Experiences of female partners of prostate cancer survivors: A systematic review and thematic synthesis

Abstract

The purpose of this systematic review and synthesis of studies reporting qualitative data was to understand the gendered experiences of female partners of prostate cancer survivors to inform psychosocial support for women. We searched Medline, PsycINFO, EMBASE, AMED, CINAHL, Cochrane Database of Systematic Reviews, and Sociological Abstracts for articles on 15 and 16 April 2019, and again on 30 November 2020. English language articles published in peer-reviewed journals were included if they reported solely on findings describing the perspectives of the female partners. Extracted data were analysed using line-by-line coding, organization of codes into descriptive themes, and development of analytical themes. A theoretical framework was then selected to organise the relationships between issues that were found to be central to the experiences of female partners. Of 4839 articles screened, 14 met inclusion criteria, reporting 13 studies with a total sample of 359 female partners. Ussher and Sandoval's theory to describe the gendered positionings of cancer caregivers accommodated the thematic findings. The overarching theme reflected the substantive psychosocial impact of prostate cancer on female partners. Women's experiences were influenced by self-positioning (as part of a couple; provider of support to their male partner; resilient; and guided by faith and spirituality), being positioned by their partners' response (manager of male partner's psychological distress or strengthened by male partner's positive response) and by their broader contexts (family members and social networks; clinicians and the health system; and cultural values and customs). Findings highlight the need to avoid reductionist approaches to gender. Greater consideration of 'contextualised femininities', or conceptualising the influence of gender roles, relations, and identities within the wider life course contexts of female partners is required in the design and delivery of psychosocial support services.

Key words: Prostate cancer; female partners; qualitative research; gender; positioning theory; systematic review

What is known about this topic:

- Female partners may experience more distress than the prostate cancer (PCa) survivor, however PCa survivorship research has largely focused on the psychological and physical effects of PCa treatments on men.
- Research recognises the influence of gender roles, relations, and identities, on the experiences of female cancer caregivers.
- Taking a gender lens may offer important insights to support female partners.

What this paper adds:

- The progressive use of gender is key to advancing caregiver wellbeing.
- Women’s experiences are influenced by self-positioning, positioning by their partners’ responses, and by their broader social and cultural contexts.
- ‘Contextualised femininities’ should be considered in the design and delivery of women’s health services.

Introduction

Prostate cancer (PCa) is the most commonly occurring male cancer, and the fifth leading cause of cancer death in men worldwide (Bray et al., 2018). Advancements in detection and treatment mean that men are living longer with PCa. However, for many men and their partners, this means living with negative iatrogenic sequalae that may persist for many years (Couper et al., 2006). For example, while androgen deprivation therapy (ADT) is effective in slowing disease progression and increasing survival, ADT is associated with multiple, often debilitating side-effects which manifest as changes in physical, cognitive, social and sexual functioning (Rhee et al., 2015). Men's experience of treatment side-effects that involve changes in sexual function and intimacy will have an impact on their partners (Beck et al., 2009).

To date, research on PCa survivorship has largely focused on the psychological and physical effects of PCa treatments on men (Hyde et al., 2019). The psychosocial impact on female partners is less well described, however, research suggests that they may experience more distress than survivors (Chambers et al., 2013; Couper et al., 2006). Uncertainty about the future (61%), shock (44%), and fear of death of their male partner (44%) are key concerns post-diagnosis and treatment for women, with the latter two concerns predicting higher psychological stress (Lehto et al., 2018). Studies report that 23% - 36% of female partners experience anxiety (Chambers et al., 2013; Hyde et al., 2018), up to 11% experience depression (Hyde et al., 2018), and up to 6% experience high cancer-specific distress (Hyde et al., 2018). This psychological distress has also been found to persist over-time (Harden et al., 2013; Hyde et al., 2018). Up to 70% of female partners 12 months post-treatment for localised PCa report that treatment negatively impacts their sexual relationship with their partner (Ramsey et al., 2013), and up to 35% of partners experience high fear of cancer recurrence (van de Wal et al., 2017). Predictors of increased psychological distress include higher caregiver burden and women who perceive PCa as more threatening (Hyde et al., 2018). Negative appraisal of caregiving has been found to adversely impact the cancer-specific and mental health quality of life of female partners at 3 years post-treatment (Harden et al., 2013). Assuming traditional female gender caregiver roles may have significant emotional costs for the female partners of PCa survivors (Chambers et al., 2013). This is reflected in research on female cancer caregivers, more broadly, with women caregivers reporting greater caregiver burden and more unmet needs than male cancer caregivers (Perz et al., 2011).

