their partners. In many cases, sexual encounters became one-sided.	“I’ve gone through a period of anger about it, where I felt like I was the only one bringing anything to the table. In reality of course, I am. I am the only one bringing anything to the table, but it didn’t stop me from feeling angry about that loss.” (pg. 459)	Interpersonal / Intimacy	U			F205
Some women were uncomfortable with this imbalance.	“I can’t satisfy his needs any longer, so basically what I’m doing is asking him to satisfy me.” (pg. 459) “I’m thinking, he can’t do anything and here I am getting all the pleasure. It’s just for me, and I just think it’s only making him feel worse. It’s just a reminder of what he can’t do.” (pg. 459)	Interpersonal / Intimacy	U			F206
Several women reported that they struggled with an imbalance in pleasure. They expressed a strongly held belief that they should not be the only one receiving sexual pleasure.	“I even felt bad because I want him to enjoy it as much as I do.” (pg. 460)	Interpersonal / Intimacy	U			F207
A new challenge was to cope with their continuing sexual desire that was no longer satisfied or expressed through sexual experiences.	“I don’t. I shut down completely. I just don’t want to, even when he says, “Oh, I’ll, you know, give you an orgasm” or something. I don’t want to, I just, I just…” (pg. 460)	Interpersonal / Intimacy	U			F208
A real challenge existed for the partner in trying to cope with her still present sexual desire. These women described how challenging it was to ignore or disregard their own sexual desire or arousal.	“You have to… learn to put it aside, I guess, and go on. I find that if we, or if I do try to become, well, sexually active, it’s sad because you just, you can’t get anywhere.” (pg. 460)	Interpersonal / Intimacy	U			F209
Without their sexual relationship as evidence, some partners began to doubt that they were still physically attractive to their partner. Some women even reported doubting that their partner was still in love with them.	“There’s times where I could just eat him, I just love him so much. It’s really hard because, I don’t know if he does. I doubt that he’s that close or has the same feelings [toward me]. I doubt it all the time.” (pg. 461)	Interpersonal / Intimacy	U			F210
Those who stopped sexual activity struggled with grief over the loss of a significant part of their relationship. Those who maintained sexual activity were also unable to avoid grief because they grieved over the way sex used to be. Some found that trying to have sex after ADT was too painful and emotionally distressing.	“I find that if we do try to become sexually active, I get very, very, very depressed. It’s a reminder of what you used to have.” (pg. 461) “In my experience of being a wife and a lover, I loved being able to pleasure him in that way. It’s a joy, a wonderful gift. It feels like I’ve stopped being able to be a gift giver. I had to grieve that loss.” (pg. 461)	Interpersonal / Intimacy	U			F211
Not having the indisputable interest indicated by their partner’s sexual advances resulted in the women doubting their attractiveness.	“It’s the fact that I could walk across the room naked, which before would trigger certain things in my husband, most of them delightful to me, but it just didn’t happen anymore.” (pg. 461)	Interpersonal / Intimacy	U			F212

	"I don't feel the same about myself. Before, if you wear something sexy, it would turn him on. Well obviously, I can't turn him on anymore, so you feel different about yourself." (pg. 461)					
Author: Williams et al, 2014						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Women's fears generally diminished as time went by, although a few mentioned fear of recurrence.	"I don't know. I think that—that something is going to get messed up inside and—and revive [the cancer]. I don't know. I get very scared." (pg. 309)	Psychological / Emotional Needs	U			F213
Women worked to present a strong face to their husband. Even after the initial shock, however, women explained the importance of concealing their emotions and showing their husband that they had everything under control.	"I pretended to have a lot of strength to not show him that—that in reality I was going down." (pg. 310) "I got very sad to see him like that, but I tried to be strong and say, "I think that the last thing he wants is to see that someone feels defeated, right?" … I put my pains aside… I had to shower him. I had to change him. I had to help him in all that I could, right?" (pg. 310)	Psychological / Emotional Needs	U			F214
A few women received very little support at all, and these women clearly carried a greater burden than those who were supported.	"When he went back to work, and well, I stayed home by myself. Here, by myself in the hills. And that is how I am daily: by myself from six in the morning until five in the afternoon that he comes home, five thirty. I am by myself here. Can you believe? With nothing to do, just, like the saying goes, thinking only bad thoughts." (pg. 312)	Social Needs	U			F215
The majority of women's fears came with their husband's initial diagnosis. They also described fear of losing their husband.	"It's when you hear the word 'cancer.' Well, you think that, like you are going to lose the person… Well, I thought that if I lost him, it was going to be difficult." (pg. 309)	Spiritual Needs	U			F216
Most indicated that it was essential to trust in God, and firmly believed that God would ensure their husband's recovery.	"No, I had—I had a lot of faith in God that no… I put him in the hands of God so that He could heal him." (pg. 312)	Spiritual Needs	U			F217
Their faith allowed them to use the experience of their husband's cancer as an opportunity to change their life in a positive way.	"I mean, you stop working, you stop a lot of things, and you have rest. And in that you sort of look back and say, I have been doing this, I have been doing that. I mean, it's like God gives you that opportunity to—to think about and to see what is good, what is bad, what you should change." (pg. 312)	Spiritual Needs	U			F218
Women cited anxiety, difficulty, and frustration when dealing with the symptoms and side effects of their husband's disease and treatment, particularly when they were dealing with their own health problems.	"It was difficult… I was sick from having all of those illnesses, and then his problem. Well, I got worse, and… I don't like to see blood… I would wash his parts and I would dry him and put his diapers on him, oh man. I found it difficult with him, but thank God, we got through it. Look now—now he puts his diaper on by himself. Now, well, he can do it, right? But before, I—I would take him by the hand to the bathroom and—and I would clean him, wash him, and I would put his diaper on." (pg. 309)	Physical / Daily Living Needs	U			F219

They often spoke about dietary changes in “we” terms, seeming not to have thought twice about changing their own diet along with their husband’s after his diagnosis.	“When they gave us the news that he had cancer, we started to go walking. The way we cook at home changed a lot. Uh, we added more vegetables, more fruits. Uh, we try to cook with not that much fat.” (pg. 311)	Physical / Daily Living Needs	U			F220
Women generally said that their husband’s erectile dysfunction did not affect them much personally, although many assumed that it would have affected other women.	“It has not affected me at all, sincerely… because I have been a woman that has not been very demanding… Yes, there are women that are affected by it, but… we are different, and we have different ways of acting. And it hasn’t affected me at all because we have been married forty-one years.” (pg. 309)	Interpersonal / Intimacy Needs	U			F221
They did, however, worry about their husband’s reaction to erectile dysfunction and put his feelings first. One described how she used to like being physically affectionate with her husband but stopped because she worried that he would think she wanted to have sex.	Not reported	Interpersonal / Intimacy Needs			NS	NS69
A few also explained how they tried to dispel their own sexual feelings so that they would not increase the impact erectile dysfunction had on their husband.	“And I try to—to dispel some things or some [sexual] desire that I have with other things… Going out to have fun, taking trips, and perhaps relaxing and going to the beach, who knows? So I try to understand and get through things, right?” (pg. 310)	Interpersonal / Intimacy Needs	U			F222
Women mentioned attempting any sexual alternative to vaginal intercourse, although others described refocusing their intimate life on holding hands or cuddling.	“He tried, and he feels that he finishes, but he expects it to be like it was before the operation… So that he won’t feel bad, I tell him that perhaps over here, through the rectum he can maybe do it. But no, I know that—I don’t—no.” (pg. 310)	Interpersonal / Intimacy Needs		C		F223
Women often felt that the experience had brought them closer to their husband and improved their relationship.	“We have always had good communication since we got married. Everything has been good with our relationship, but I think that… it did improve a little more. We communicate a little more. For anything, we are both there, something that before well, maybe we left something out, right?” (pg. 312)	Interpersonal / Intimacy Needs	U			F224
These women, whose relationship was (often) in bad shape before their husband’s diagnosis, saw their situation worsen.	“different, because there is nothing anymore, there is nothing, nothing, nothing of nothing. No affection not even a hug, not even a—nothing… As if you were just living with someone, everything is cold.” (pg. 312)	Interpersonal / Intimacy Needs	U			F225
They worked to manage the reactions of their family members through showing that same strong front.	“I talked to [my children] since the beginning when they first told us. And I always told them, look, we are all going to support him. We are going to take it like something normal and talk to him. “We are with you, and we are going to fight, and we are going to help you fight.” …So, he has that support.” (pg. 310)	Family Related Needs	U			F226
Some women relied primarily on family members of their own generation, such as their siblings and siblings-in-law, whereas others relied on children or even grandchildren for support.	“More than anything, the company of my siblings… of my family members. Well, I’d always talk with them even if it’s over the phone. But I’d also be talking to them as they encouraged me more also.” (pg. 311) “Well, more than anything over the phone [laughs]. Yes, over the phone. Sometimes every third day I am calling my daughters in Tijuana, and then here in Santa Paula I have a son… He understands me as well.” (pg. 311)	Family Related Needs	U			F227

	“You know what has helped us? I think that if the two of us were alone we’d be depressed, but my small grandchildren are here. They come and make noise. They sleep here. In other words, they keep us active. “Take us here, Grandpa!” And there goes Grandpa with them, taking them where they want. All of that helps one forget things.” (pg. 311)					
Some women experienced moments when they needed support and did not receive it, often in the early stages of treatment.	“I did have the necessity to—to share the load, right? … But well, there was nobody [at the hospital]. Nobody spoke Spanish… [crying] I was so desperate that the lady who was there… she turned around and she took out three sheets from her notebook. She gave them to me, and she gave me a pen, and I started to fill it out, and it relaxed me a little bit, right?” (pg. 312)	Family Related Needs	U			F228

Author: Wittmann et al, 2014

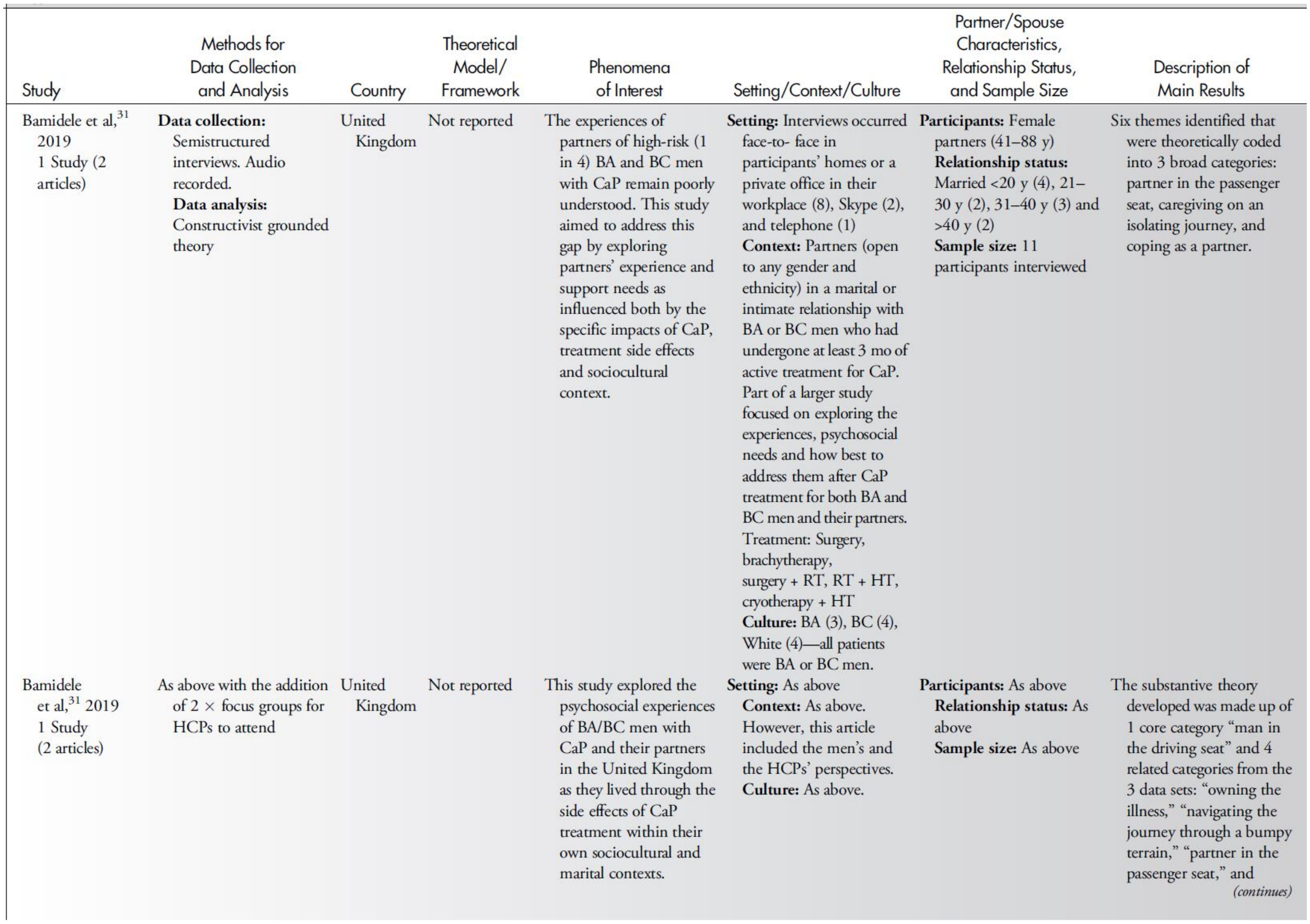
Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Partners wished for some form of counselling or peer support, although not all were sure they would have participated. Two partners said they did not want to discuss personal matters with others.	Not reported	Barrier			NS	NS70
While wishing for support, partners were unsure of what they needed and whether they would use it.	Not reported	Barrier			NS	NS71
Cancer centres survivorship program provided support. The study facilitated conversation about sex.	“I think that was a good thing that we did the study because you get all this brought out.” (pg. 2513)	Facilitator	U			F229
Some female partners, including a pre-menopausal one, reported lower sexual desire than their male partner. Despite menopause, some partners retained robust desire.	“I don’t know whether I’m just sensual or whether a lot of women are like me… I mean I’m 70 but I still enjoy sex” (pg. 2511)	Interpersonal / Intimacy Needs	U			F230
Partners acknowledged sexual losses and decrease in frequency but were more philosophical. Thus partners, while also acknowledging sexual losses, were less distressed than the patients.	“…you can’t get discouraged because sometimes it works, sometimes it doesn’t….” (pg. 2512)	Interpersonal / Intimacy Needs		C		F231
Partners thought that good communication and ongoing sexual activity were more important that erectile function.	“I think you just have to, um, let the partner know that, um, you know the strength or length of an erection is not the most important thing, that the most important thing is that you can be intimate with one another and give each other pleasure, um, and just feel closeness and love.” (pg. 2512)	Interpersonal / Intimacy Needs	U			F232
Partners that communicated about sexual changes, challenges and worries about performance found that communication helped focus away from worry about erections and performance.	Not reported	Interpersonal / Intimacy Needs			NS	NS72
In couples that were not connecting sexually, two partners felt unable to pursue sexual activity out of sensitivity to the men	Not reported	Interpersonal / Intimacy Needs			NS	NS73

who withdrew because of immense sadness about the loss of erectile function.						
Several described additional obstacles such as relationship problems.	"I've often told him before (laugh) it really does mean a lot, how you also treat me out of the bedroom." (pg. 2512)	Interpersonal / Intimacy Needs	U			F233
Most, no matter how frustrated with the current status of their sexual relationship, planned to continue to work on sexual recovery – 2 patients and 2 partners anticipated adapting to a relationship without partnered sex.	Not reported	Interpersonal / Intimacy Needs			NS	NS74
More than half had been responders in sexual activity pre-op; now they thought they should initiate as they saw the men struggling with worry about performance.	"…all of the sudden those roles have changed where I should be the more aggressive one, and now, you know, he's to be the passive one…so I don't do it, you know…old habits are hard to break." (pg. 2513)	Interpersonal / Intimacy Needs	U			F234
All partners saw their role in the patients' recovery of erections as providing emotional support and encouraging men to engage in rehabilitation activities.	"Especially in the beginning…. I felt like I was almost nagging him to, you know, 'practice'." (pg. 2513) "I'd like to think that he recognizes that I'm there for him no matter what." (pg. 2513)	Interpersonal / Intimacy Needs	U			F235
All partners attempted to resume sexual relationships by being available. Post-menopausal diminished libido did not affect this attitude of wishing to be helpful sexually.	"My role is to be there when he wants to have intercourse or wants to try." (pg. 2513)	Interpersonal / Intimacy Needs	U			F236
Partners did not always find their sexual interest welcome. They believed that the men were too worried about performance to respond. This left partners with a sense of uncertainty about how to fulfil their sexual role.	"I did actually speak to him and said, 'You know, even if you can't make love, just remember that the touching is still part of it.' I mean, um, I have in the past ruffled his hair at the back and I'll put my hand on his knee if we sit down and things like this, and he tended to drift away totally." (pg. 2513)	Interpersonal / Intimacy Needs	U			F237
All partners said that recovering sexual relationship was important to them – reported having had unmet sexual needs during the recovery.	"I would like him to be happy and, you know, I have needs. I was not as sexually active as he was…but I yeah, it was very important." (pg. 2513)	Interpersonal / Intimacy Needs	U			F238
Author: Wootten et al, 2014						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Access to support and knowledge about where to ask for support was also identified by partners as a significant problem.	"I definitely think …somewhere in those early stages … [if someone] suggested …seeing someone or seeing a counsellor it would have made a big difference for me… for both of us." (pg. 1255)	Health Care Service / Comprehensive Cancer Care Needs	U			F239
Partners from couples who were experiencing higher emotional distress found it difficult to feel confident to ask questions of the doctors and were often reluctant to express their concerns.	"I'm not going to ask things which is probably another thing we need to address, the protocol of what wives can know …so you just kind of think 'should I say something now? No maybe I'll do it when, or maybe tomorrow morning after we've got some sleep." (pg. 1254)	Health Care Service / Comprehensive Cancer Care Needs	U			F240
The type and variety of information obtained appeared to be directly related to the level of emotional well-being.	"I really didn't think there was enough information for me about… um… expectations around recovery and what I could do for him or to help him or how I can be supportive." (pg. 1254)	Health Care Service / Comprehensive Cancer Care Needs	U			F241

Partners reported feeling the need to be positive and not show their own emotions.	“He said you know ‘it’s alright for you, you’re not going through it’ and I then had to sort of try to get it across to him ‘you don’t seem to understand I am trying to keep so calm and so cool and not let you know I just wanted to fall down in a heap but you’re not allowed to do that you don’t do that you know’ but the thing is how do you find that balance.” (pg. 1254)	Psychological / Emotional Needs	U			F242
Partners spoke about feeling constantly anxious, worried, and unable to openly discuss their concerns which, in turn, let to increased anxiety and isolation.	“He thinks it’s just his battle that’s what I find really difficult’ …I’ve found it a very isolating experience.” (pg. 1255)	Psychological / Emotional Needs	U			F243
This role of responsibility was identified by many partners as resulting in feeling worn out by the experience but unable to take time out for themselves.	“I’ve been very practical in my support…doing the dishes or doing something like that or keeping the house running.” (pg. 1255)	Physical / Daily Living Needs		C		F244
This role of responsibility was identified by many partners as resulting in feeling worn out by the experience but unable to take time out for themselves.	Not reported	Physical / Daily Living Needs			NS	NS75
In couples in which the man did not cope well, partners were distressed, and the relationship was impacted by a lack of open communication and/or sexual intimacy.	“He became totally single minded. In my opinion feelings just closed up… went to a separate room and we’re still in separate room.” (pg. 1254)	Interpersonal / Intimacy Needs	U			F245
Some couples found that even physical touch triggered significant emotional distress.	“It [is] harder to do something [hug, or touch] that reminds you how terrible your loss is.” (pg. 1254)	Interpersonal / Intimacy Needs	U			F246
The impact of the change in sexual functioning on the relationship was challenging for most partners. Minimisation of the loss associated with the sexual changes experienced also appeared to prevent open communication.	“I heard him say to someone “oh impotence doesn’t worry me”, which absolutely floored me…I thought he didn’t care about us not being intimate anymore.” (pg. 1255)	Interpersonal / Intimacy Needs	U			F247
The cost of erectile function aids (such as Viagra) and attitudes to sexual aids were stated as barriers.	Not reported	Interpersonal / Intimacy Needs			NS	NS76
Some partners were surprised at how long recovery of sexual function took and thought this should be more explicitly communicated before treatment.	Not reported	Interpersonal / Intimacy Needs			NS	NS77
Many partners also commented that they were not prepared for the adjustment required and would have benefited from some guidance in this area.	Not reported	Interpersonal / Intimacy Needs			NS	NS78
The majority of partners reported feeling a sense of loss of intimacy at some level, and for most, this was not related to sex, per se, but rather to the loss of closeness in the relationship.	“Literature infers you can dodge the bullet on ED [but there will be a] level of damage – [literature] needs to be more explicit that from patients point of view surgery can save [you] from cancer but [can] bugger their lives.” (pg. 1255)	Interpersonal / Intimacy Needs		C		F248
Some partners spoke about feeling subtly directed by the man to not talk about the CaP experience and a perception that the CaP was his concern and not theirs.	“I found my husband made it more difficult for me at the stage when he found out he’d had prostate cancer he wouldn’t tell anyone, I couldn’t tell anyone, didn’t want to tell boo which made it really difficult.” (pg. 1255)	Family Related Needs	U			F249

Abbreviations: Healthcare Professional (HCP), Prostate Cancer (CaP),

Supplementary Table 1: Characteristics of the Included Studies



Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
Bamidele et al,[31] 2019 1 Study (2 articles)	**Data collection:** Semistructured interviews. Audio recorded. **Data analysis:** Constructivist grounded theory	United Kingdom	Not reported	The experiences of partners of high-risk (1 in 4) BA and BC men with CaP remain poorly understood. This study aimed to address this gap by exploring partners' experience and support needs as influenced both by the specific impacts of CaP, treatment side effects and sociocultural context.	**Setting:** Interviews occurred face-to- face in participants' homes or a private office in their workplace (8), Skype (2), and telephone (1) **Context:** Partners (open to any gender and ethnicity) in a marital or intimate relationship with BA or BC men who had undergone at least 3 mo of active treatment for CaP. Part of a larger study focused on exploring the experiences, psychosocial needs and how best to address them after CaP treatment for both BA and BC men and their partners. Treatment: Surgery, brachytherapy, surgery + RT, RT + HT, cryotherapy + HT **Culture:** BA (3), BC (4), White (4)—all patients were BA or BC men.	**Participants:** Female partners (41–88 y) **Relationship status:** Married <20 y (4), 21–30 y (2), 31–40 y (3) and >40 y (2) **Sample size:** 11 participants interviewed	Six themes identified that were theoretically coded into 3 broad categories: partner in the passenger seat, caregiving on an isolating journey, and coping as a partner.
Bamidele et al,[31] 2019 1 Study (2 articles)	As above with the addition of 2 × focus groups for HCPs to attend	United Kingdom	Not reported	This study explored the psychosocial experiences of BA/BC men with CaP and their partners in the United Kingdom as they lived through the side effects of CaP treatment within their own sociocultural and marital contexts.	**Setting:** As above **Context:** As above. However, this article included the men's and the HCPs' perspectives. **Culture:** As above.	**Participants:** As above **Relationship status:** As above **Sample size:** As above	The substantive theory developed was made up of 1 core category "man in the driving seat" and 4 related categories from the 3 data sets: "owning the illness," "navigating the journey through a bumpy terrain," "partner in the passenger seat," and

(continues)

Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
							"HCPs recognizing the difference."
Boehmer and Babayan,[32] 2004	**Data collection:** Individual face-to-face interviews (in a few cases telephone interviews. Audiotaped and transcribed. **Data analysis:** Grounded theory	USA	Not reported	To present men's and their female partners' thoughts about ED that may result from treatment. The focus of this analysis was on understanding men's and their female partners' reaction to potentially losing sexual capacity.	**Setting:** Not reported **Context:** Men diagnosed with PCa and their partners (female only) were interviewed separately. Interviews occurred as soon as patients had made their choice but before treatment had commenced. Aside from 2 men with prior history of cancer, this had been their first diagnosis. 13 of 21 men identified their partner as their "trusted other" and therefore these were the females included in the analysis. Treatment: surgery, brachytherapy, EBRT **Culture:** White (11), African American (2)	**Participants:** Female partners (average age, 55 y) **Relationship status:** Partnered between 2 and 43 y (average of 25 y). **Sample size:** 13 participants interviewed (21 men with PCa interviewed).	Among women, a dominant theme was the existence of other relationship dimensions, while being aware about the gravity of his feelings about potency. Both groups were worried about the impact of ED on their relationship. (Men's perspective consistently included the theme that ED threatened an important aspect of their identity and their reactions to the possibility of losing their sexual capacity due to PCa-related treatment was connected to their current level of sexual function).
Bruun et al,[33] 2011	**Data collection:** Semistructured interviews (at 2 time points), tape recorded and transferred to a program that facilitates analysis of sound data **Data analysis:** Phenomenological hermeneutic framework (Ricoeur's narratives and interpretation)	Denmark	Not reported	Life with incurable PCa from the perspective of the female partner with the intent of better understanding female partners' everyday experiences.	**Setting:** Interviews occurred in homes (4) or at hospital (1). **Context:** Partners (female only) of men recently diagnosed with incurable PCa. Interviewed 3 and 10 mo after the male partner diagnosis. Patients were not interviewed. Treatment: Not reported	**Participants:** Female partners (54–73 y) **Relationship status:** married (4) and cohabitating (1). All had children. **Sample size:** 5 participants interviewed.	One main theme: Coping with life Three subthemes: Aspects of loneliness (imposed and self-inflicted), informal care, and the significance of relationships.

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
					Culture: Danish (Danish-speaking)		
Dieperink et al,[34] 2016	**Data collection:** Participated in 1 of 2 focus groups (male/female split). Semistructured, recorded, and transcribed verbatim **Data analysis:** Giorgi's phenomenological approach	Denmark	Not reported	(1) Explore the lived experience of men and their partners living with sexual problems and the impact of this on the marital relationship after RT and ADT for PCa. (2) Explore the couple's experience and the role of a structured rehabilitation program for couples after men have undergone radiotherapy with ADT.	**Setting:** Rehabilitation Centre Dallund (following a 4-d residential stay) **Context:** PCa survivors and their partners (women only) were interviewed via focus groups at the end of a 4-d residential rehabilitation program. Focus for the rehab program was sexual problems, cohabitation, and intimacy. Treatment: All men were treated with ADT (for 6 mo to 3 y), all but 1 received RT with curative intent. **Culture:** Danish Caucasians	**Participants:** Female partners (58–74 y) **Relationship status:** Together for several years with grown up children (7), 1 elderly couple known each other <5 y (and had been married before). **Sample size:** 8 couples (therefore 8 women in the partner focus group).	Focus group interviews revealed 3 themes: negative impact of sexual dysfunction on the relationship; other physical and psychological consequences of late adverse effects; communication issues and partner feelings of frustration Rehabilitation program revealed 4 themes: importance of peer support; importance of time and space for reflection; improved communication; optimism after rehabilitation.
Ervik et al,[8] 2013	**Data collection:** In-depth interviews, tape recorded and transcribed verbatim **Data analysis:** Phenomenological hermeneutic framework	Norway	Not reported	To explore how the daily life of female spouses is affected by their husband's PCa	**Setting:** Interviews occurred in spouses' homes (8) or at university hospital (1) **Context:** Spouses (female only) of men receiving potential curative treatment for PCa within the previous 4 y. Patients were not interviewed. Treatment: RP (+/− additional endocrine therapy or RT); RT alone **Culture:** Not reported	**Participants:** Female spouses (52–68 y) **Relationship status:** married between 23–48 y (8) or <5 y (1) **Sample size:** 9 participants interviewed	Four themes: Strong and optimistic versus vulnerable and overstrained, maintaining a partner's sense of manhood, being on the sideline, and the need for relationships outside the immediate family.
Evertsen and Wolkenstein,[35] 2010	**Data collection:** Focus groups (observed by independent note-	USA	Caring for Patients with Cancer	To begin to explore the interaction of the female partner with the	**Setting:** Focus groups were conducted at the clinic where the male patients	**Participants:** Female partners (47–77 y) **Relationship status:**	Three main themes: more support (validation, information, emotional

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
	taker), audiotaped and transcribed. **Data analysis:** Framework approach		(modification of Kolb model)	patient's physicians (primary care and urologist) and her support needs associated with treatment of and recovery from PCa	were receiving treatment **Context:** Partners (female only) of patients diagnosed with PCa over the past 2 y. Patients were not interviewed. Treatment: Surgical PCa treatment prior to focus groups **Culture:** Non-Hispanic/White (12); Black (1); unknown (1)	Married (13) **Sample size:** 14 participants divided into 2 focus groups (7 per group).	support), role of physician (transfer of care), partners' relationship changes (support, primary communicator, and caregiver).
Feltwell and Rees,[36] 2004	**Data collection:** Mini focus group and 8x couple interviews. Audio taped and transcribed in full **Data analysis:** Theme analyzed using iterative process	United Kingdom	Not reported	To explore in depth the rich views and experiences of men with PCa and their partners concerning the information-seeking and information-avoiding behaviors of partners	**Setting:** Focus group—not reported Couple interviews—participants own homes **Context:** Men and their partners (female only) were interviewed. Number of months since men's diagnosis ranged from 20 to 61 mo. Treatment: HT, watchful waiting, RT. **Culture:** White	**Participants:** Female partners (age range not reported) **Relationship status:** Married **Sample size:** 6 female participants as part of a couple. Mini focus group n = 4 Couple interviews n = 8	Three related themes: Partners' information-seeking behaviors, partners' information-avoiding behaviors, and the conflict between seeking and avoiding information.
Harden et al,[37] 2006	**Data collection:** Semistructured interview. Tape recorded and transcribed verbatim. **Data analysis:** Preliminary coding and theme development.	USA	Family, Stress, Adjustment, and Adaptation Model (McCubbin)	To examine the experiences of men with PCa and their partners according to their life cycle cohort: 50–64 y (late middle age), 65–74 y (young-old) and 75–84 y (old-old), using a life span developmental perspective.	**Setting:** Couples were interviewed in their own home, or other location of the couple's preference **Context:** Men and partners (female or male) were interviewed together. Three different age groups represented (50–64 y, 65–74 y, and 75–84 y). Partners didn't necessarily fall into the same age category.	**Participants:** All partners were women (age range of partners not individually reported) **Relationship Status:** Married more than 20 y on average **Sample size:** 15 couples (15 men and 15 partners —5 men in each age category).	Three general themes emerged: Couples' daily lives, their dyadic and family relationships, and developmental issues.

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
					Attempts made to equally represent different phases of illness in each cohort (1) newly diagnosed with localized disease—2–4 mo following RP or EBRT (2) biochemical recurrence—1-3 mo after having 2 consecutive confirmed rises in PSA levels (3) advanced phase—1–3 mo after clinical evidence of recurrence or continued progression of disease. Treatment: Not reported **Culture:** 14 men and 14 women Caucasian. One man and 1 spouse (2 different couples) were Native American		
Ka'opua et al,[38] 2005 1 Study (2 articles)	**Data collection:** 2 waves of semistructured interviews (at 6-mo intervals). Audio taped and transcribed verbatim **Data analysis:** Grounded theory and content analysis	USA	Not reported	This study describes elderly wives of PCa survivors' perspectives of adaptation to the enduring challenges of PCa survival and considers their experience in the context of ethnicity.	**Setting:** all but 2 participants were interviewed in their own homes **Context:** Elderly API wives (female only) whose husbands survived ≥5 y beyond initial diagnosis of PCa. Mean years since diagnosis was 8.3 y. Patients were not interviewed. Treatment: RT, RP, Combination of treatments	**Participants:** Elderly API wives (60–86 y) **Relationship status:** Married >45 y (22). Others not reported. **Sample size:** 26 participants interviewed (38 initially interviewed however, the 12 White participants were not included in the analysis)	Continuous learning was the most common phenomenon as reflected in 4 types of adaptive work: involvement in husband's health, affirmation of the marital bond, normalization of adversity, and participation in personally meaningful acts.

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
					Culture: Native Hawaiian (3), Chinese (7), Filipino (3), Japanese (13), White (12)—not included in the analysis		
Ka'opua et al,[39] 2007 1 Study (2 articles)	As above.	USA	Discusses stress-appraisal-coping framework	To identify wives' challenges at the nexus of long-term PCa survivorship and aging, describe the function of SBR (spiritually based resources) in coping, describe common themes in adaptation among wives using SBR.	**Setting:** Interviews were conducted in locations convenient to the participants **Context:** Wives (female only) of elderly PCa survivors. Mean years since diagnosis 8.5 y. SBR use was only explored if women initiated the discussion of spirituality or religiosity. Patients were not interviewed Part of a larger survey investigating quality of life among long-term (>5 y) PCa survivors. Treatment: All but 1 husband received some type of treatment. Either RT, surgery, or both. **Culture:** All US citizens—White (8), Japanese (8), Chinese (6), Filipina (3), Native Hawaiian (3)	**Participants:** Wives (55–86 y) **Relationship status:** Married but not specifically reported **Sample size:** 28 participants (from the 38 enrolled) who reported SBR use.	Although wives' spiritual beliefs were rooted in diverse traditions, common themes in SBR use were detected: An embracing spirit was the overarching theme, as characterized by acceptance of change, adversity as opportunity for growth, and proactive coping. SBR facilitated adaptation in 4 core areas: marriage preservation and couple intimacy, personal growth, and continuous learning, health-related attitudes and behaviors, and community connections.
Kelly et al,[40] 2015	**Data collection:** In-depth interviews. Transcribed in full. **Data analysis:** Coding, categories and overarching themes.	United Kingdom	Not reported	To determine the impact of treatment for PCa on intimacy and sexual expression/relationships from the perspective of couples	**Setting:** Interviews carried out in participants' homes **Context:** Men and partners (same-sex couples included) were interviewed either as couples or on their own,	**Participants:** Female and male partners (age range of partners not individually reported) **Relationship status:** Not reported **Sample size:** 8 partner	Four categories: Social influences and language used to describe the loss or recovery of sexual activities, discussing sexual activity with clinicians, the clash of

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
					depending on preference. Men had completed treatment at least 2 y prior to minimize short-term treatment effects. Treatment: EBRT, Surgery or ADT **Culture:** White British (with 44% from minority ethnic backgrounds—Greek, African Caribbean, Chinese, North African, and Filipino)	participants (6 couples interviewed together; 2 couples interviewed individually).	individual versus couple paradigms of PCa recovery, and the re-integration of sexual activities into the relationship.
Pinks et al,[16] 2018	**Data collection:** 3 × 2 h focus groups followed by 2 × 1 h telephone interviews conducted over 3-mo period. Semistructured interviews recorded and transcribed verbatim. **Data analysis:** Thematic analysis	Australia	This area of research was not bound by theoretical frameworks.	Limited partner research exists. This study aimed to address this gap in the literature by gathering data directly from partners and exploring a deeper understanding of their experiences of PCa survivorship to help inform healthcare service providers.	**Setting:** not reported **Context:** Intimate or married partner (open to both female and male partners) of a man whose initial PCa treatment had been completed at least 12 mo prior to the study commencement. Treated for localized PCa. Patients were not interviewed. Treatment: RP, RT, HT and other treatments. **Culture:** Caucasian	**Participants:** Female partners (48–88 y) **Relationship status:** relationships ranged between 3–67 y. **Sample size:** 16 participants Each focus group (3) comprised of 4–5 participants. Interviews (2) conducted via phone for those unable to attend.	Five salient themes: emotional caregiver burden, not knowing what to expect, suffering in silence, grieving the loss of sex and intimacy, and the invisible victim of PCa.
Primeau et al,[41] 2017	**Data collection:** Exploratory purposive semistructured interviews. Recorded and transcribed verbatim. **Data analysis:** Framework analysis	United Kingdom	Model of Consultation for Prostate Cancer Care	To explore the experiences of patients with metastatic PCa and their partners/caregivers, as well as the interprofessional team, with a nurse-led multimodality	**Setting:** Interviews conducted in participants' homes or in a cancer care center. **Context:** Men affected by metastatic PCa, their partners/caregivers (gender not specified) and INT members were all	**Participants:** Partners/caregivers. Gender not specified (62–77 y) **Relationship status:** Not reported **Sample size:** 7 participants interviewed	Standard Group: Themes related to physical, psychological/emotional, intimacy/sexual, patient/clinician communication unmet supportive care needs emerged. Intervention: Themes included being listened to

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
				supportive care intervention	interviewed. Qualitative component of a feasibility RCT comparing standard care to ThriverCare intervention. Treatment: ADT **Culture:** Not reported		by someone who could facilitate emotional expression, provision of individually tailored information and receiving practical help and evidence-based advice for managing the consequences of cancer and its treatment.
Rossen et al,[42] 2016	**Data collection:** Semistructured interviews (but in all cases the spouses ended up having an open dialogue). Digitally recorded and transcribed verbatim **Data analysis:** Grounded approach through constant comparative analysis	Denmark	Not reported	To explore how the PCa diagnosis and the participation in their partner's behavioral lifestyle intervention influenced the spouse's life and relationship with their partner and how they handled the situation	**Setting:** Interviewed alone in their own home (7) or at the Danish Cancer Society (1) **Context:** Spouses (gender criteria not specified) of men with low risk, early-stage PCa. Patients were not interviewed. The men had completed a 6-mo intervention of the NILS an education program on vigorous activity and healthy diet, including high intake of whole-grain rye. Spouses were encouraged to attend all meetings. Treatment: Active surveillance **Culture:** Danish	**Participants:** Female spouses (55–68 y) **Relationship status:** Not reported **Sample size:** 8 participants interviewed	Three main themes (with subthemes): (1) Feeling insecure—lack of information, anxieties (2) Coping—Seeking information, setting information aside, active support, communication (3) Feeling reassured—active support, confidence/hopefulness, communication
Sanders et al,[43] 2006	**Data collection:** focus group (comprised 3 × 30-min segments) **Data analysis:** Not reported	USA	Not reported	Couples (surviving PCa) experiences and concerns regarding intimacy in their relationships	**Setting:** Not reported **Context:** Focus group comprised of couples (partner gender not specified) who were survivors of PCa, with	**Participants:** Women (38–75 y) **Relationship status:** Not reported **Sample size:** 10 participants	Findings suggested that men and women think and respond differently to intimacy and relationship challenges that occur as a result of PCa diagnosis,