Both female and male partners play an important role in supporting PCa survivors (Couper et al., 2006; Lehto et al., 2018). This is increasingly recognised in the literature with a number of reviews including the experiences of partners. A qualitative metasynthesis by Collaco and colleagues (2018) on the experiences of couples affected by PCa, identified that partners can feel unsupported and 'relegated to the side-line' by health professionals, and having their own needs go unaddressed (Collaco et al., 2018). Other reviews have focused specifically on partner quality of life (Hammond & Montgomery, 2018), black and minority ethnic patients' and partners experiences (Rivas et al., 2016), and the role of women (spouses and other family members) in African American men's screening and treatment decision-making (Bergner et al., 2018). While these reviews bring a focus on the experiences and needs of partners, the majority have not used a gender lens or explored the overarching spectrum of female partner experiences. An important ongoing area of PCa survivorship research concerns male partners of PCa survivors having different and diverse experiences and needs (Ussher et al., 2018). Bergner et al.'s (2018) qualitative metasynthesis is the only review to examine women's roles as spouses or other family members using a gender lens (Bergner et al., 2018). The review found women play key roles in screening and decision making as counsellors, coordinators and confidants (Bergner et al., 2018). The identity and experiences of female cancer caregivers can be influenced by how they position themselves and are positioned by others, such as health professionals, family members and friends, in relation to their role as caregivers (Ussher & Sandoval, 2008). This suggests that taking a gender lens in exploring the experiences of female partners of PCa survivors may offer insights to inform tailored psychosocial support interventions.

While good quality evidence exists for effective psychosocial and psychosexual interventions for men, evidence of acceptable and effective interventions for female partners remains unclear (Chambers et al., 2017), and the optimal method of screening for partner distress has not been identified (Hyde et al., 2019). There is increasing recognition of the need for further research to understand partner or caregiver-specific issues to inform evidence-based approaches to support their health and well-being (Chambers et al., 2017; Couper et al., 2006; Gilleece et al., 2019; Hyde et al., 2019). In particular, research addressing the experiences of female partners of PCa survivors (Arrington, 2005) increasingly recognises the potential influence of gender roles, relations, and identities (Lim et al., 2015; Ussher & Sandoval, 2008). That said, research specific to femininities in these contexts of caring for men with PCa is emergent at best (Kim et al., 2019). We undertook a synthesis of qualitative data from studies solely reporting the experiences of female partners to distil patterns and diversity across health care contexts to synthesise what is known and provide recommendations for addressing knowledge and practice gaps (Tong et al., 2012). This review aims to understand the gendered experiences of female partners of PCa survivors to inform psychosocial support for women.

Methods

The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach (Moher et al., 2009) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong A et al., 2012) guided this review.

Protocol Registration

The protocol for this review was registered with the PROSPERO register (PROTOCOL NUMBER).

Eligibility Criteria

Included studies report original qualitative data in the English language, are published in peer-reviewed journals, and exclusively report findings that describe the perspectives of female partners of PCa survivors. Qualitative data took the form of direct quotations from participants. Data collection methods could include interviews, focus groups, or open-ended survey items.

Studies were excluded if they reported the perspectives of caregivers, partners or other participants who did not identify as female partners of PCa survivors (e.g., children, extended family members, or male partners). Studies were also excluded if the female partners participated in data collection as part of a dyad or couple with PCa survivors. Although a number of qualitative studies have been conducted with dyads (Gray et al., 2000; Gray et al., 1999; Lavery & Clarke, 1999), the males' responses may influence female partners (Bruun P et al., 2010) and as such, were excluded due to the focus of the review.

Search Strategy

We searched Medline, PsycINFO, EMBASE, AMED, CINAHL, Cochrane Database of Systematic Reviews, and Sociological Abstracts for studies reporting original qualitative data from 15 to 16 April 2019. The searches were re-run on 30 November 2020 to ensure any eligible studies had not been published while the thematic synthesis was being conducted. The reference lists of included articles and relevant literature reviews were also searched. Medical Subject Headings (MeSH) and key words were used to guide the search according to three key search concepts; 1) prostate cancer, 2) perspectives and experiences, and 3) partners (see Table 1 for an example). When developing the search strategy with a health librarian we initially included an additional search concept for ‘female/women’ but found this was too limiting, and adjusted the search for broader ‘partner’ concepts to gather all the partner/caregiver studies. We then used the inclusion/exclusion criteria to select studies that exclusively looked at female partners. The search terms and strategy were tailored to each database in consultation with the health librarian. The database search results were imported into Covidence online software to manage the screening process.