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
					treatment completed in the last 1.5–8 y. Focus group was divided into 3 segments. To describe experiences (*a*) as couples, (*b*) individual men and women in concurrent break out groups, (*c*) couples regarding current intimacy and relationship needs. Treatment: RP, Proton beam RT +/− EBRT. **Culture:** 9 couples reported ethnicity as White.		and treatment. Healthcare providers must consider the relationship and intimacy needs that are unique to men, women, and couples.
Sinfield et al,[44] 2008	**Data collection:** Semistructured interviews. Audio-taped and fully transcribed. **Data analysis:** Framework approach (thematic analysis)	United Kingdom	Not reported	To gain an in depth understanding of the experiences of care of men with PCa and their partners	**Setting:** Interviews conducted in patients' own homes. **Context:** Men tested or treated for PCa in the last 6 mo and their partners (gender not specified) were interviewed. Treatment: newly diagnosed, yet to be treated, active monitoring (no treatment), curative (RP or RT+/− HT), or stabilizing treatment (HT) **Culture:** White (8), Afro-Caribbean (1), South Asian (1)	**Participants:** Female partners (age range not reported) **Relationship status:** Not reported **Sample size:** 10 participants	Although there was no widespread dissatisfaction with care, patients reported problems throughout care. The 2 main problems were that throughout care patients' and partners' information needs were often not identified or met, and patients' preferred role in decision-making about testing and treatment was not explored.
Tanner et al,[45] 2011	**Data collection:** 2 × open-ended questions on 2 × longitudinal surveys.	USA	Not reported	To understand the effects of PCa on the female partners of PCa patients	**Setting:** Surveys sent out to participants' homes **Context:** Part of larger longitudinal study over	**Participants:** Female partners (average age, 65 y) **Relationship status:** not reported.	Three overarching themes: coping with life in the face of cancer, encountering difficult emotions related

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
	Data analysis: Content/ descriptive analysis (grouped into categories according to similarity of content)				8 y. Men, who were survivors of PCa and their partners (female only) completed surveys biannually for the first 1.5 y and then annually. 2 open-ended questions were embedded in the surveys to collect female partners' perspective. Treatment: not reported **Culture:** White (87%). No further data reported.	**Sample size:** 113 women (364 women enrolled in larger study.)	to partner's illness, and learning to live with relationship changes
Walker and Robinson,[46] 2012	**Data collection:** Unstructured open-ended interviews. Audio-recorded and transcribed verbatim **Data analysis:** Grounded theory	Canada	Not reported	To describe the sexual struggles that couples encounter when attempting to adapt sexually to ADT	**Setting:** Not reported **Context:** Men and their intimate partners (female only) were interviewed as couples. Men had been on ADT for a minimum of 3 mo and were not currently receiving other treatments. Time since diagnosis (8 mo to 15 y), time on ADT (4 mo to 3 y). Treatment: ADT only **Culture:** Not reported	**Participants:** Female partners (32–82 y) **Relationship status:** married 1 mo to 60 y (16), dating 1–5 y (2) **Sample size:** 18 heterosexual couples (therefore 18 female partners)	Three categories of sexual struggle were identified: Adjusting to changes to sexual relationship (changes to sex, fatigue, and absence of sex) Nonmutuality (expressing affection, connection/withdrawal, willingness to engage sexually, initiation of sex, his libido, experience of pleasure, and her libido Attitudes and perceptions (doubt, grief, decreased self-esteem, and negative attitudes toward sex.
Williams et al,[47] 2014	**Data collection:** In-depth, semistructured telephone interviews at 3 time points (average time between baseline and T3 was 10 mo). Audio recorded and	USA	Not reported	To describe the experiences of low-income Latina's longitudinally as their husbands recovered from RP for PCa, as well as to develop a	**Setting:** Telephone interviews **Context:** Men and partners (gender not specified) were recruited from a longitudinal survey. Interviews with	**Participants:** Female partners (36–63 y) **Relationship status:** Not reported **Sample size:** Recruited 28 (10 lost to follow-up at	Found an overarching process of normalization across all time points, with some themes: Working against normality—feelings and changes that that

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
	transcribed verbatim. **Data analysis:** Coding, categories and overarching themes.			framework for understanding the strategies they used when caring for their husbands and coping with his illness and its side effects.	patients and partners were conducted separately (in Spanish). Only partner results reported in this article. Patients had a RP within the previous 6 mo. Treatment: RP **Culture:** Latino (Mexico, Central America, and South America). Had lived in US between 1 and 40 y.	T2 and 10 lost to follow-up at T3) = 8.	challenged women's feelings of normality. Working toward normality—women's efforts and outside influences working toward that sense of normality.
Wittmann et al,[48] 2014	**Data collection:** Interviews. Digitally recorded and transcribed verbatim **Data analysis:** Grounded theory iterative process	USA	Grief theory (biopsycho-social)	Partner sexual function has been viewed as a factor in men's erectile function recovery after prostatectomy for PCa. However, patients' and partners' perceptions on the role of the partner in couples' sexual recovery has not been studied. We wanted to understand those perceptions and to see whether their perceptions were congruent.	**Setting:** Interviews conducted in a Midwestern academic cancer center **Context:** Men and their partners (open to male or female) were interviewed separately. 9 Men had ED, 6 female partners were post-menopausal, and the male partner had post-prostatectomy ED. Mean time since surgery was 14.3 mo for men (13. 6 mo for partners) Treatment: Surgery for localized PCa. One patient required additional RT. **Culture:** Not reported	**Participants:** Male and female partners (mean age 58.3 y). **Relationship status:** Relationships averaged 30-years in length. **Sample size:** 9 participants (7 females as part of a couple, 1 × male as part of a couple and 1 × female partner alone).	Three related themes emerged: Couples' perceptions of the overall sexual recovery of the couple at the time of the study, patients' perception of the importance of the partners' emotional and logistical support as well as interest in sex, and partners' desire to be fully supportive of the men but finding their role complicated and sometimes difficult to fulfill.
Wootten et al,[5] 2014	**Data collection:** Semistructured Focus groups recorded and transcribed verbatim. One structured individual interview	Australia	Not reported	To explore the experiences of partners of men diagnosed and/or treated for CaP to better understand the impact of CaP on the partner	**Setting:** not reported **Context:** Partners (male or female) of men diagnosed and/or treated for PCa 6 mo to 3 y prior to study commencement.	**Participants:** Female partners (43–76 y) **Relationship status:** Intimate spouse or partner **Sample size:**	6 main themes: Influence of a man's response to PCa on the partner; need to be involved in treatment and medical decision making; supporting a man who is

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Study	Methods for Data Collection and Analysis	Country	Theoretical Model/ Framework	Phenomena of Interest	Setting/Context/Culture	Partner/Spouse Characteristics, Relationship Status, and Sample Size	Description of Main Results
	Data analysis: Thematic analysis				Patients were not interviewed. Treatment: RP only, RT only or combined (+/– HT). 3 still under active investigation. **Culture:** Not reported	27 participants. Including 6 focus groups (4–5 participants in each) and 1 telephone interview	experiencing a loss of masculinity; degree of congruence between each partner's coping response; constrained communication and changed roles and increased practical management.

Abbreviations: ADT, androgen deprivation therapy; API, Asian/Pacific Islander; BA, Black African; BC, Black Caribbean; CaP, prostate cancer; EBRT, external beam radiation therapy; ED, erectile dysfunction; HCP, healthcare professional; HT, hormone therapy; INT, intervention; NILS, Nordic Lifestyle Intervention Study; PCa, prostate cancer; RCT, randomized controlled trial; RP, radical prostatectomy; RT, radiation therapy; SBR, Spiritually based resources.

Supplementary Table 2: Overview of Primary Findings

Author: Bamidele et al, 2019 (1 study, 2 papers) – women's perspective

Finding	Illustration	Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Felt unrecognised and excluded from their husbands newly diagnosed cancer journey. This was mostly attributed to the men not sharing their concerns about their CaP illness with their partner and also lack of information from HCPs to specifically address partners' needs.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS1
Narratives from some women showed that although they accompanied their husband to his clinical appointments, they were minimally involved in conversations that took place.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS2
Only a few of the women reported being actively engaged e.g. scheduling their husband's appointments, taking notes for them during consultations and helping the men to search for information online when asked.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS3
Women's perceptions were also that HCPs showed limited awareness and interest in partners' experiences and needs. This seemed to compound the women's distress as they were further pushed towards a peripheral position.	Not reported	Health Care Service / Comprehensive Cancer Care			NS	NS4
The women suggested that HCPs specifically engaging and supporting partners of CaP patients could facilitate coping by reducing isolation and uncertainty and also help sensitise men towards the unmet needs of their partners.	"…I think if we have an avenue, perhaps as you have come, for the person to talk to the two of us so as to extract this type of conversation, because when you are in a situation you want to see that pain from your own point of view alone, it might not have occurred to him that this woman that is taking care of him has some emotional needs as well, has some needs that are not being met as well, if it comes from an outsider, it will be very effective because if it comes from me, he will say you this woman you have come again, you are always complaining and whining, but if someone else says it, if a counsellor or psychologist says that in the presence of both couple I think it will be very helpful…"	Health Care Service / Comprehensive Cancer Care Needs	U			F1
The women described how they were psychologically affected in terms of feeling shocked at their husbands CaP diagnosis; worried about the potential consequences of the disease on their individual marital and family lives; having uncertainties around recovery outcomes and processes; and lacked information on how best to support themselves and their husbands through the disease trajectory.	"…I was very worried, but I did not show it to him at the time because he needed a supportive person… I wasn't sure how it will affect him being a man because, you are not really told about that sort of thing…I think information is important and especially if you know some people em especially women if they are younger, if they do have quite a good sexual relationship with their husband, how it will affect their relationship, you know because nobody really tells you anything like that, you are not really supported with that…" (pg. 1092)	Health Care Service / Comprehensive Cancer Care Needs	U			F2

The psychological and emotional impact of the CaP on partners was not recognised by the men or HCPs. For example, a participant expressed disappointment at her husband's exclusive focus on his illness without showing much insight or acknowledging how the CaP had significantly affected her as his partner.	"…he was acting as if he was the only one who had been through the diagnosis…I could argue my stress has been more, I used to say to him, we have both been very very stressed and he said well you do not know what you are talking about, I do not think he ever, I do not think he ever grasped the level of stress I was under the whole time…" (pg. 1092)	Psychological / Emotional Needs	U			F3
Faith played a central role in helping them cope with their psychological and emotional concerns. They prayed to God that their husband would not die from the CaP and drew strength from believing their prayers were answered.	"…because I was reassured that he would be ok, he would be fine and through prayers... having prayers… we believe er, I believed in healing…" (pg. 1092)	Spiritual Needs	U			F4
Felt insecure about the possible economic impact on them and their wider family if their husband died from his CaP illness	"…I was obviously very worried because I knew then he had to have operation, I knew then that would affect us, because in many respect not just as a man but he is a very active, strong person, he is also the main breadwinner, you know he's also head of the family…he was always the strong male of the family, you know, so it was how it would affect everybody else and that was quite you know, worrying for me…" (pg. 1092)	Physical / Daily Living Needs	U			F5
Husbands had always taken the lead in the sexual relationship and women felt reluctant to initiate sex and change this routine, as they felt their husband's personal self-esteem could be affected. Current lack of psychosexual support was also a source of concern.	"…and I think because we had a very straightforward sexual relationship which was based on penetration and mutual satisfaction, neither of us was particularly skilled in any other kind of play really, I find that I am actually very anxious, because he is not getting an erection very quickly, maybe he is not finding me attractive or I am not doing what I should be doing I feel that I have not got the skills to help him, so that makes me extremely anxious, I guess anxious is not good for your libido but yea I am struggling with that…" (pg. 1092)	Intimacy / Interpersonal Needs	C			F6
Older women (over 65yrs) reiterated that couples staying with each other in good and bad times is culturally ideal within BA and BC marriages.	"…well in the Caribbean to be quite honest, you just stick together, so I guess it's the same thing there as it would be here you know, you just have to stick together, support each other... that's it…" (pg. 1092)	Intimacy / Interpersonal Needs	U			F7
Partners expressed feelings of exclusion as husbands took sole ownership of their CaP and exercised as autonomous right to steer treatment and recovery decisions whilst wives assumed a background supporting role.	"…he had pretty much made his decision before he came to me, he had already made his decision, he very much owned the illness and did not want to share, I will say did not want to share the burden…" (pg. 1092)	Family Related Needs	U			F8
Concerns were heightened where the man had not prepared a will prior to his diagnosis and they (women) perceived the subject as too sensitive to discuss	"…how long will he have to live, for instance the issue of will, what is going to happen to me, in African set up, you dare not mention it to your husband at that time, because it would mean you are thinking ah ah so that was the major one but with an English person they are free to talk about it, they can seek help, but I have not been able to, with him you dare not, so I was, I felt boxed in" (pg. 1092)	Family Related Needs	U			F9
Many women reported they were only given information as much as their husband was willing to share.	"…I would prefer, my husband to be more interactive, more communicative than he is, something is poking you then talk to me about it but I tend to be the one that has to draw out everything … I guess any problems will be on his side because he tends to hold his feelings back… (long pause), it hurts…" (pg. 1092)	Family Related Needs	U			F10

Some women explained that their husband’s controlling attitude towards their illness mirrors the men’s position as the head of the family and natural leaders in their nuclear and extended family settings.	“…I do not think African men, I do not think they like being told because, culturally it’s like they tell people what to do, they do not like being told so …” (pg. 1092)	Family Related Needs	U			F11
Although they actively provided moral and practical support for their husband, they themselves had limited support due to their husband’s reluctance to disclose the CaP diagnosis among wider members of their social network. This constrained the women’s access to the much-needed support for themselves and increased their feelings of isolation. CaP threatened their husband’s cultural identity as a BA/BC man. Where husbands did allow some disclosure, it was limited to immediate family members, employers, close friends, and church pastors – women described the support from these avenues as excellent.	“…he did put an embargo on me discussing it with my friends… because my natural instinct would have been to discuss it, I think it was so sensitive to him, you know to his identity really, he did not want me to be talking about it with them so I really had to take it inwards, there wasn’t anybody to talk to about it…” (pg. 1092)	Family Related Needs	U			F12
The women expressed that their unconditional love and loyalty towards their husband made them feel obliged to prioritise his wellbeing over their own psychological and emotional needs.	Not reported	Family Related Needs			NS	NS5
Author: Bamidele et al, 2019 (1 study, 2 papers) – Men and women perspective						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Women further expressed disappointment at the lack of professional support focused on partners within the current health care.	Not reported	Health Care Service / Comprehensive Cancer Needs			NS	NS6
Women's psychological and emotional distress was also attributed to their feelings of financial insecurity if their husband died from the CaP	Not reported	Physical / Daily Living Needs			NS	NS7
The women were distressed by their husbands’ lack of recognition for the psychological impact the CaP experience had on them as partners. Some women said their husbands autonomously took decisions on how they wanted to deal with their sexual problems without consulting with them.	“… so without letting me know, he bought erm Viagra tablets a couple of times …” (pg. 1716)	Interpersonal / Intimacy needs	U			F13
Women's psychological and emotional distress was also attributed to their feelings of financial insecurity if their husband died from the CaP, lack of couple-focused psychosexual support, and especially communication barriers with their husband regarding how treatment-related sexual dysfunction was impacting on their marital intimacy.	“… I felt the burden because I am somebody that talks … you know women we talk … it's a form of healing and letting everything out, but he doesn't, the impact was the quietness, you know that he was always quiet … I don't know what is on your mind … you know the relationship wasn't that great … the sexual aspect of things went out of the window … so yea that's the main issue now because it's not easy … I ask myself is it going to be like this forever? Or is it going to correct itself? … emotionally I feel that there's something missing, and sort of when am I going to get that back… you feel a bit frustrated sometimes.” (pg. 1716)	Interpersonal / Intimacy needs	U			F14
Author: Boehmer & Babayan, 2004						

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Women emphasized that after so many years together sex does not have the importance it once had and that their love for each other was able to sustain this loss.	"He feels he has to be able to satisfy me as a man, and that kind of stuff. And we've had long conversations about that. And I think he's okay with that now. I think he's okay with that. And I don't know why he thinks that anyway. It must be a man thing. It's a boy thing. That they feel they have to do that… I don't know why he feels that way. Because our relationship is - I mean, we're soul mates. I mean, we've been together for 22 years. It's such a tight relationship we have. I mean, to me, for him to even think that bothers me - but he doesn't think that as like I'll leave him or anything like that. He thinks of it as it's his job. It's part of his job in this relationship to do that. You know, just part of it all. It's like, ''Well, it's not.'' You know? It was at one point. I mean, I think if he were 32 and this happened, then it might be a real big problem. But you know, it's not." (pg. 843)	Interpersonal / Intimacy Needs	U			F15
Being together for a shorter amount of time or being at a younger age did make a difference in reacting to the possibility of losing the capacity for intercourse.	"It has a significant impact, I think, particularly for us because we're just sort of starting out a relationship. Again, if you were invested with 25 years of a shared life, and you had your children, and you had a life built together, and your sexuality was a dimension of that but certainly, you had lots of other dimensions that you could hold onto, I think it's very different than if you're just starting out a relationship, and you're still trying to find your way within the relationship, and also look at whether it's a lasting relationship or not." (pg. 843)	Interpersonal / Intimacy Needs	U			F16
Another women described that her partner's already existing erectile dysfunction prior to treatment put a strain on their relationship. Erectile dysfunction caused by prostate cancer treatment would deprive of her of any hope for a remedy and instead would make erectile dysfunction permanent and irreversible.	Not reported	Interpersonal / Intimacy Needs			NS	NS8
They insisted that there would be a sex life after treatment. However, only the rare man or woman mentioned that their sex life would be sustained through adjusting their sexual practices.	"The impotence is a higher percentage, but it's still not definite. And there are other things that you can do to take care of it. My feeling is with a loving relationship. That's the most important. I want him to be healthy. I think that's the most important. It would be different if we were terribly vain or he didn't have a nice, comfortable relationship with me, but we do… And I think we can be creative. Who knows, we might even come up with something new and exciting [laughter]." (pg. 844)	Interpersonal / Intimacy Needs	U			F17
Couples who had already dealt with erectile dysfunction prior to his prostate cancer diagnosis assumed that they would return more or less to the level of sexual function that was known to them.	"He's already used the Viagra. Before, of course. And it's quite an interesting medication, I must say. It worked very well. So I figure, if his health is good, it probably will work again. I mean, he's not 30 anymore, but if they've got medication that will do the job, fine. There doesn't seem to be any downside to it, at least, none that I know of." (pg. 844)	Interpersonal / Intimacy Needs	U			F18
Women foresaw complete acceptance of their partners	"If he's impotent, he's still my husband. That doesn't make him not my husband. When you take the vow you said for better or for worse. So if the worse comes, he's still my husband." (pg. 845)	Interpersonal / Intimacy Needs	U			F19

Women stressed that the loss of their husband's sexual function was not that important to them personally but worried about how his dealing with it affected their relationship.	"He knows that [impotence] that's not that important to me. In the scope of things that's not that important. He knows that. But how he reacts to it when it actually happens I don't know. We'll have to wait and see." (pg. 845)	Interpersonal / Intimacy Needs	U			F20

Author: Bruun et al, 2011

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
Thoughts and experiences about the illness and the associated silence are believed to affect both the social and psychological situation. Silence about the illness from everyone around and the accompanying imposed loneliness seems to affect daily life to such a degree that exhaustion can develop in the attempt to cope with life.	Not reported	Psychological / Emotional Needs			NS	NS9
Even though self-inflicted loneliness could be of positive significance, the study also showed that one's own needs were disregarded, perhaps out of a sense of duty to support the male partner.	Not reported	Social Needs			NS	NS10
An apparent isolation in the home – an isolation that can be the couple's strategy to avoid daily questions about the illness and its consequences. In this physical and social isolation, self-inflicted loneliness can be one way to support the male partner.	"We stay more or less at home on our own." (pg. 296)	Social Needs		C		F21
Isolation in the home can be experienced over time as a further burden on top of the male partner's illness. The wish to get out and be among other people, and that the need for social company and conversation becomes stronger over time.	"I don't like being here (at home); I need to be out where there are other people." (pg. 296)	Social Needs	U			F22
Love between the partners was the foundation for and an important dimension of having the strength to cope with life. The strength found in love is not considered to lessen over time but is more obvious.	*Three months* - "A tenderness between us, it's like we look after one another a lot." (pg. 296) *Ten months* - "We really look after each other a lot; we've always done so, but recently, it's perhaps been a bit more obvious." (pg. 297)	Spiritual Needs	U			F23
For some female partners, faith in God contributes to a foundation of peace in life in relation to the illness. Faith did not become less significant over the period; on the contrary, it was strengthened.	"It (faith) helps us, especially because we believe in life after death, we have somewhere to take our anxiety and our joy and our whole life...it means one takes it all more calmly." (pg. 297) *Ten months* - "I pray to God whenever there's anything..." (pg. 297)	Spiritual Needs	U			F24
Informal care has changed over time from needing to be constantly available to providing care in the usual sense where warmth and closeness are expressed.	"It's about care, but hardly at all about duty (care burden)." (pg. 296)	Physical/Daily Living Needs	U			F25
An attempt is made to live with the illness in everyday life, so it is invisible and dominates as little as possible. This approach ignores the illness and is believed to be a tool to control the	"We don't let it have too much influence on our daily lives... we're both agreed on that, so we do what we usually do." (pg. 296)	Physical / Daily Living Needs		C		F26

consequences of the illness and thereby a way of managing to live with it.						
There was an imbalance between looking after oneself and looking after others. The capacity for self-care is weakened because the need to look after others overshadows the recognition of one’s own needs.	“I’m the type to put myself last and make sure everyone else is okay.” (pg. 296)	Physical / Daily Living Needs	U			F27
Informal caregiving takes up a lot of time in daily life. The first few months of the illness, there is little time for anything apart from a range of duties in connection with the partner’s illness.	“I spend all my time on caring for my husband.” (p. 296)	Physical / Daily Living Needs	U			F28
The female partner experienced the man’s silence as a discomforting factor in their joint daily life that contributed to the couple isolating themselves from each other. The female partner found herself alone with her thoughts and feelings, which intruded on her in connection with the partner’s illness.	Not reported	Interpersonal / Intimacy Needs			NS	NS11
A culture and value system where it is meaningful to help and support each other. This shows natural care and concern, where there are no boundaries to prevent assisting and supporting the family.	“We can go (to the family) if we need help.” (pg. 297) “But if there’s anything, no matter how small...I know I can just ring my son and daughter-in-law.” (pg. 297)	Family Related Needs	U			F29
This experience of loneliness seems to become worse if the family and the social network pretend the illness does not exist and do not talk about it.	“People really don’t want to hear about the illness and especially not the children.” (pg. 296)	Family Related Needs	U			F30
A dilemma was experienced with regard to care for the family in that their own needs were put aside. The need is expressed here as a will or a duty to provide care and thereby ensure others are looked after.	“I have always wanted to help others.” (pg. 296)	Family Related Needs		C		F31
The need or duty to provide care for the family is considered to be completely fundamental, and the duty of care is never questioned for the partner and family in the course of the illness.	Not reported	Family Related Needs			NS	NS12

Author: Dieperink et al, 2016

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
The possibility of exchanging stories seemed to reduce the participants’ feelings of loneliness and stigmatization. Normalisation was obtained by telling individualized but similar stories about disease, late effects, and marital problems. All participants’ appreciated the facts of not knowing any of the other couples beforehand.	Not reported	Facilitator			NS	NS13
The women claimed that the residential stay allowed the time and space to work with problems. They enhanced the importance that the staff saw the spouses as individual but	“You should not overrule the significance of being away from everything, with nature and a lovely place to be, and to be in it, in another way, than if you are sitting in a coincidental conference room”. (pg. 26)	Facilitator		C		F32

connected persons and the sessions provided room for both laughter and tears.						
The diverse information from different health professionals at the hospital confused the couples. They were usually satisfied with the information about the treatment, but they wanted more information and guidance about the impact on their everyday life as a couple and as a family, and e.g., how to talk with their grown-up boys about the risk of prostate cancer.	"They (health professionals) still have a lot to learn about giving information". (pg. 25)	Health Care Service / Comprehensive Cancer Care Needs		C		F33
Before treatment, all men were told that their sexual function would decline, but several of them could not believe it until it really happened. Some of the women felt neglected when the physicians directed the information about sex only towards the men.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS14
The majority of both men and women experienced that the sexual decline involving erectile dysfunction and a lack of libido slowly had caused a distance between them as couples, although none of them wanted this to happen.	"It was shocking to learn, that we wasn't able to maintain the intimacy, although we had agreed to maintain it, as the sexual ability disappeared. It surprised us, and it leaked out just quietly – not by one day to the other, and maybe therefore we didn't realize it before it was too late." (pg. 24)	Interpersonal / Intimacy Needs	U			F34
Both men and women emphasized the psychological changes as the most significant, and some of the men claimed the new experience of a quick temper. This caused bickering and rows between the spouses.	"When we came here, I was almost going into panic, because last week it went crazy in our house. We were both very aware that we can't live like this anymore. We couldn't find any tools to go further." (pg. 25)	Family Related Needs	U			F35
The women felt they had to be strong in order to comfort and support the partner, and to spare the rest of the family. All these tasks caused some of the women to forget taking care of themselves.	"I am always asked how my husband is doing, but in one year, no one has asked me how I am." (pg. 25)	Family Related Needs		C		F36
Author: Ervik et al, 2013						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Talking to other wives in support groups for spouses was especially valuable for those who had attended learning and coping seminars or seminars at the rehabilitation centres. The context of these seminars provided room for greater openness about their inner feelings.	''I was amazed that I was able to talk so much about our relationship… We were in an environment where the leader of the group was very straightforward with her questions... About marital relations, many cried. They were afraid of being alone it became so natural to talk about *everything.''	Facilitator	U			F37
Although the spouses played an active role in providing care, they simultaneously felt relegated to the sideline. Particularly encounters with healthcare providers at the hospital during treatment and at follow-up visits.	''I did talk with physicians and nurses… but clearly, they are busy and engaged with the patients, and then you move to the side line.'' (pg. E11)	Health Care Service / Comprehensive Cancer Care Needs	U			F38
The experience of being ignored was difficult for spouses because of their strong involvement in their husbands' illness experiences.	''In the hospital, the patient is the focus; it feels a bit hard when I do so much.'' (pg. E11)	Health Care Service / Comprehensive Cancer Care Needs	U			F39

Many of the spouses voiced anxiety about information being withheld by their partners, and they emphasized the importance of having the same information as their husbands for managing their own well-being and for helping their partners. Therefore, encounters with healthcare providers were seen as an important arena for gaining information. The spouses were often responsible for taking the initiative to obtain information. When taking the initiative themselves, however, the spouses experienced the encounters as satisfactory and important.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS15
Healthcare workers provided information about technical remedies, such as syringes or medication to promote erections, but at home, couples had to find ways to manage the situation themselves.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS16
The spouses felt caught in a situation where they had to balance supporting their husbands' needs with managing their own anxiety.	''Regardless of whether it is cancer or another serious illness, it is very hard to be the next of kin, and perhaps few understand how hard it is when serious illness strikes I am the next of kin, and I am supposed to be strong. Sometimes it is difficult'' (pg. E10)	Psychological / Emotional Needs	U			F40
The anxiety diminished for most spouses after the first few months. The strain of being supportive continued, however, and a feeling of exhaustion grew for those who had lived with the illness for years.	"It is hard to be the one who has to listen and reassure all the time. It is a difficult situation for me as well." (pg. E10)	Psychological / Emotional Needs	U			F41
Those with the longest experiences gave voice to a growing need to focus on their own feelings and experiences. Some wondered if their strong involvement in their husbands' experiences and methods for dealing with the illness were accompanied by a risk of ignoring their own needs.	''I was extremely afraid of hurting XX, and I was afraid of hurting myself as well. I was so focused on him that, in a way, I forgot myself. In retrospect, I have cried very little (tearful).'' (pg. E12)	Psychological / Emotional Needs	U			F42
Many spouses felt that they had to suppress their own feelings to maintain the effort of being supportive over time. They emphasized the need to be positive and remain in good spirits.	''being strong and calm.'' / ''not being hysterical.'' (pg. E10) ''I have to stay positive; there is no use in collapsing. I can collapse for a while but not stay that way; you have to face it; it will not disappear.'' (pg. E10)	Psychological / Emotional Needs	U			F43
Spouses described the provision of practical help as something that brought them closer to their husbands as a couple and something that they did out of love for their partners.	"I had to help him take care of the wound (change the dressing after surgery). We are very open with each other and have no inhibitions. I think that it is very positive to work together on those issues, to help each other… Nobody knows what old age brings; we have to help each other. We just have to." (pg. E10)	Spiritual Needs	U			F44
Focusing on themselves was an emotional experience when talking about the impact of the illness on daily life and their thoughts about the future.	"I am used to taking care of myself when dealing with practical issues… sometimes, I find things to be difficult emotionally. Obviously, one is always anxious and afraid of being alone… one is used to being two; thus, everything becomes different the day one is by oneself." (pg. E11)	Spiritual Needs	U			F45

Many spouses felt that their husbands' illness had brought them closer as a couple.	"…After being married for many years, partners often take each other for granted… The illness brought us close together, we felt more on the same wavelength." (pg. E12)	Spiritual Needs	U			F46
Although the experience was difficult, the spouses all felt that it was important to be able to support their husbands, whom they loved and cared for, and some felt that the illness experience provided an opportunity to appreciate the good things in life and to live their lives differently.	Not reported	Spiritual Needs			NS	NS17
The husbands' illness was frequently referred to as a shared challenge for the couple.	"we are in this together." (pg. E10) "we will make it." (pg. E10)	Physical / Daily Living Needs	U			F47
Most spouses felt that their husbands became more dependent on them and that many husbands therefore required ample psychological support in daily life.	''He has become more dependent on me being with him and on us doing things together. I do not know if he feels unsafe in a way… so I do have to go with him (to a learning and coping seminar).'' (pg. E10)	Physical / Daily Living Needs	U			F48
Many spouses described their efforts to reassure their husbands that their sexual problems were something that they faced together and that they both had to be patient. For one woman, it became especially important to convince her husband that his altered sexual performance would not result in her breaking off the marriage.	"I tried not to hurt him but to reassure him that he means as much to me today as before, as a lover and also for the person he is." (pg. E10)	Interpersonal / Intimacy Needs	U			F49
In dealing with sexuality issues, some spouses made jokes to try to relax the situation, and one woman bought literature with sensual content for inspiration. Other spouses had accepted a life without intercourse. They dealt with the situation by focusing on their own age and facets of sexuality other than intercourse.	"After menopause, I lost interest (in sex) … we are very close… and that nearness means a lot to me." (pg. E10)	Interpersonal / Intimacy Needs	U			F50
Sexual dysfunction was experienced as difficult for both partners, and therefore, they felt especially relieved when they were able to have intercourse.	"Tablets enhanced the desire, but it is artificial; the naturalness was lost, and it felt unpleasant. It was great when we managed without any remedies and other influences, a great moment." (pg. E10-E11)	Interpersonal / Intimacy Needs	U			F51
Some felt it to be difficult and hurtful when their husbands did not express sexual desire.	"After a while, I felt something was missing because of his lack of desire, more than I would have imagined… It was tough to hear him compare embracing me with hugging a trunk." (pg. E11)	Interpersonal / Intimacy Needs	U			F52
The spouses did not want to expose their husbands' situation to others, especially when dealing with intimate issues.	"(I was) letting my husband down." (pg. E11)	Interpersonal / Intimacy Needs		C		F53
They did not wish to excessively worry or involve their children, and they did not wish to expose their husbands' problems to others. Professional healthcare providers with expertise in prostate cancer and peers were preferred.	"Actually, it would have been acceptable to be able to speak with someone you do not need to relate to on a daily basis, someone who is not involved with your own family" (pg. E12)	Family Related Needs	U			F54
Although they understood why the men were the centres of attention and support from family and friends, they reflected on their own situations as the ones standing by.	"Only one person has asked me how we are doing; everybody asks how everything is with him." (pg. E11)	Family Related Needs	U			F55

Encounters with people in public were described as potentially difficult, both when the husbands did not want to tell others that they had prostate cancer and when they were open about their illness. Some spouses felt that it was particularly difficult to hide their own feelings when meeting people they knew, and they encouraged their husbands to be more open toward others to make the situation easier for them as spouses.	Not reported	Family Related Needs			NS	NS18
Other spouses described a more passive approach to their support and justified this approach by noting that their husbands were calm about the situation.	"…(I) have not accompanied him anywhere because he deals so well with the situation himself... Maybe he sometimes may have wanted me to go with him (to the hospital), but I have been more - 'Ok if I do not have to accompany you, I have work to do" (pg. E10)	Family Related Needs	U			F56
Author: Evertsen et al, 2010						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
They did not know what questions to ask which left them unprepared. They relied on the primary care physician and urologist to tell them what they needed to know, both the good and the bad.	"Maybe they don't tell us these {bad} things because they don't want us... to put ideas in our head." (pg. 2-3) "I think the men need to be told upfront...they need to come out and say...this can be a real problem. This is what's going to happen." (pg. 3) "Is he {husband} the unusual one, or is he not the usual one?" (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F57
Some of the women suggested that they needed doctors, both the urologist and primary care physician, to be honest and give "more practical information" about how difficult and long the recovery is going to be.	"It's all trial and error… if you could share that information that would be helpful." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs		C		F58
Some of the participants said that the doctors ''were very respectful'' in regard to any questions that they would have but ''not really worried about me {emotionally} at all.''	"He {primary care doctor} would ask 'how are you doing' and you would say 'fine' and that's it. They don't ask any more questions… I am not saying he doesn't take the time to talk to me, but he talks about the issue that I'm in there for." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F59
Many of the women said that they tried to seek comfort from their own primary care providers but were disappointed with the lack of information and support they received.	"I have never talk with my family physician...I was never asked how I felt." (pg. 3) "...they {treating doctors} were not really worried about me at all. And I guess I wasn't surprised with that. I think actually... now that you've asked that question, I think I would have been very surprised if they had been worried about me. I just didn't... I mean, that never occurred to me. So that's an interesting question." (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F60
One woman noted that she was frustrated by the lack of ongoing support for her husband after surgery from his primary care physician and urologist. She said that she would bring her husband into the clinic with numerous symptoms and was told to wait and see what happens.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS19
A few participants noted that they received more information and support from the primary care doctor than the urologist.	"He'll sit there with you...ask you about the family, everything. He'll say 'well, and how are you' and I have a bit of a habit of saying 'I'm	Health Care Service / Comprehensive Cancer Care Needs	U			F61

	OK’ {Doctor says,} ‘What do you mean by OK? Why don’t you tell me what...why it isn’t fine." (pg. 3) “.... He answered all the questions that we both asked, and we both had our list of questions and he would get them from both of us. You know, both of us would come at him with different types of questions, and we both felt very confident with the doctor.” (pg. 3) “...we went in and we saw the primary care physician at that point and talked with him about the various options. So he was very helpful, very supportive. Obviously has some opinions but talked through all of the options, pros and cons, before we actually made the decision.” (pg. 3)					
One woman noted that her partner was disappointed that his primary care physician did not visit him in the hospital after surgery.	“His primary care just never came by to see him...he didn’t stop by because he couldn’t bill me.” (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs	U			F62
General discussion emerged during the focus groups regarding inconsistencies in who should be providing follow-up, whether the urologist or primary care physician. One woman suggested that a team approach to the treatment and follow-up of prostate cancer could ease some of the burden on the patient and their family members.	“...they were on their own until the next appointment.” (pg. 3) “...once you’re done seeing the urologist, you’re still going back to your primary doctor. And if there are problems with one, the primary doctor needs to know about that. For further treatment down the line”. (pg. 3) “If I have a question I would call the {urologist}. Those would be the first ones I would pick to phone and call.” (pg. 3)	Health Care Service / Comprehensive Cancer Care Needs		C		F63
Two participants suggested the addition of a visiting nurse to help by answering questions and assisting with care-giving duties.	“relieve a little stress.” (pg. 4)	Health Care Service / Comprehensive Cancer Care Needs		C		F64
All participants believed they did not receive enough information and were thrown into an unfamiliar role as a caregiver instead of a companion.	“The wife in something like this is very much involved,” (pg. 2) “this diagnosis affects the wife as well.” (pg. 2)	Health Care Service / Comprehensive Cancer Care Needs		C		F65
In addition to more information, the female partners identified a strong need for emotional support from family, friends and others going through the same diagnosis. It was important for them to feel like what they were going through was normal.	‘’When you find this out {diagnosis} you need to talk to somebody and that somebody’s just not there.’’ (pg. 3)	Social Needs	U			F66
Participants emphasised the need for additional support.	“why isn’t there a group for me to go to?” (pg. 2)	Social Needs	U			F67
Discussion of shared experiences through support groups was mentioned by many of the women as important for both the patient and their partner to feel like what they were going through was normal.	Not reported.	Social Needs			NS	NS20
The lack of information and increased time serving as a caregiver rather than a couple caused increased stress for the female partner and at times took a significant toll on the	“You just don’t know where they’re going to be from day to day. Cause one day they’re one way, and the next day they’re in a different mood and the next day... this is bothering them and that was where I	Physical / Daily Living Needs		C		F68

couple’s relationship causing increasing tension and even arguing.	wasn’t prepared. I just...I knew we had to get through but I think you go through that big trauma period and then you hit a point where you go, ‘okay, now we’ve got that sort of under control. We’re not sure where we’re going with it yet but it’s kind of under control,’ and that’s when things sometimes get out of control. And you’re their back at home, and they’re going through all these different things emotionally. Well you’re sucked into all that stuff. I mean, you don’t know from day to day how they’re going to handle it.” (pg. 4) “We are still trying to figure it all out. It was a big change for both of us.” (pg. 4)					
The couple’s relationship during the diagnosis and treatment seemed to shift from the male patient attending doctor’s appointments alone to the couples attending appointments together. One of the women lamented this relationship change when describing her partner’s use of the words “we” and “us” to describe his illness. However, she noted a difference in classification when faced with her own illness. A number of women expanded on this statement.	“when I had breast cancer, it wasn’t ‘our’ breast cancer. It was my breast cancer.” (pg. 4) “From the very beginning of the process, we always did it together and I think it was just assumed... the two of us assumed that we would do it together.” (pg. 4)	Physical / Daily Living Needs	U			F69
Several women noted that physical changes during treatment and recovery caused changes to their relationship.	“But everything’s still not quite the same because now you’re told you’ll heal up, but when you have major surgery, your whole body goes through a change. And he seemed to like… he got moody, and, you know, crabby, and so I just kind of went ‘OK’ cause you know… I don’t know what to do”. (pg. 4) “After two weeks my husband couldn’t even get out of bed because of the pain... the discomfort... I mean I wasn’t prepared for that.” (pg. 4)	Physical / Daily Living Needs	U			F70
The physical effects of the diagnosis decreased the men’s activity levels leaving the wife to take on more duties around the house.	“There’s so much that’s affecting their masculinity....” (pg. 4) “This is sixteen months later, we only go places where he can be near a restroom because he always feels like he has to go.” (pg. 4)	Physical / Daily Living Needs		C		F71
One of the women said that her husband felt a “loss of manhood” due to a decrease of sexual function as well as the innate instinct to provide for his family during this time.	“a woman can’t know what it’s like mentally to a man not to be able to have sex and still have the desire.” (pg. 4) “A man in his fifties...ending your sex life as you knew it, it’s a big step. Especially with my husband, it was a big...a big blow to his ego and our sex life stopped as we knew it.” (pg. 4)	Interpersonal / Intimacy Needs		C		F72