Screening

Ten percent of the database search results were assessed on title and abstract independently by (FIRST AUTHOR) and (SECOND AUTHOR), who met to discuss inconsistencies and reach consensus. The remaining results were assessed by (FIRST AUTHOR). Full-text articles that potentially met inclusion criteria were then reviewed independently for inclusion by (FIRST AUTHOR) and (SECOND AUTHOR). Conflicts were resolved by discussion.

Data Extraction

Descriptive details of the included studies were recorded in an Excel spreadsheet by (FIRST AUTHOR) describing country of origin, sample characteristics (sample size, sociodemographics, type and stage of PCa and treatments undergone by partner), study characteristics (data collection, conceptual approach), and findings (themes identified by the authors).

Quality Appraisal

Appraisal of the quality of qualitative research is an ongoing area of debate (Dixon-Woods et al., 2007; Tong et al., 2012). Quality appraisal of the included studies was conducted to provide an overview of quality, but was not considered in the synthesis of data due to the lack of an accepted standardised method (Booth, 2019; Dixon-Woods et al., 2007). Quality appraisal was conducted independently by two authors (FIRST AUTHOR and THIRD AUTHOR) who established final agreement on ratings through discussion. Studies that used interviews and focus groups for data collection were appraised using the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007), where the score indicates the number of criteria included in the article (possible range 0-32, where 32 indicates all criteria included). The 21-item Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014) was used to appraise one study which collected data through open-ended survey questions, where a score of 1 indicates poor inclusion of items in the reporting of a study and a score of 21 indicates full inclusion of items.

Synthesis

This synthesis of qualitative data followed Thomas and Harden’s (Thomas & Harden, 2008) thematic synthesis approach, which involves three stages: line-by-line coding, organization of codes into descriptive themes, and development of analytical themes (see Figure 1 for data synthesis process). Several approaches are available for the synthesis of qualitative studies (Nye et al., 2016); however, the thematic synthesis approach was chosen due to its focus on evidence for practice-based relevance and intervention development which best aligned with our aim to inform psychosocial support for women.

Free line-by-line coding was carried out independently by two authors (FIRST AUTHOR, SECOND AUTHOR) using NVivo software. Free codes were kept as close to the primary data as possible. Coding was carried out on primary data located in the “Results” or “Findings” sections of each article. The two authors met to agree on codes. Disagreements were resolved by consensus. The free codes were organized into descriptive themes by two authors (FIRST AUTHOR, SECOND AUTHOR) and then confirmed through discussion with (THIRD AUTHOR). A theoretical framework was then sought to assist in the development and organisation of analytical themes. The theoretical application of positioning theory to map the gendered dimensions of cancer caregivers by Ussher and Sandoval (2008) was adapted to organise the relationships and issues central to the experiences of female partners of PCa survivors (Ussher & Sandoval, 2008). Positioning developed as an alternative concept to ‘role’ in understanding the ways humans develop self-hood (Davies & Harre, 1990). Positioning embraces the dynamic aspect of encounters between humans rather than individuals’ static uptake of ‘roles’ through observation of societal ‘role models’ (Davies & Harre, 1990). How people position themselves and are positioned by others is influenced both by their own subjective experiences of gendered identities and intersections with culture, for example, as well as their knowledge of societal role expectations around these identities and relations (Davies & Harre, 1990). Ussher and Sandoval (2008) found that the identity and experiences of female cancer caregivers can be significantly influenced by how they position themselves and are positioned by others, such as health professionals, family members, and friends, in relation to their role as caregivers (Ussher & Sandoval, 2008).

Results

Selected Studies

Of the 4839 articles screened, 14 articles met the inclusion criteria (Bamidele et al., 2019; Bottorff et al., 2008; Bruun et al., 2011; Ervik et al., 2013; Evertsen & Wolkenstein, 2010; Ka'opua et al., 2007; Ka'opua et al., 2005; O'Brien, 2017; Pinks et al., 2018; Rossen et al., 2016; Street et al., 2010; Tanner et al., 2011; Williams et al., 2014; Wootten et al., 2014), reporting 13 studies (see Figure 2), representing the voices of 359 female partners. The majority of articles (n=10) included female sex as a specific eligibility criterion. Most were conducted in the United States of America (Evertsen & Wolkenstein, 2010; Ka'opua et al., 2007; Ka'opua et al., 2005; O'Brien, 2017; Tanner et al., 2011; Williams et al., 2014), followed by Australia (Pinks et al., 2018; Street et al., 2010; Wootten et al., 2014), Denmark (Bruun et al., 2011; Rossen et al., 2016), England (Bamidele et al., 2019), Canada (Bottorff et al., 2008), and Norway (Ervik B et al., 2013). Over half (n=8) reported the ethnicity of women, with four studies reporting samples where the majority of women identified with a non-Caucasian ethnicity (Black African, Black Caribbean, Latina, Native Hawaiian, Chinese, Filipina, and Japanese) (Bamidele et al., 2019; Ka'opua et al., 2007; Ka'opua et al., 2005; Williams et al., 2014) (see Table 2 for study characteristics).