Author: Feltwell et al, 2004

Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
One partner explained that although she wanted to talk to other women whose partners had prostate cancer when her husband was first diagnosed with the disease, she did not want to get information from other women at the time of the interview, because she thought it would be too frightening.	“I don’t feel the need to at the moment [talk to other partners]. At the time [around diagnosis] I felt as though I wanted to know something or talk to somebody who had had the experience . . . in some ways you know people who’ve had it… and that’s why sometimes people don’t want to know because err… it’s frightening.” (pg. 182)	Barrier	U			F73

One partner explained how she once wanted to ring a help-line to get some prostate cancer information but did not ring because her husband did not want her to.	"I did once see a helpline for prostate cancer sufferers and there was a number, and there was also a local number actually and I was going to phone but my husband said… But my husband didn't want it." (pg. 183)	Barrier	U			F74
Some partners actively sought information about prostate cancer from a variety of sources and providers, including healthcare professionals. One partner explained how she sought information about her husband's condition by asking his consultant questions.	"I go in [to see the consultant] with him [husband] because I question him [consultant]. I question Dr X." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F75
Some partners suggested that they had to actively seek information in order to get their information needs met. One partner explained that she would not have been told any information about her husband's condition by his consultant if she had not actively sought information from him by asking questions.	"You wouldn't get to know anything [if you don't ask for the information]. Yes, I do the same with my own doctor if I want to know I ask her straight out. I think it pays you, go in and ask what you want to know." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F76
Some partners failed to seek information because they felt disempowered and lacked confidence in seeking information. One partner explained how she felt unable to seek information from her husband's consultant because she did not feel included in the patient–physician consultation.	"Now, like the lady, she asks, now I don't because Mr. X, he's completely looking at Rupert [husband], not me, he is talking to Rupert… so I don't say nothing, 'cause I'm not the type to push forward, although you want to know." (pg. 182)	Health Care Service / Comprehensive Cancer Care Needs	U			F77
Partners failed to seek information from consultants because they felt that their time was pressured within the consultation. One partner explained that she would like to have talked openly with the consultant but the idea that he was a busy man stopped her from pursuing questioning him.	"We're not wimps… we want to know the facts, but by the same rule you are very conscious that they are very busy people and you can't sit and have a chat, you don't feel that you can open up for a chat like this." (pg. 183)	Health Care Service / Comprehensive Cancer Care Needs	U			F78
Partners failed to seek information from sources like leaflets because they were not aware of the existence of such materials. Other partners avoided seeking information from sources such as the Internet because they felt they were too old.	"Oh, I don't use it." (pg. 183) "I wouldn't know where to start." (pg. 183)	Health Care Service / Comprehensive Cancer Care Needs		C		F79
One partner explained how she and her husband avoided talking about prostate cancer in order to get back to normal, but sometimes found it difficult to gauge when she should talk about the disease with her husband.	"We haven't got an ostrich attitude to it but I find it difficult to know when it's right to talk about it." (pg. 182)	Family Related Needs	U			F80
Author: Harden et al, 2006						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
(Young-old developmental stage): Many in the group expressed a nagging worry about their future together. One wife said that they frequently talked about their situation in the middle of the night, discussing treatment situations and modifying plans. Another wife said she worried about his status.	''I faced my own breast cancer (a survivor) and that doesn't bother me. It's something I live with. But I'm having a much harder time with his. I worry. I worry all the time (she cries).'' (pg. 373)	Psychological / Emotional Needs		C		F81

(Young-old developmental stage): Another wife hated seeing her husband in pain but felt his overall attitude toward the cancer helped her to cope with the situation. (Worry seemed to be a constant companion of wives in the young-old group.)	''I don't like the idea that our lives are going to end or we are going to be separated. And a lot of times, I start feeling sorry for myself, not for him but for me, to be by myself.'' (pg. 373)	Spiritual Needs		C		F82
(Late middle age developmental stage): A diagnosis of cancer caused couples to re-evaluate their priorities. It helped them realign their priorities to more meaningful goals for them.	"What has hit me the most is realizing the importance of the small things and doing those things. We don't take it for granted at all." (pg. 372)	Spiritual Needs	U			F83
(Young-old developmental stage): Frequently commented that they had a good life. They had been able to do the things they had planned. Felt comfortable with their accomplishment.	''We have said many times that we have been blessed. We have a wonderful family. We have gone together and been married for over fifty years. We just feel very blessed that the Lord has given us these wonderful kids and grandkids. He (her husband) has said many times, 'If I die tomorrow, I will have lived a wonderful life'. And that is really how I feel too.'' (pg. 373)	Spiritual Needs	U			F84
(Late middle age developmental stage): Household plans frequently had to be postponed related to a lack of energy. Wives expressed the need to be constantly vigilant, monitoring their husband's status and using that as a determinant of activities for the day. Wives spoke longingly of activities they used to enjoy together.	"It slowed him down; for example, he can't do some of the outdoor things he likes to do. In some ways, we just kind of adapt what we are doing." (pg. 371)	Physical / Daily Living Needs	U			F85
Two wives who were currently active in the work force expressed distress and guilt because they could not be present with their husband at all doctor's visits and treatments. This was a source of great concern for wives.	''I couldn't be there for all his treatments because I had to work, and I felt bad because I wasn't there supporting him all the time… we discussed it and the best thing for me to do was to work and not lose my job, because if I lose my work, I lose our insurance and possibly our house. So, it was important for me to work, but it was hard. I just had to be strong and keep things going.'' (pg. 371)	Physical / Daily Living Needs	U			F86
Would have been easier to accept their diagnosis if they were older.	''We would have had at least enough time to work to retire. So, at best we would have had medical care. I don't have any. There is no retirement benefit.'' (pg. 373)	Physical / Daily Living Needs	U			F87
(Old-old development al stage): When couples in this age group discussed living with prostate cancer, both husbands and wives discussed it as a couple's disease. Wives were often proactive in looking for new treatment options and discussing them with the doctor.	''we decided''… ''when we had treatment,''… ''we accepted it.'' (pg. 374)	Physical / Daily Living Needs		C		F88
(Late middle age developmental stage): [related to: men no longer getting sexual reminders and now need to think more about showing affection] His wife said she felt left out at first, but after discussing her feelings with her husband they were able to adjust.	Not reported	Interpersonal / Intimacy Needs			NS	NS21
(Late middle age developmental stage): [related to: hormone therapy causing impotence] His wife explained the changes they made:	"We do a lot of hugging. We just spend a lot of time together. So it has basically not been a hard thing for me. But he feels bad that he is not meeting my needs. I think men have an idea that to meet your emotional needs it means sex. Well, actually that is a very small part.	Interpersonal / Intimacy Needs		C		F89

	So, it was a hard thing for me to get across to him that I'm doing very well." (pg. 372)					
(Young-old developmental stage): Although some of the couples discussed changes in their normal intimacy patterns, they did not express distress related to these changes. One wife said she thinks about the changes in their sexual activity.	"It seems strange that we have the lack of sexual activity now because we weren't like that before. But I'm accepting it; he's accepting it and we're okay with it. He tells me, 'I'm going to be 72 years old, what else do you expect?" (pg. 373)	Interpersonal / Intimacy Needs	U			F90
(Old-old developmental stage): Although intimacy seemed important in this age group, this group raised less concern than what was voiced in the younger age groups.	"We don't even talk about it or think about it. We're together all the time." (pg. 374)	Interpersonal / Intimacy Needs	U			F91
Author: Ka'opua et al, 2005 (1 study / 2 papers)						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Giving hope to the sick through the sharing of their experience with prostate cancer offered couples opportunities to integrate illness experiences into the larger fabric of their lives.	"This is my husband, a kind hearted person who gives of himself to others. When we go to the doctor, we "talk story" with other patients. If they're really sick, we encourage them. When we give hope, we get hope back." (pg. 151)	Spiritual Needs	U			F92
Women in the study said that they participated in spiritual, health promoting, and charitable activities from which they derived a sense of purpose and a context for examining the meaning of cancer, aging, and adversity in their lives. More often than not these were activities that wives shared with their husbands.	"We're active in the support group. It's important to help others and a way we practice our faith." (pg. 151)	Spiritual Needs		C		F93
Across the trajectory of their husbands' illness and survival, women relied on various types of spirituality and religion to understand the meaning of change in their lives and thus were able to adopt a flexible, yet proactive, approach that allowed for continuous adaptation to life's adversity.	"My husband was very depressed. Chi classes helped us be positive and learn from life. When bad things happen, you try to see the lesson in it for you." (pg. 151) "His cancer made me more resourceful… I learned to pray and meditate on all the things that were stressful." (pg. 151)	Spiritual Needs	U			F94
Women reported that they continued to learn through coping with challenges related to their husband's cancer, as well as with other experiences of illness and aging.	"Through my husband's cancer, other experiences, even his death — I've come to understand that changes don't have to define our lives. We can adjust and go through it." (pg. 149)	Spiritual Needs	U			F95
Women helped their husbands navigate the medical system. They reported accompanying their husbands to medical appointments and treatments, discussing treatment options with their husband and other family members, and providing or facilitating social support.	"We rode the bus to the city for radiation, a trip that took the whole day. I go with him because he's limited in talking English and I help answer questions… then I know what is going on." (pg. 149) "The doctor said that my husband had two treatment choices. We came home and had a family *pule* [prayer] about what to do. We talked as a family and then made the decision." (pg. 150) "Japanese men have a *samurai* streak—they're private with feelings. It was difficult for him to go to support group, so we both went. Sometimes I put my head down and didn't look at the men who were talking because what they were saying seemed so personal and I didn't want them to be embarrassed." (pg. 150)	Physical / Daily Living Needs	U			F96

Women worked to affirm the couple bond, especially in light of changes associated with treatment side effects.	“The doctor asked if sex is important to us. He explain to us that my husband will be ‘half man, not full man.’ When we come home, I say to my husband: ‘don’t worry. I have strong independence.’ I would be lying if I said it is not a problem. We went still sleep in separate rooms.” (pg. 150) “Permanent impotence, a treatment side effect! But we’ve had 45 nearly perfect years together and sex is like the frosting on the cake. Too many marriages have gone under the rocks because of impotence. The main thing is the cake. From the beginning we decided we have our cake” (pg. 150) “The only thing that separates married people is death. I do my best so that he can use his life in old age” (pg. 150)	Interpersonal / Intimacy Needs	U			F97
With respect for their husbands’ dignity and self-esteem, the wives learned to reframe their husbands’ changes as part of the normal aging process and thus approached sensitive discussions about changes in sexual intimacy. Humour was used sometimes to initiate such discussions.	“I joke with him ‘if you had to get cancer, why this one’ because we both know the prognosis… and we laugh… joking is one way to recognize what’s going on and deal with it.” (pg. 150)	Interpersonal / Intimacy Needs	U			F98
Almost all the couples who wanted to restore their sexual intimacy found an acceptable solution, including use of medication to help husbands have an erection, oral sex, more kissing, and caressing. They also found alternative ways to express intimacy without sexuality. Affirmation of the marital bond was expressed through shared activities seen by the wives as romantic, spiritual, playful, or companion-like.	Not reported	Interpersonal / Intimacy Needs			NS	NS22
In the face of daily deficits and physical disabilities, the wives encouraged their partners to keep a positive attitude.	“When he is downcast, I comfort him and remind him there will be a time when all suffering will end, so take heart. God will provide. Enjoy what we have!” (pg. 150)	Family Related Needs	U			F99

Author: Ka’opua et al, 2007 (1 study / 2 papers)

Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Although cognitively prepared by health care providers to anticipate treatment side effects, wives felt that they were not offered guidance or suggestions to help cope with the husband’s impotence and incontinence as threats to emotional and sexual intimacy.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS23
Developing and sustaining community connections through meaningful participation in spiritual communities and secular groups reinforced spiritual learning and provided opportunities to give and receive social support.	Not reported	Spiritual Needs			NS	NS24
The majority of women participated in service activities that specifically provided succour and healing to others, such as providing Healing Touch services to cancer patients, sharing	Not reported	Spiritual Needs			NS	NS25

knowledge of Chinese herbal medicines, and reaching out to newly diagnosed patients.						
Across diverse traditions, engaging in service to others reflected the belief that caring for others was integral to personal well-being.	"Honouring the sacred in everyday life." (pg. 35) "Commitment to we – not I" (pg. 35)	Spiritual Needs		C		F100
Service often preceded cancer diagnosis, and in long-term survival, continuing participation in service activities helped women maintain a semblance of normalcy in the face of changing conditions.	Not reported	Spiritual Needs			NS	NS26
Notably, some wives said that their experiences as the spouse of a cancer patient / survivor motivated them to help others cope with cancer. During the period of long-term survival, women engaged in activities that included coordination of cancer support groups convened in either conventional health care or spiritually based settings, providing Healing Touch program therapy to cancer patients, and sharing information about complementary and alternative medicine believed to reduce cancer risk and alleviate distress.	Not reported	Spiritual Needs			NS	NS27
Through service to others, women affirmed their spiritual connection, nurtured a sense of purpose across the trajectory of survival and adaptation, and furthered the integration of their own experience with cancer.	Not reported	Spiritual Needs			NS	NS28
Not reported (Community connections and meaningful Participation)	My church community is an extended family. When my body was weary, the bishop visited and sent others to help." (pg. 34)	Spiritual Needs		C		F101
Not reported (Community connections and meaningful Participation)	"Because of my experience I wanted to comfort others. I got certified to do Healing Touch with cancer patients." (pg. 34)	Spiritual Needs		C		F102
Not reported (Community connections and meaningful Participation)	"My husband and I run a prostate cancer support group. This is how we take our faith out into life." (pg. 34)	Spiritual Needs		C		F103
In the process of adapting to such challenges, women became keenly aware of life's ephemeral nature, which punctuated a search for purpose and positive meaning in adversity. In this search women relied on spiritual beliefs and practices to cope with changes and attain a quality of life congruent with valued life priorities.	"Religion and spirituality have a lot to do with coping. You have to believe in something that's greater than yourself otherwise life seems hopeless." (pg. 32)	Spiritual Needs	U			F104
Two of them practiced family rituals that were termed as "ancestral reverence" or "ancestor worship" (that is, going to grave sites with offerings to ensure ancestors' comfort in the afterlife, praying to ancestors) and stressed that these spiritual practices offered them a sense of comfort and cultural continuity.	"In traditional Chinese culture we believe that the ancestors watch over us from the life beyond and appear at times of despair to give that extra strength to accept things that can't be changed." (pg. 32)	Spiritual Needs	U			F105
A minority of women said that they were "spiritual but not religious." For these women, spirituality was derived from a	"Feel the awesome power of the universe, see my trials and tribulations from a bigger perspective, and be inspired to go on."	Spiritual Needs	U			F106

more personal system of beliefs and practices. The sacred source was described as a “guiding light,” “the source of all good,” or “nature.”	(pg. 33)					
The sanctity of the marriage was frequently referenced. Prayer or meditation and inspirational readings offered women optimism and motivated affirmation of the marital bond as a “covenant” between God and both members of the couple, as “God’s gift,” and as a challenge of resolving “spiritual brokenness.”	Not reported	Spiritual Needs			NS	NS29
In some cases, couples used SBR together, and such shared experiences provided both partners with an opportunity for introspection, empathic communication, and mutual social support. For example, one couple used prayer, inspirational reading, and fasting to deal with the husband’s incontinence and related social anxiety.	“These [practices] help us to concentrate our minds to the problem. Through consciously working to be closer to our Heavenly Father, we believe that we can better understand and support each other.” (pg. 35)	Spiritual Needs	U			F107
Spiritual stagnation was avoided through discovery of life’s lessons, and crises generally were embraced as opportunities for enhanced understanding.	“How you look at your life is a choice. Each day you can choose to be holy [by] showing love and compassion, learning to appreciate whatever life brings with a grateful openness.” (pg. 35)	Spiritual Needs	U			F108
Beliefs related to acceptance of illness, aging, dying, and death as part of life; human choice or active will; and collaboration with the sacred source were all cited. From the premise of these beliefs, women accommodated physical disabilities and deficits, tried different solutions (for example, new medications, complementary and alternative treatments) for palliation and healing, and modified lifestyles (for example, dietary habits, exercise practices) to reduce disease risk or control existing medical conditions. In the majority of cases, a proactive attitude of wellness promotion and health maintenance was expressed.	Not reported	Spiritual Needs			NS	NS30
Not reported (Health-focused attitudes and behaviours)	“We accept that aging and death are part of life. We know we’re going to have physical problems as we get older—so, we work to prepare spiritually, emotionally, physically.” (pg. 34)	Spiritual Needs		C		F109
Several women stated that sexual intercourse could not be restored because of treatment - related impotence; in most cases, wives learned to appreciate that their husband was alive, focused on helping their husband stay healthy through lifestyle modifications, and found closeness through deepening the marital friendship or spiritual relationship.	“Our relationship is different, but he’s still my guy. We’re good friends. We pray together every night, holding hands. It’s hard to stay angry with each other when you do that.” (pg. 33)	Interpersonal / Intimacy Needs	U			F110
Reservation of the marriage was a key focus of women’s adaptive work and in most cases involved the cultivation of couple intimacy. Characteristic actions included affirmation of the marital bond, efforts to understand problems from the husband’s perspective, and finding new ways to share intimacy.	Not reported	Interpersonal / Intimacy Needs			NS	NS31

Women reported efforts to understand their husband’s experience of treatment and survival, sought to reinforce the husband’s sense of masculinity, and nurtured the marital bond through modified sexual practices (e.g. caressing, oral sex, baths) and other nonsexual means (e.g. shared social activities).	Not reported	Interpersonal / Intimacy Needs			NS	NS32
Not reported (Preservation of marriage/couple intimacy)	“Losing our sexual relationship was hard. I talked to God daily asking for help to find other ways to be close to my husband.” (pg. 34)	Interpersonal / Intimacy Needs		C		F111
Not reported (Preservation of marriage/couple intimacy)	“Marriage is a covenant relationship a sacred promise made to each other and with God. In keeping this promise comes the working out of problems in marriage.” (pg. 34)	Interpersonal / Intimacy Needs		C		F112
Not reported (Preservation of marriage/couple intimacy)	“It’s important not to feel deprived in your marriage. That’s an erosion of God’s gift. Find out why you feel deprived. Correct it. Amen.” (pg. 34)	Interpersonal / Intimacy Needs		C		F113
Author: Kelly et al, 2015						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Health care professionals in outpatient clinics had communicated their understanding of the expected pattern of sexual recovery of patients and their partners.	“We found … (the nurse practitioner) very good and explained about sex life. Her information helped a lot.” (pg. 134)	Health Care Service / Comprehensive Cancer Care Needs	U			F114
Talking about sex and intimacy was an important topic, requiring a senior clinician to give the topic the gravitas it deserved.	“I think you have to have a doctor or a nurse or somebody who’s in a senior position who is quite sympathetic and knows how to be able to sit down and talk to a couple, because I think that’s very important really, you know it’s no good like the couple going in and seeing the consultant or the doctor or the nurse and they’re just flippant with them, they don’t explain things.” (pg. 134)	Health Care Service / Comprehensive Cancer Care Needs	U			F115
The majority of this sample did not feel that clinicians had discussed sexual functioning well and reported that such concerns were not always appropriate to share with friends / family.	“Unconsciously, I was really scared. I wish I’d had somebody like you (the researcher), what I would call a professional that’s, because it’s not something that you can talk about to close friends because, it’s too intimate”. (pg. 135)	Health Care Service / Comprehensive Cancer Care Needs	U			F116
There were also examples where the private impact had probably not been appreciated by health professionals. One of the members of the two gay couples who took part spoke of how his partner had become ‘very fat after the hormone therapy’ and his partner does not now ejaculate.	“This was very hard to come to terms with, a fattish old man.” (pg. 135) “Joint ejaculation had been very important to us, now he says I’m coming, I’m coming! but there’s no visible signs.” (pg. 135)	Health Care Service / Comprehensive Cancer Care Needs	U			F117
The man also spoke of feeling guilty at finding his partner unattractive since hormone therapy but had felt unable to discuss this—certainly not with a health professional.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS33
Learning had been experiential rather than anything given to the couple as an information package associated with the treatment choices.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS34

Partners often reported feeling excluded from the events relating to the cancer and its impact.	"I would have liked, just once in a while, for the consultant to say, "How is your wife getting on? I really feel out of it and the fact was of course, I was affected." (pg. 136)	Health Care Service / Comprehensive Cancer Care Needs	U			F118
Partners were rarely asked during clinics about their own needs in relation to the effects of the diagnosis and treatment outcomes. They were rarely made to feel they had a genuine contribution to make to the medical consultation.	*Interviewer:* "Did they ask you, questions in terms of you know, were you okay?" *Partner:* "No they never did, they were very nice but I think the… medical establishment in general is still rather formal." *Interviewer:* "There's no guidance, for same sex couples?" *Partner:* "No, that's right, and that really would have been helpful." (pg. 136)	Health Care Service / Comprehensive Cancer Care Needs		C		F119
It was noteworthy that women would often speak of the problem in joint terms rather than just the mans'.	"we had a small, fairly flaccid penis" (pg. 133)	Physical / Daily Living Needs	U			F120
One partner, who found it difficult to express her frustration at her husband's ED, and his complacency towards it.	"I'm dying… of thirst… of food" (pg. 133) "A little cuddle? No! I'm starving." (pg. 133)	Interpersonal / Intimacy Needs		C		F121
Partner's understood the gradual process involved in resuming sexual expression after prostate cancer treatment.	"Rome wasn't built in a day" (pg. 133)	Interpersonal / Intimacy Needs		C		F122
[Expectation of resuming full sexual activity as soon as practicable] Partners expressed the belief in taking things at a more steady pace.	"He was too anxious to try to please me and nothing would happen at all and I would say, 'Don't be silly, you wait and see another couple of months will be fine and give it time and don't jump the gun too quick. You know, you're not ready yet'. After a while it was fine. I think it was a natural reaction." (pg. 134)	Interpersonal / Intimacy Needs	U			F123
Some couples told the interviewer that they had not talked with each other about sexual concerns either before or after treatment.	"No, we didn't actually. I was very patient, because I think you have to be like that, you can't just like click your fingers and everything's going to come back to normal because it's a big operation and he was very ill and it's just basically, if you love somebody enough it's just, you just must sort of have patience and wait and then everything is fine." (pg. 136)	Interpersonal / Intimacy Needs		C		F124
Couples discovered that although penetrative sex may not be possible, other forms of intimacy and sexual activity were still available, and again the issue of orgasm without full EF was mentioned.	"One thing that I picked up on, which I thought was quite extraordinary was that you can have an orgasm with a flaccid penis." (pg. 136)	Interpersonal / Intimacy Needs	U			F125

Author: Pinks et al, 2018

Finding		Domain	Unequivocal (U)	Credible (C)	Not Supported (NS)	Label
The focus group process had provided an opportunity to talk about things that they would not have discussed in any other context.	"We do talk to a certain degree but it's not quite the same… I just feel better for being in this group and having an opportunity to talk about things that I've kept bottled up. Some of the things I've said here this morning I wouldn't say to anyone else." (pg. 56)	Facilitator	U			F126
Younger participants sought support from healthcare teams and were happier to share the responsibility of care for their partner.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS35

Participants described how important it was to have information and someone to talk to before treatment, when they did not know what questions to ask or what to expect and was when their anxiety was high.	"I got really angry and frustrated at the lack of information. You need to know at the beginning what sort of changes will happen, especially in your sexual life…this type of information is not something you can put in a brochure, you need to be able to talk to someone, sexual counselling or someone who can help you figure out what you need to do and how to prepare for what's going to happen." (pg. 54)	Health Care Service / Comprehensive Cancer Care Needs	U			F127
Their interactions with healthcare professionals focused only on treatment choices and that the implications had not been fully explained to them. Medical teams were only focused on curing the cancer and were reluctant to discuss the impact of sexual dysfunction on their quality of life.	"The doctors certainly didn't give us any help on the sexual side of things, they never mentioned it, basically it felt like they were saying "I'm here to cure the cancer I'm not here to help you with anything else." I believe the medical profession has got this mindset that once they have treated the cancer then they think that you don't need to worry about anything else." (pg. 54-55)	Health Care Service / Comprehensive Cancer Care Needs	U			F128
Some participants said they felt they were left to deal with it on their own and were just given a "bag of information to take home and read" when they wanted support and information to help prepare for changes in their relationship. Participants described having a sense of helplessness and uncertainty that had left them feeling distressed.	"I Felt absolutely useless, I really wanted to do something to help my husband, but I didn't know where to turn as there wasn't any information for the wives… I just needed someone to talk to, I remember going off and just crying as I didn't know what to do to help him." (pg. 55)	Health Care Service / Comprehensive Cancer Care Needs	U			F129
Many reported they did not have an opportunity to express their concerns with the specialist and said they were made to feel that their needs were not important. Participants agreed that prostate cancer was actually a couple's disease and that the impact on partners should also be considered.	"He only spoke to my husband about what he thought or was worried about, it was as if I wasn't there. The urologist didn't consider the fact that he was treating the partner of somebody else… I think this is a really important issue because it's the kind of cancer that affected both of us. I think doctors really need to treat the couple rather than the man." (pg. 57)	Health Care Service / Comprehensive Cancer Care Needs	U			F130
Few had sought help from counsellors, whilst most didn't know where to obtain support. Many participants felt that their partners were so consumed in their own illness that they had no awareness of what they were going through, or the needs they may have.	"He was so focused on what was happening with him that he hadn't thought about was happening to me… I felt so alone, I just wanted to escape to somewhere where I wasn't thinking about it…I just needed some respite, but nobody seemed to care." (pg. 57)	Psychological / Emotional Needs	U			F131
The experience of emotional caregiving had started to take its tole to the point where they were struggling to cope.	"I didn't know how to cope with his moods, he has always been the support for me and I was trying to support him, but I felt absolutely useless… I know it's been very hard for him to mentally readjust to the whole thing but I'm really struggling, I don't know what to do, I've tried everything." (pg. 54)	Physical / Daily Living Needs	U			F132
Some participants shared how erectile dysfunction had left their husbands feeling less of a man because they could not perform sexually. This resulted in many men withdrawing from the relationship which left participants grieving a loss of intimacy both physically and emotionally.	"If I'm being honest, I'm missing that intimacy … as far as he was concerned the sexual side of our relationship was finished and that didn't seem to bother him, but it upset me … He just withdrew totally from the relationship…it didn't seem to matter to him what I wanted or needed…now it feels like we are just acquaintances rather than husband and wife." (pg. 56)	Interpersonal / Intimacy Needs	U			F133
Some who had had an active sexual life prior to treatment, expressed feeling more distressed by the sexual dysfunction in their relationship. These participants described exploring new intimacy options as a couple, even those who relied on what was familiar before the cancer diagnosis were willing to	Not reported	Interpersonal / Intimacy Needs			NS	NS36

encourage their partner and take the lead, which they said they had not done before.						
Some partners, who had been married for a long time explained that sex had not been part of their relationship for several years, thus, finding satisfaction in companionship.	Not reported	Interpersonal / Intimacy Needs			NS	NS37
Most women admitted that they simply withdrew from the physical side of the relationship as well in an attempt to cope with their loss and protect their partner from his.	"There was definite withdrawal on my side, in fact it was all my side…I didn't want to put him in that position and remind him of his sexual issues… making him feel inadequate, I didn't want him to think that I thought he was less of a man." (pg. 56)	Interpersonal / Intimacy Needs	U			F134
All the participants agreed that intimacy was important to them and that they would have benefitted from support to help them adjust to the intimacy changes in their relationship.	Not reported	Interpersonal / Intimacy Needs			NS	NS38
Participants felt a sense of responsibility to be the sole provider of emotional support and encouragement to try to help their partner cope.	"It was almost like once his sexuality had gone, he wanted to die, he gave up. He has been suffering from depression for quite a few years now, I try to cheer him up and encourage him to do things…to get involved just so he had other things in his life, but he won't. His life just revolves around me…I've had to be his backbone, it's so exhausting". (pg. 53)	Family Related Needs	U			F135
Older participants struggled alone as best they could, describing a sense of duty and stoicism to take on the caregiver responsibility. These women expressed feeling an expectation that it was their role to look after their husband when he was ill and that they felt they should be happy that their partner was alive. This perspective had left them feeling a sense of guilt and shame when they were unable to cope.	Not reported	Family Related Needs			NS	NS39
Most participants shared how they were constrained by their partners, and how their partners were unwilling to talk about their issues.	"Communication is a big issue for us. I've said, "unless we know what each other's thinking we can't help each other," but he's very private… also he didn't really want anyone else to know about this… I've had to respect his wishes, but it has left me with no one to talk to." (pg. 55)	Family Related Needs	U			F136
Some younger participants described how they had taken the lead to ensure important issues were discussed.	Not reported	Family Related Needs			NS	NS40
Other women who had always been able to discuss issues with their partner prior to prostate cancer continued to talk openly during survivorship.	Not reported	Family Related Needs			NS	NS41
Many older partners found it harder to talk and described how they came from an era where men did not talk about their feelings and the intimate side of their relationship was not discussed.	Not reported	Family Related Needs			NS	NS42
All participants agreed that they needed help in being able to vocalize some of their feelings, so they did not have to suffer in silence. Even those in close relationships admitted they held	Not reported	Family Related Needs			NS	NS43

back on discussing some things that they felt would upset their partner.						
Author: Primeau et al, 2017						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Participants felt they were given time to share emotional concerns with Prostate Cancer Support Nurse (PCSN).	"[The specialist nurse] answered my questions when I asked about what hot spots [were], and she explains it to you in detail and you understand what she is saying. Since we have come into contact with the specialist nurse, we have been able to ask her things, because she sits and listens to you and asks you questions." (pg. E246)	Facilitator	U			F137
They lacked clinical information on diagnosis. Did not fully understand the information or implications for treatment.	"[The clinician] said it was prostate cancer, and [my husband] had hot spots. But they never explained to us what the hot spots were and where they were." (pg. E246)	Health Care Service / Comprehensive Cancer Care Needs	U			F138
They expressed uncertainty about treatment and progression of cancer. They were unsure of how often the extent of metastases would be assessed and how their care team would monitor their condition.	"Is it going to spread more? And how would they know, other than asking [the specialist nurse] if he could have a scan to see if it was spreading?" (pg. E245)	Psychological / Emotional Needs	U			F139
The main physical needs were related to managing the long-term side effects of ADT.	"I would have liked some advice on how to cope with this tiredness" (pg. E245)	Physical / Daily Living Needs	U			F140
Couples spoke of financial implications and consequences of man living with a palliative cancer diagnosis.	"I mean, I gave up my work. I was due to retire, but I gave up my work earlier… I would have probably carried on working as I was not due state pension until now, but I do get an occupational pension as well. I took the decision to be the carer. But I just felt that I was not giving my best to my job, and so I felt it was time to stop." (pg. E245)	Physical / Daily Living Needs	U			F141
Most couples were comforted they still had each other, seemed to appreciate continued companionship, and accepted the adjustment in their intimacy. However, change in sexual function had a major negative impact on some couples' quality of life, which was a struggle to adjust to.	"You weigh it all up, I would rather have [patient 150/1]. I would rather have companionship and [patient 150/1] than a sex life, you know, life changes and priorities, you know. Rather companionship, I just put up with it." (pg. E246)	Interpersonal / Intimacy Needs	U			F142
Author: Rossen et al, 2016						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Spouses all mentioned that their partners participating in the lifestyle intervention helped them cope because they knew their husbands were doing something.	"I was happy that he participated in the lifestyle intervention. Really happy about it. I relaxed more because I knew something was being done." (pg. E5)	Facilitator	U			F143
At this stage of their husband's disease, most women did not feel that they had to supress their own needs (e.g., their need for information or to communicate with others for support). This is due to their ability to initiate satisfactory coping action and the information received through NILS that has led them to believe their husbands are not ill at this stage. One of them talked about	"Greater patience in our everyday lives. All the little things. I don't know if I am better at it, but I'm aware of it if he doesn't have as much patience as he had otherwise." (pg. E7) "I don't think there is a difference, not now. There is no big difference. Because I don't feel he is sick anymore." (pg. E7)	Facilitator		C		F144

needing to have a little more patience with her husband in their everyday life.						
The framework of active surveillance and the behavioural lifestyle intervention fostered confidence in spouses to embrace supportive role toward their husbands.	"I felt very safe with my husband going to check-ups. I rely a lot on professional knowledge and the scientific values. I think the knowledge we have gotten from the doctor, and the NILS team has been really good. And we have been able to ask questions." (pg. E6) "Because you feel you can do something with your diet and exercise - even though there are no guarantees that it will work but being able to do something. Not just sitting around like a victim. I think that's the reason we don't really consider him a cancer patient." (pg. E6) "It was like, when you were in a project, you relaxed because you knew he was under surveillance, and he went through it all. Nothing left to chance there." (pg. E6)	Facilitator	U			F145
One of the spouses felt that she would have benefitted from extra support in the form of consultations with a doctor or psychologist about her anxieties. This woman did not feel she could talk to anyone in her social network.	"That would have been good. Getting to know, 'Missus, your husband is in a very early disease stage. Don't worry so much.'" (pg. E6)	Health Care Service / Comprehensive Cancer Care Needs		C		F146
Several of the spouses reported feeling anxious and frustrated with what they considered to be insufficient information about the situation provided by health professionals at the time of their husband's diagnosis.	"How were we to know what a disease stage means? We just knew it was cancer. I was sure that my husband was going to die." (pg. E4) "There was a really bad follow-up on what it means to get a prostate value (PSA) that requires some sort of treatment or surveillance." (pg. E5)	Health Care Service / Comprehensive Cancer Care Needs	U			F147
They also pointed out that receiving information from doctors or seeking it themselves had helped them a great deal.	"I think you get a whole lot of information, and I think that is really nice. A lot of things that you didn't know. I think that's what you do when you get a disease." (pg. E5)	Health Care Service / Comprehensive Cancer Care Needs	U			F148
All spouses talked about worries while waiting for test results.	"But it's really tough. It's wonderful when he has just had the test and gets told that it hasn't increased a lot. Then it's great for about a month. But then you start to worry, what about next time? And what if it has increased, what then? Do we choose the operation or what?'' (pg. E5)	Psychological / Emotional Needs	U			F149
While spouses acknowledged issues that caused them to worry and feel anxious, they also described how they tried not to focus on worrisome issues so as to avoid overly disrupting their everyday life activities.	"You have to be careful not to dwell on it. You have to remember to keep it where you can say, ''Now we are setting it aside.'' It can easily rear its head again, if something happens, but you also have to set it aside. You have to be careful not to focus on it all the time because then I think you could get some weird thoughts." (pg. E5) "I think I am good at keeping a lid on it. We shouldn't think about it all the time. And I don't. It's there, but it's not what you go around thinking about." (pg. E5) "I once had a very good psychologist who gave me some tools to say, ''Okay, there is a worry. On a scale from 1 to 10. How big is that worry''? A very, very rational approach. And then to say, ''Okay there is a worry and it is there. Don't sweep it under the carpet, it is	Psychological / Emotional Needs	U			F150

	there. It is there but you have to set it aside.'' Then you can take up that worry if the PSA values go up, for example." (pg. E5) "He knows I don't think of him as a cancer patient. I get a little…, when he gets a letter where it says ''cancer patient,'' I think, ''He is not a patient yet.'' You are not a patient until you are sick." (pg. E5)					
Most spouses did not feel a need at this stage to receive extra support through consultations with a psychologist or support groups with other women (lifestyle intervention project is a reason for this).	"Maybe if it progresses and starts to be a threat in another way than it feels today." (pg. E6) "I think that I haven't had that great a need to talk about it and that I haven't had so much focus on this disease thing because he has been so good at taking advantage of these things [exercise and rye]. I believe it has made a huge difference." (pg. E6)	Psychological / Emotional Needs	U			F151
In general, the spouses used their social network and communicated with their husband, children, family, friends, or coworkers about their husbands diagnosis and their own anxieties.	"If I'm worried, I'm very bad at hiding it. And if I'm hiding it, I'm sure the people around me, including my husband, notice that I'm feeling bad. So, it's better to put it into words, maybe they're sad words, but you know what, I'm thinking about this, and it worries me. But I think, I put it into words, and when it's said, it's much easier. Maybe it's hard and maybe there is no solution, but saying it out loud, I think that's important." (pg. E6)	Psychological / Emotional Needs	U			F152
Immediately after the diagnosis, some found it hard to talk about it, but this got easier over time.	"I thought sometimes at work, ''You have to get some work done now.'' My thoughts were all over the place. The further I came along, the easier it was to talk about it." (pg. E6)	Psychological / Emotional Needs	U			F153
Most had sporadic anxieties about their situation. They worried about the progression of the disease, their husband dying, and what was going to happen in the future.	"It's there, but I don't think about it all the time. It always comes to the surface at some point when you lie awake and can't sleep. That's how it is for me, I think. But I don't think it is taking over our lives. It comes when it comes. Sometimes, some sort of event starts something that makes you think about it." (pg. E5)	Spiritual Needs		C		F154
Most spouses actively supported partners with regard to practical concerns in relation to diagnosis. They helped them seek information and accompanied them to doctors' appointments. Some even arranged doctors' appointments for them.	"I have been with him every time there has been something. That has been good, because then you know what it's all about." (pg. E6)	Physical / Daily Living Needs	U			F155
One spouse did not talk to anyone about her anxieties.	"I don't talk to anyone about it. Not even my husband. He knows that I speculate a lot about it. He knows that I don't sleep that well at night; I feel a bit like we must talk as little as possible about it. You don't start to say, ''Oh I feel so bad, I am so afraid there is something wrong with my husband and I sleep so badly at night.'' I just don't do that. I don't do that. There are maybe a few I mention to that I don't sleep very well at night because I can't stop speculating, and then they say, ''You have got to stop with that.'' (pg. E6)	Family Related Needs	U			F156
Several of them actively supported their husbands in their lifestyle intervention. They did not see it as a nuisance, and some even took it up as a hobby	"Sometimes we all eat rye, but we have other things on the table as well because the other family members don't always want to eat rye pasta. But it's not a problem." (pg. E5)	Family Related Needs	U			F157

	“I have never got as much exercise as I have since my husband joined this project. It gives me energy. I have gotten several friends to exercise as well. So it has been really positive being a part of this. I make sure he gets exercise. Sometimes he comes home and says, ‘‘I don’t feel like it today, I am tired, do I have to go?’’ Then I say to him, ‘‘You have to.’’ (pg. E5)					
Author: Sanders et al, 2006						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Couples did agree that receiving individualised information and personal coaching from healthcare providers would be more useful than being provided with a list of resources to contact. Thus tailoring the method of delivering information about prostate cancer survivorship in a manner that uniquely meets the needs of men and women, as well as their needs as couples is important.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS44
Women stated that they wanted to participate in support groups with other women.	Not reported	Social Needs			NS	NS45
Another woman commented that she wanted to talk about sexual issues and the loss of sexual desire with other women without men in the room.	Not reported	Social Needs			NS	NS46
Not reported (Comments demonstrating differences between men’s and women’s perspectives on communication, intimacy, and relationships).	“I mean, us women really enjoy getting together. We can communicate really well and share, you know, but men may not be comfortable with that.” (pg. 506)	Social Needs		C		F158
Women reported feeling that their roles changed from being protected and cared for to a more active role of emotional caretaking.	“Now, all of a sudden, I’m protecting him and taking care of him.” (pg. 505) “having to build up his ego” (pg. 505) “I started working on my husband from the day we found out he had cancer, working on his ego” (pg. 505)	Physical / Daily Living Needs	U			F159
Not reported. (women’s perspectives on communication, intimacy, and relationships).	“Our roles are changing. He used to be my protector; now, all of a sudden, I’m protecting him and taking care of him, and it’s kinda odd.” (pg. 506)	Physical / Daily Living Needs		C		F160
Women also reported that sex was different since treatment and that they felt unattractive and not wanted.	“I don’t feel like a woman anymore: He doesn’t have a reaction.” (pg. 505)	Interpersonal / Intimacy Needs	U			F161
The women talked about wanting to show warmth and affection in other ways.	“It’s being more overtly warm and loving towards him; I pat him on the butt, pour his coffee, hug him on the forehead.” (pg. 505)	Interpersonal / Intimacy Needs	U			F162
The women spoke of a loss of affection from the men because the men feared it might lead to the expectation of sexual performance.	Not reported	Interpersonal / Intimacy Needs			NS	NS47

Women reported a lack of romance in their intimate lives and frustration at the lack of available sexual information.	Not reported	Interpersonal / Intimacy Needs			NS	NS48
They felt that sex had become too clinical between them and their partners. For example, too much preparation and planning were involved, which contributed to a lack of spontaneity.	"You don't always want to be the initiator." (pg. 505)	Interpersonal / Intimacy Needs		C		F163
Not reported. (women's perspectives on communication, intimacy, and relationships).	"I think that was such a giant aspect of what we all go through… If we had just talked about sex." (pg. 506)	Interpersonal / Intimacy Needs		C		F164
Not reported. (women's perspectives on communication, intimacy, and relationships).	"we should remember you are never too old to have a date night… it just means enjoying each other… it doesn't have to be the full thing." (pg. 506)	Interpersonal / Intimacy Needs		C		F165
Not reported. (women's perspectives on communication, intimacy, and relationships).	"It made us different as a couple… The sex has to be different… and I decided to make me feel like him… less sexual." (pg. 506)	Interpersonal / Intimacy Needs		C		F166
The women believed they had to be active as women and had to work learning what they could about the disease and how best to proceed.	Not reported	Family Related Needs			NS	NS49
Not reported. (women's perspectives on communication, intimacy, and relationships).	"As women, we buck up and take care of business… walking of being genuinely concerned… but not breaking out and making him unduly alarmed." (pg. 506)	Family Related Needs		C		F167
Not reported. (women's perspectives on communication, intimacy, and relationships).	"I don't think he would have done anything about it. It was like denial… They didn't want to do any surgery, but I insisted something should be done." (pg. 156)	Family Related Needs		C		F168
Author: Sinfield et al, 2008						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
They also confirmed that the urology nurse specialist provided an important source of information.	Not reported.	Facilitator			NS	NS50
Partners often encouraged the patient to go to their family physician with their symptoms but did not attend the appointment themselves. Consequently, their understanding of the situation was often limited by the extent of the family physician's explanation and the ability of the patient to remember and report what had been said. Neither they nor the patient understood the reason for referral.	"I had never heard of a PSA test um obviously I read up about it afterward and I know a little bit about it now but at the time I didn't know that's how a diagnosis, you know one of the ways of diagnosing." (pg. 94)	Health Care Service / Comprehensive Cancer Care Needs		C		F169
Partners usually accompanied the patients when they attended the hospital for further tests even though they had not been invited or encouraged to do so by the family physician or the hospital. They were pleased that they had attended the hospital to support the patient and reported positive experiences (e.g. the hospital facilities and their treatment by staff), as well as	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS51

negative ones (e.g. unclear what was happening and felt ignored or excluded during explanations).						
Partners felt that it was important that they were invited to attend the appointment with the specialist because having heard what was said first hand, they found it easier to take part in subsequent discussions.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS52
Partners were keen to support the patient, by accompanying them and asking questions about issues that the patient was unlikely to raise.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS53
Some felt that their concerns were not taken seriously or that they were perceived as trouble, as the specialist gave the impression that they did not wish to be questioned.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS54
Partners sometimes had to take initiative to be included in consultations and, where they reported they had their own information and support needs, these were not met in the consultation.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS55
Partners sometimes has to take initiative to be included in consultations and, where they reported they had their own information and support needs, these were not met in the consultation.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS56
Partners echoed the importance of being clear about practical arrangements for dealing with side-effects of treatment (e.g. where to get supplies of continence pads, erectile dysfunction).”	“Erm I think one thing that I didn’t have at that stage which might have been helpful is to have a one to one with somebody just on my own cos I don’t think that ever happened.” (pg. 94)	Health Care Service / Comprehensive Cancer Care Needs		C		F170
Partners identified the provision of written information as useful.	Not reported	Health Care Service / Comprehensive Cancer Care Needs			NS	NS57
One partner reported that she made regular contact with a charity to build a supportive relationship. Many of the partners referred positively to their experience of attending a support group and the access they had to the urology nurse specialist at these meetings.	Not reported	Social Needs			NS	NS58
Other unmet needs included practical support with shopping and support for themselves.	Not reported	Physical / Daily Living Needs			NS	NS59
The monitoring of patients was re-assuring for their partners, some of whom took a leading role, developing a better understanding of the process and requesting tests on behalf of the patient.	Not reported	Family Related Needs			NS	NS60
Author: Tanner et al, 2011						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**

They reported feeling secure with and completely confident in the medical care their partner received and had faith that their partner's cancer would be cured.	"great time" (pg. 155) "wonderful experience" (pg. 155)	Health Care Service / Comprehensive Cancer Care		C		F171
Female partners reported feeling helpless, sad, violated, scared, and "waiting for the next thing to happen."	"I often feel as if I'm sitting on a block of ice that is slowly melting, and when it melts my husband's cancer will be back—if it ever really was gone." (pg. 155)	Psychological / Emotional Needs	U			F172
Many talked about living in a state of silent suffering, watching as their partners suffered, and refraining from sharing their own experiences in an attempt to not hurt their partner's feelings.	"More and more we are tied together as the husband's health deteriorates and he becomes more dependent on his wife. A wife suffers silently as she watches a beloved husband lose his health and gradually his independence. I don't suppose there is much of a way to gauge that kind of pain. It is of the hearth. It definitely saps the pep out of a girl." (pg. 155-156)	Psychological / Emotional Needs	U			F173
Not reported (Emotions)	"I detest cancer. I watched it slowly consume my mother. The fact that my husband is now fighting it makes me feel old and vulnerable." (pg. 156)	Psychological / Emotional Needs		C		F174
Not reported (Emotions)	"I worry about my husband, with his PSA going up. What can we do for him, to help him? How bad his pain will be if there is medicine that could help him." (p. 156)	Psychological / Emotional Needs		C		F175
Not reported (Emotions)	"For some reason I don't feel as angry as I did—life is just too short to waste it on negative stuff." (pg. 156)	Psychological / Emotional Needs		C		F176
Outside relationships became harder to maintain as a partner's illness limited the ability to continue usual socializing activities.	Not reported	Social Needs			NS	NS61
Women discussed how their lives were totally changed by their partner's illness or treatment. They reported being unable to maintain their usual couple activities because of their partner's mental or physical limitations and how things such as travel and socialization with friends were inhibited by their partner's health problems.	Not reported	Social Needs			NS	NS62
Not reported (Treatment-related issues)	"My husband has a lot of body pain which keeps us from social activities as a couple. . ." (pg. 156)	Social Needs		C		F177
Many women also reported that, overall, they were happy. This viewpoint was maintained in spite of reporting on the additional workload, insecurity about the future, and emotional stress brought on by their husband's condition. In addition, spirituality, prayer, and being thankful were main threads running through these women's responses, and many women connected their happiness to their relationship with God.	Not reported	Spiritual Needs			NS	NS63
Not reported (God/spirituality)	"The church is the center of our world." (pg. 156)	Spiritual Needs		C		F178

Not reported (God/spirituality)	"Because of our connection with God, we are both doing the best we can for our health and putting our trust in God." (pg. 156)	Spiritual Needs		C		F179
Not reported (God/spirituality)	"I worry every day about losing him but thank God for every day we have together." (pg. 156)	Spiritual Needs		C		F180
Not reported (God/spirituality)	"I . . . am praying that everything will be all right." (pg. 156)	Spiritual Needs		C		F181
Frequently, women reported coping with acute health problems or surgeries or dealing with chronic health conditions of their own, and some discussed how they found themselves reliant on their ill partner for care.	"He makes most of the decisions and helps me to take the medicines I need." (pg. 155) "He deals with all the nasty stuff I hand out while I'm in pain". (pg. 155)	Physical / Daily Living Needs	U			F182
Some shared how they found themselves struggling to care for other ill family members or deal with the death of loved ones in the face of their own or their partner's health challenges.	Not reported	Physical / Daily Living Needs			NS	NS64
Women also discussed the need to deal with other life stressors such as being forced to learn new household skills ranging from managing for the family finances to dealing with household repairs.	Not reported	Physical / Daily Living Needs			NS	NS65
Many women recognized the need to maintain life balance by actively striving to continue their regular activities in spite of these lifestyle challenges. This included continuing both leisure activities (eg, belly dancing, lunching with friends) and activities of daily living (eg, getting one's hair done, going to work).	Not reported	Physical / Daily Living Needs			NS	NS66
Humour and patience were helpful tools women used to deal with the physical and personality changes they observed in their partner, as was the focus on fighting the cancer together, and on self-care activities such as dietary changes, new exercise programs, and complementary and alternative therapies.	Not reported	Physical / Daily Living Needs			NS	NS67
Frequently, women reported mourning the loss of a sexual relationship with their partner.	"I do miss my partner's automatic sexual responses as there has always been a terrific chemistry between us as well as tremendous goodwill. We both mourn this loss." (pg. 156-157) "One of the things that is missing in our life is sex. I miss the closeness and good feelings I always felt." (pg. 157)	Interpersonal / Intimacy Needs	U			F183
Women shared feelings of disbelief that this had happened to them, their acceptance of their new reality, their search for alternatives to sexual relations, and an increased focus on intimacy. They also reported a desire to confirm their experiences with others.	"It would be interesting to find out if other people have become impotent." (pg. 157)	Interpersonal / Intimacy Needs	U			F184
Some shared that their partner's diagnosis affected their philosophy of life and that their focus had become more attuned	"We are so looking to that time when we can resume our lovemaking and have a normal life." (pg. 157)	Interpersonal / Intimacy Needs		C		F185

to living an intentional high-quality, love-filled life while enjoying the time they had left together. Others reported living in a state of limbo as they awaited some future event that would indicate a return to "normal."						
The majority also reported changes in their sex lives ranging from minor inconveniences during sex to complete lack of sexual relations, and most attempts to improve their partner's sexual functioning were unsatisfactory.	"The sex sucks!" (pg. 157) "It's like living with a best friend now." (pg. 157) "I have a hard time believing that the radiation and/or cancer can cause this disinterest in me." (pg. 157)	Interpersonal / Intimacy Needs	U			F186
Some women attributed these sexual changes to advancing age and did not perceive it as a problem, whereas others reported that the lack of a sexual relationship was driving them apart and that they felt as if they were losing touch as time went on.	Not reported	Interpersonal / Intimacy Needs			NS	NS68
Some women reported re-evaluating their relationship in light of the changes experienced in their partners.	"I do not know my husband anymore. He has become a different person. I have to think about my future: to continue like this or be done. Which is worse?" (pg. 157)	Interpersonal / Intimacy Needs	U			F187
They reported feeling betrayed by their spouse's lack of sharing and were reluctant to risk increasing their partner's suffering by talking about personal experiences with them.	"He refuses to discuss his lack of sexual performance or seek medical help. I feel unloved, undesirable, and useless. When I try to discuss this, he feels sorry for himself, ignores or gets angry, and blames me or gets mean." (pg. 157)	Interpersonal / Intimacy Needs	U			F188
Women acknowledged that how they and their partners deal with each other and how they take care of themselves are both important.	"My husband will never be the same person. I believe he gets very frustrated because he can't perform sexually… There is nothing I can do anymore. I already tried to be the perfect wife. It doesn't work anymore… I decided to fill my life with many activities… to help me with it and not to get ill. I take one day at a time, and I love to look after myself. He is what he is, and I have to let him be what he wants to be." (pg. 158)	Interpersonal / Intimacy Needs	U			F189
Not reported (Marriage/children)	"After just celebrating 60 years of marriage, we find we pretty much know what each other is thinking or what we'd like to do." (pg. 156)	Interpersonal / Intimacy Needs		C		F190
Not reported (Relationship issues)	"My husband's cancer has had an impact on our relationship and philosophies of life. It has been the catalyst that smoothes out the bumps in the road of life. What is important has changed and how we live our life every day has become much more positive. The little annoyances of life seem much less important and planning and maintaining a high quality of a love-filled life has become very important." (pg. 156)	Interpersonal / Intimacy Needs		C		F191
Not reported (Sexual issues)	"Even with the use of Viagra, at times it's not possible to have intercourse. This is very hard for both of us since a great marriage must have intimacy in order to survive. He has been so good to see to it that I am satisfied but even then desire for sex has left him. This has been a big adjustment for me because he was always so virile and so easily aroused. I was slower and not as interested in sex as he was, for years. Now it seems the roles have switched; I crave the intimacy that	Interpersonal / Intimacy Needs		C		F192

	sex brings, and his interest just is not there. He could live without sex!” (pg. 156)					
Not reported (Coping)	“I spend time each day doing nutritional research on what studies have been helpful in defeating cancer in lab experiments, realizing that this may not apply to humans but looking for every possible edge to help him defeat the cancer.” (pg. 156)	Family Related Needs		C		F193
Author: Walker et al, 2012						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
The nature of sexual and intimate experiences had to be renegotiated. Often this process included changing the goal of the sexual encounter from orgasm to experiencing other pleasurable sensations.	“We [now] like having nice dinners, we like having a nice bottle of wine. I still like to somehow get involved sexually, even though it doesn’t involve intercourse.” (pg. 454)	Interpersonal / Intimacy	U			F194
For some this intimacy could not be adequately replicated in any other way. To stop having sex would mean to stop being intimately and emotionally connected. Maintaining sex, despite changes, was the best way for them to maintain intimacy.	“I think it’s a part of who you are, to share this with your partner, and maintain it, as best as you can.” (pg. 456)	Interpersonal / Intimacy		C		F195
Some were attempting to use oral erectile medications, erectile aids, or toys to restore sexual activities. These methods were appreciated.	“I always touch him when he’s touching me. Even if he doesn’t get an erection; I still need to feel him. Even though we’re playing with a toy, I don’t find it enjoyable unless I fantasize that it’s actually him.” (pg. 456)	Interpersonal / Intimacy	U			F196
Another partner shared how she appreciated being able to focus on touch and physical affection without it always having to turn into something entirely sexual.	“I love the cuddling; I love the touch. I would actually say that that’s one of the gifts at this time: there hasn’t been the sexual urgency with the reduced testosterone.” (pg. 457)	Interpersonal / Intimacy	U			F197
Replacing sex with another valued intimate activity seemed to be a common strategy that allowed them to maintain relational intimacy.	“We can’t do this [sex] anymore, but let’s find something that we can do to replace that. We try to always have something planned to look forward to, like a little holiday, or going out to a dinner theatre, live music, or something like that. That maybe replaces some of those other activities, but still we get a lot of pleasure and enjoyment out of it.” (pg. 457)	Interpersonal / Intimacy	U			F198
A strategy was to consider that sex was no longer a priority (age did not influence this).	“The reason it didn’t really affect us that much is because there are other parts to the relationship. That’s just one little part of it, and we were able to bypass it.” (pg. 457)	Interpersonal / Intimacy	U			F199
Partners often expressed that their relationships had suffered from a loss of expressed affection. Partners usually continued to exhibit affection in the same way they always had, whereas displays of affection became less common from the patient. Without intercourse as a clear indication of attraction – doubt feelings.	“When he does do things to show me, he loves me, it’s because I’ve had to get angry about it. If he just took the initiative on his own, without having to be told.” (pg. 457)	Interpersonal / Intimacy	U			F200
Not all reported that ceasing intercourse was accompanied by fewer expressions of affection.	“I was relieved that he still wanted to cuddle, kiss, and tell me he loves me. I thought that if the libido was gone, that all that good stuff would be gone. But it wasn’t, so that was great.” (pg. 458)	Interpersonal / Intimacy	U			F201

Partners felt a sense of isolation and the imbalance in connection became a significant challenge that affected sense of intimacy. To avoid isolation, the women tended to facilitate conversation, and were particularly persistent in making a conscious effort to engage their partner in discussion.	“I spent a lot of time really trying to get an understanding of what’s going on for him, so that I can look back and understand. So that next time it comes up, maybe we cannot go into the same ugly places.” (pg. 458)	Interpersonal / Intimacy	U			F202
They indicated that they were embarrassed to have to “ask” for sex, and struggled with the thought that, if they had to ask him to participate, he must view sexual activity as a chore.	“When he does help me out [sexually], I almost feel like I’ve had to ask him, because we’ve had to resort to using a toy now, and I almost feel like I’m being selfish. And I’m worried about us using a toy, like how does that make him feel?” (pg. 459)	Interpersonal / Intimacy	U			F203
Successfully maintaining sex was associated with a shift in who was responsible for initiation.	“I took over the role of initiator, which has been wonderfully freeing for both of us. It has added richness to our intimacy and allowed him “off the hook” to start what he has no inclination for.” (pg. 459)	Interpersonal / Intimacy	U			F204
Several women reported that they felt they were putting in more “effort” than their partners. In many cases, sexual encounters became one-sided.	“I’ve gone through a period of anger about it, where I felt like I was the only one bringing anything to the table. In reality of course, I am. I am the only one bringing anything to the table, but it didn’t stop me from feeling angry about that loss.” (pg. 459)	Interpersonal / Intimacy	U			F205
Some women were uncomfortable with this imbalance.	“I can’t satisfy his needs any longer, so basically what I’m doing is asking him to satisfy me.” (pg. 459) “I’m thinking, he can’t do anything and here I am getting all the pleasure. It’s just for me, and I just think it’s only making him feel worse. It’s just a reminder of what he can’t do.” (pg. 459)	Interpersonal / Intimacy	U			F206
Several women reported that they struggled with an imbalance in pleasure. They expressed a strongly held belief that they should not be the only one receiving sexual pleasure.	“I even felt bad because I want him to enjoy it as much as I do.” (pg. 460)	Interpersonal / Intimacy	U			F207
A new challenge was to cope with their continuing sexual desire that was no longer satisfied or expressed through sexual experiences.	“I don’t. I shut down completely. I just don’t want to, even when he says, “Oh, I’ll, you know, give you an orgasm” or something. I don’t want to, I just, I just…” (pg. 460)	Interpersonal / Intimacy	U			F208
A real challenge existed for the partner in trying to cope with her still present sexual desire. These women described how challenging it was to ignore or disregard their own sexual desire or arousal.	“You have to… learn to put it aside, I guess, and go on. I find that if we, or if I do try to become, well, sexually active, it’s sad because you just, you can’t get anywhere.” (pg. 460)	Interpersonal / Intimacy	U			F209
Without their sexual relationship as evidence, some partners began to doubt that they were still physically attractive to their partner. Some women even reported doubting that their partner was still in love with them.	“There’s times where I could just eat him, I just love him so much. It’s really hard because, I don’t know if he does. I doubt that he’s that close or has the same feelings [toward me]. I doubt it all the time.” (pg. 461)	Interpersonal / Intimacy	U			F210
Those who stopped sexual activity struggled with grief over the loss of a significant part of their relationship. Those who maintained sexual activity were also unable to avoid grief because they grieved over the way sex used to be. Some found that trying to have sex after ADT was too painful and emotionally distressing.	“I find that if we do try to become sexually active, I get very, very, very depressed. It’s a reminder of what you used to have.” (pg. 461) “In my experience of being a wife and a lover, I loved being able to pleasure him in that way. It’s a joy, a wonderful gift. It feels like I’ve stopped being able to be a gift giver. I had to grieve that loss.”	Interpersonal / Intimacy	U			F211

	(pg. 461)					
Not having the indisputable interest indicated by their partner's sexual advances resulted in the women doubting their attractiveness.	"It's the fact that I could walk across the room naked, which before would trigger certain things in my husband, most of them delightful to me, but it just didn't happen anymore." (pg. 461) "I don't feel the same about myself. Before, if you wear something sexy, it would turn him on. Well obviously, I can't turn him on anymore, so you feel different about yourself." (pg. 461)	Interpersonal / Intimacy	U			F212
Author: Williams et al, 2014						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Women's fears generally diminished as time went by, although a few mentioned fear of recurrence.	"I don't know. I think that—that something is going to get messed up inside and—and revive [the cancer]. I don't know. I get very scared." (pg. 309)	Psychological / Emotional Needs	U			F213
Women worked to present a strong face to their husband. Even after the initial shock, however, women explained the importance of concealing their emotions and showing their husband that they had everything under control.	"I pretended to have a lot of strength to not show him that—that in reality I was going down." (pg. 310) "I got very sad to see him like that, but I tried to be strong and say, "I think that the last thing he wants is to see that someone feels defeated, right?" … I put my pains aside… I had to shower him. I had to change him. I had to help him in all that I could, right?" (pg. 310)	Psychological / Emotional Needs	U			F214
A few women received very little support at all, and these women clearly carried a greater burden than those who were supported.	"When he went back to work, and well, I stayed home by myself. Here, by myself in the hills. And that is how I am daily: by myself from six in the morning until five in the afternoon that he comes home, five thirty. I am by myself here. Can you believe? With nothing to do, just, like the saying goes, thinking only bad thoughts." (pg. 312)	Social Needs	U			F215
The majority of women's fears came with their husband's initial diagnosis. They also described fear of losing their husband.	"It's when you hear the word 'cancer.' Well, you think that, like you are going to lose the person… Well, I thought that if I lost him, it was going to be difficult." (pg. 309)	Spiritual Needs	U			F216
Most indicated that it was essential to trust in God, and firmly believed that God would ensure their husband's recovery.	"No, I had—I had a lot of faith in God that no… I put him in the hands of God so that He could heal him." (pg. 312)	Spiritual Needs	U			F217
Their faith allowed them to use the experience of their husband's cancer as an opportunity to change their life in a positive way.	"I mean, you stop working, you stop a lot of things, and you have rest. And in that you sort of look back and say, I have been doing this, I have been doing that. I mean, it's like God gives you that opportunity to—to think about and to see what is good, what is bad, what you should change." (pg. 312)	Spiritual Needs	U			F218
Women cited anxiety, difficulty, and frustration when dealing with the symptoms and side effects of their husband's disease and treatment, particularly when they were dealing with their own health problems.	"It was difficult… I was sick from having all of those illnesses, and then his problem. Well, I got worse, and… I don't like to see blood… I would wash his parts and I would dry him and put his diapers on him, oh man. I found it difficult with him, but thank God, we got through it. Look now—now he puts his diaper on by himself. Now,	Physical / Daily Living Needs	U			F219

	well, he can do it, right? But before, I—I would take him by the hand to the bathroom and—and I would clean him, wash him, and I would put his diaper on.” (pg. 309)					
They often spoke about dietary changes in “we” terms, seeming not to have thought twice about changing their own diet along with their husband’s after his diagnosis.	“When they gave us the news that he had cancer, we started to go walking. The way we cook at home changed a lot. Uh, we added more vegetables, more fruits. Uh, we try to cook with not that much fat.” (pg. 311)	Physical / Daily Living Needs	U			F220
Women generally said that their husband’s erectile dysfunction did not affect them much personally, although many assumed that it would have affected other women.	“It has not affected me at all, sincerely… because I have been a woman that has not been very demanding… Yes, there are women that are affected by it, but… we are different, and we have different ways of acting. And it hasn’t affected me at all because we have been married forty-one years.” (pg. 309)	Interpersonal / Intimacy Needs	U			F221
They did, however, worry about their husband’s reaction to erectile dysfunction and put his feelings first. One described how she used to like being physically affectionate with her husband but stopped because she worried that he would think she wanted to have sex.	Not reported	Interpersonal / Intimacy Needs			NS	NS69
A few also explained how they tried to dispel their own sexual feelings so that they would not increase the impact erectile dysfunction had on their husband.	“And I try to—to dispel some things or some [sexual] desire that I have with other things… Going out to have fun, taking trips, and perhaps relaxing and going to the beach, who knows? So I try to understand and get through things, right?” (pg. 310)	Interpersonal / Intimacy Needs	U			F222
Women mentioned attempting any sexual alternative to vaginal intercourse, although others described refocusing their intimate life on holding hands or cuddling.	“He tried, and he feels that he finishes, but he expects it to be like it was before the operation… So that he won’t feel bad, I tell him that perhaps over here, through the rectum he can maybe do it. But no, I know that—I don’t—no.” (pg. 310)	Interpersonal / Intimacy Needs		C		F223
Women often felt that the experience had brought them closer to their husband and improved their relationship.	“We have always had good communication since we got married. Everything has been good with our relationship, but I think that… it did improve a little more. We communicate a little more. For anything, we are both there, something that before well, maybe we left something out, right?” (pg. 312)	Interpersonal / Intimacy Needs	U			F224
These women, whose relationship was (often) in bad shape before their husband’s diagnosis, saw their situation worsen.	“different, because there is nothing anymore, there is nothing, nothing, nothing of nothing. No affection not even a hug, not even a—nothing… As if you were just living with someone, everything is cold.” (pg. 312)	Interpersonal / Intimacy Needs	U			F225
They worked to manage the reactions of their family members through showing that same strong front.	“I talked to [my children] since the beginning when they first told us. And I always told them, look, we are all going to support him. We are going to take it like something normal and talk to him. “We are with you, and we are going to fight, and we are going to help you fight.” …So, he has that support.” (pg. 310)	Family Related Needs	U			F226
Some women relied primarily on family members of their own generation, such as their siblings and siblings-in-law, whereas others relied on children or even grandchildren for support.	“More than anything, the company of my siblings… of my family members. Well, I’d always talk with them even if it’s over the phone. But I’d also be talking to them as they encouraged me more also.” (pg. 311)	Family Related Needs	U			F227

	“Well, more than anything over the phone [laughs]. Yes, over the phone. Sometimes every third day I am calling my daughters in Tijuana, and then here in Santa Paula I have a son… He understands me as well.” (pg. 311) “You know what has helped us? I think that if the two of us were alone we’d be depressed, but my small grandchildren are here. They come and make noise. They sleep here. In other words, they keep us active. “Take us here, Grandpa!” And there goes Grandpa with them, taking them where they want. All of that helps one forget things.” (pg. 311)					
Some women experienced moments when they needed support and did not receive it, often in the early stages of treatment.	“I did have the necessity to—to share the load, right? … But well, there was nobody [at the hospital]. Nobody spoke Spanish… [crying] I was so desperate that the lady who was there… she turned around and she took out three sheets from her notebook. She gave them to me, and she gave me a pen, and I started to fill it out, and it relaxed me a little bit, right?” (pg. 312)	Family Related Needs	U			F228
Author: Wittmann et al, 2014						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Partners wished for some form of counselling or peer support, although not all were sure they would have participated. Two partners said they did not want to discuss personal matters with others.	Not reported	Barrier			NS	NS70
While wishing for support, partners were unsure of what they needed and whether they would use it.	Not reported	Barrier			NS	NS71
Cancer centres survivorship program provided support. The study facilitated conversation about sex.	“I think that was a good thing that we did the study because you get all this brought out.” (pg. 2513)	Facilitator	U			F229
Some female partners, including a pre-menopausal one, reported lower sexual desire than their male partner. Despite menopause, some partners retained robust desire.	“I don’t know whether I’m just sensual or whether a lot of women are like me… I mean I’m 70 but I still enjoy sex” (pg. 2511)	Interpersonal / Intimacy Needs	U			F230
Partners acknowledged sexual losses and decrease in frequency but were more philosophical. Thus partners, while also acknowledging sexual losses, were less distressed than the patients.	“…you can’t get discouraged because sometimes it works, sometimes it doesn’t….” (pg. 2512)	Interpersonal / Intimacy Needs		C		F231
Partners thought that good communication and ongoing sexual activity were more important that erectile function.	“I think you just have to, um, let the partner know that, um, you know the strength or length of an erection is not the most important thing, that the most important thing is that you can be intimate with one another and give each other pleasure, um, and just feel closeness and love.” (pg. 2512)	Interpersonal / Intimacy Needs	U			F232
Partners that communicated about sexual changes, challenges and worries about performance found that communication helped focus away from worry about erections and performance.	Not reported	Interpersonal / Intimacy Needs			NS	NS72

In couples that were not connecting sexually, two partners felt unable to pursue sexual activity out of sensitivity to the men who withdrew because of immense sadness about the loss of erectile function.	Not reported	Interpersonal / Intimacy Needs			NS	NS73
Several described additional obstacles such as relationship problems.	"I've often told him before (laugh) it really does mean a lot, how you also treat me out of the bedroom." (pg. 2512)	Interpersonal / Intimacy Needs	U			F233
Most, no matter how frustrated with the current status of their sexual relationship, planned to continue to work on sexual recovery – 2 patients and 2 partners anticipated adapting to a relationship without partnered sex.	Not reported	Interpersonal / Intimacy Needs			NS	NS74
More than half had been responders in sexual activity pre-op; now they thought they should initiate as they saw the men struggling with worry about performance.	"…all of the sudden those roles have changed where I should be the more aggressive one, and now, you know, he's to be the passive one…so I don't do it, you know…old habits are hard to break." (pg. 2513)	Interpersonal / Intimacy Needs	U			F234
All partners saw their role in the patients' recovery of erections as providing emotional support and encouraging men to engage in rehabilitation activities.	"Especially in the beginning…. I felt like I was almost nagging him to, you know, 'practice'." (pg. 2513) "I'd like to think that he recognizes that I'm there for him no matter what." (pg. 2513)	Interpersonal / Intimacy Needs	U			F235
All partners attempted to resume sexual relationships by being available. Post-menopausal diminished libido did not affect this attitude of wishing to be helpful sexually.	"My role is to be there when he wants to have intercourse or wants to try." (pg. 2513)	Interpersonal / Intimacy Needs	U			F236
Partners did not always find their sexual interest welcome. They believed that the men were too worried about performance to respond. This left partners with a sense of uncertainty about how to fulfil their sexual role.	"I did actually speak to him and said, 'You know, even if you can't make love, just remember that the touching is still part of it.' I mean, um, I have in the past ruffled his hair at the back and I'll put my hand on his knee if we sit down and things like this, and he tended to drift away totally." (pg. 2513)	Interpersonal / Intimacy Needs	U			F237
All partners said that recovering sexual relationship was important to them – reported having had unmet sexual needs during the recovery.	"I would like him to be happy and, you know, I have needs. I was not as sexually active as he was…but I yeah, it was very important." (pg. 2513)	Interpersonal / Intimacy Needs	U			F238
Author: Wootten et al, 2014						
Finding		**Domain**	**Unequivocal (U)**	**Credible (C)**	**Not Supported (NS)**	**Label**
Access to support and knowledge about where to ask for support was also identified by partners as a significant problem.	"I definitely think …somewhere in those early stages … [if someone] suggested …seeing someone or seeing a counsellor it would have made a big difference for me… for both of us." (pg. 1255)	Health Care Service / Comprehensive Cancer Care Needs	U			F239
Partners from couples who were experiencing higher emotional distress found it difficult to feel confident to ask questions of the doctors and were often reluctant to express their concerns.	"I'm not going to ask things which is probably another thing we need to address, the protocol of what wives can know …so you just kind of think 'should I say something now? No maybe I'll do it when, or maybe tomorrow morning after we've got some sleep." (pg. 1254)	Health Care Service / Comprehensive Cancer Care Needs	U			F240

The type and variety of information obtained appeared to be directly related to the level of emotional well-being.	"I really didn't think there was enough information for me about… um… expectations around recovery and what I could do for him or to help him or how I can be supportive." (pg. 1254)	Health Care Service / Comprehensive Cancer Care Needs	U			F241
Partners reported feeling the need to be positive and not show their own emotions.	"He said you know 'it's alright for you, you're not going through it' and I then had to sort of try to get it across to him 'you don't seem to understand I am trying to keep so calm and so cool and not let you know I just wanted to fall down in a heap but you're not allowed to do that you don't do that you know' but the thing is how do you find that balance." (pg. 1254)	Psychological / Emotional Needs	U			F242
Partners spoke about feeling constantly anxious, worried, and unable to openly discuss their concerns which, in turn, let to increased anxiety and isolation.	"He thinks it's just his battle that's what I find really difficult' …I've found it a very isolating experience." (pg. 1255)	Psychological / Emotional Needs	U			F243
This role of responsibility was identified by many partners as resulting in feeling worn out by the experience but unable to take time out for themselves.	"I've been very practical in my support…doing the dishes or doing something like that or keeping the house running." (pg. 1255)	Physical / Daily Living Needs		C		F244
This role of responsibility was identified by many partners as resulting in feeling worn out by the experience but unable to take time out for themselves.	Not reported	Physical / Daily Living Needs			NS	NS75
In couples in which the man did not cope well, partners were distressed, and the relationship was impacted by a lack of open communication and/or sexual intimacy.	"He became totally single minded. In my opinion feelings just closed up… went to a separate room and we're still in separate room." (pg. 1254)	Interpersonal / Intimacy Needs	U			F245
Some couples found that even physical touch triggered significant emotional distress.	"It [is] harder to do something [hug, or touch] that reminds you how terrible your loss is." (pg. 1254)	Interpersonal / Intimacy Needs	U			F246
The impact of the change in sexual functioning on the relationship was challenging for most partners. Minimisation of the loss associated with the sexual changes experienced also appeared to prevent open communication.	"I heard him say to someone "oh impotence doesn't worry me", which absolutely floored me…I thought he didn't care about us not being intimate anymore." (pg. 1255)	Interpersonal / Intimacy Needs	U			F247
The cost of erectile function aids (such as Viagra) and attitudes to sexual aids were stated as barriers.	Not reported	Interpersonal / Intimacy Needs			NS	NS76
Some partners were surprised at how long recovery of sexual function took and thought this should be more explicitly communicated before treatment.	Not reported	Interpersonal / Intimacy Needs			NS	NS77
Many partners also commented that they were not prepared for the adjustment required and would have benefited from some guidance in this area.	Not reported	Interpersonal / Intimacy Needs			NS	NS78
The majority of partners reported feeling a sense of loss of intimacy at some level, and for most, this was not related to sex, per se, but rather to the loss of closeness in the relationship.	"Literature infers you can dodge the bullet on ED [but there will be a] level of damage – [literature] needs to be more explicit that from patients point of view surgery can save [you] from cancer but [can] bugger their lives." (pg. 1255)	Interpersonal / Intimacy Needs		C		F248
Some partners spoke about feeling subtly directed by the man to not talk about the CaP experience and a perception that the CaP was his concern and not theirs.	"I found my husband made it more difficult for me at the stage when he found out he'd had prostate cancer he wouldn't tell anyone, I	Family Related Needs	U			F249

	couldn’t tell anyone, didn’t want to tell boo which made it really difficult.” (pg. 1255)					

Abbreviations: ADT, Androgen Deprivation Therapy; ED, Erectile Dysfunction; HCP, Healthcare Professional; CaP, Prostate Cancer; PSA, Prostate Specific Antigen.