Quality of Included Studies

The average quality appraisal score for studies that were appraised using the COREQ tool was 17/32, with scores ranging from 11 to 22. The study that was appraised using the SRQR tool scored 17/21 (see Table 2 for quality appraisal scores). Most studies clearly reported the study findings with clear and consistent links between findings and supporting quotations, as well as clarity of major and minor themes. The studies also reported well on participant selection and sample characteristics, and on data coders and derivation of themes. Less consistent reporting was found around researcher characteristics and the relationship with participants, and participant involvement in data analysis. Almost half of the studies identified an underlying methodological orientation informing study design.

Synthesis of Qualitative Data

As a result of the synthesis of qualitative data, an overarching theme was developed that described the psychosocial impact of PCa on female partners which served as a backdrop to the women's descriptions of their experiences as female partners of PCa survivors. Women's gendered experiences were influenced by self-positioning (*as part of a couple*; *provider of support to their male partner*; *resilient*; and *guided by faith and spirituality)* and positioning by their partners' response (*manager of male partner's psychological distress* or *strengthened by male partner's positive response*) and their broader contexts (*family members and social networks*; *clinicians and the health system*; and *cultural values and customs*) (see Figure 3) (see Table 3 for illustrative quotes).

Psychosocial impact of PCa on female partners

PCa has been characterised by female partners as being the woman's disease as much as the man's disease due to the substantive psychosocial impact it can have on female partners (Bottorff et al., 2008; Evertsen & Wolkenstein, 2010). Female partners can experience distress characterised by anxiety and worry often due to uncertainty over disease progression and recurrence (O'Brien, 2017; Street et al., 2010; Tanner et al., 2011; Williams et al., 2014), how to cope with facing a possible future without their male partner (Ervik et al., 2013; Street et al., 2010), and what the impact on the man as head of the family may have on the family unit

(Bamidele et al., 2019). Levels of distress can fluctuate across the illness trajectory (Rossen et al., 2016; Street et al., 2010) with diagnosis identified as a particularly distressing stage (Evertsen & Wolkenstein, 2010; Street et al., 2010; Williams et al., 2014). Women also described feeling lonely and isolated, sometimes due to geographic isolation (Williams et al., 2014) as well as emotional loneliness as a result of not feeling heard and 'suffering in silence' (Bamidele et al., 2019; Pinks et al., 2018; Street et al., 2010; Tanner et al., 2011; Wootten et al., 2014). For some women, this distress was perceived as having physical health impacts such as developing shingles and high blood pressure (Evertsen & Wolkenstein, 2010; Street et al., 2010), and their own pre-existing health issues intensified the challenge of dealing with their partners' PCa (Williams et al., 2014). Women also reported difficulty with providing practical care such as managing medication and maintaining hygiene (O'Brien, 2017; Williams et al., 2014), and the strain of providing long-term emotional support (Ervik et al., 2013).

The psychosocial impact of men's sexual dysfunction varied for women. Some accepted the change in their relationship in the context of already having had children (Williams et al., 2014), and belief that declining sexual function was part of the normal aging process for both men and women (Ervik et al., 2013; Williams et al., 2014). The experience of sexual dysfunction was also characterised as a process of adjusting to unlinking loss of sex drive and attractiveness (Street et al., 2010), and reversal in the levels of sexual desire between men and women (Tanner et al., 2011). Focusing energy on other activities, such as traveling, was identified as helpful in adjusting to the loss of sexual desire (Williams et al., 2014). Other women described the impact of sexual dysfunction as hard to accept due to the implications it had for their own sexual life span (Street et al., 2010), and decrease in levels of intimacy (Bamidele et al., 2019; Pinks et al., 2018; Tanner et al., 2011). Some women described the use of sexual aids as unsuccessful (Street et al., 2010) and that these decreased the naturalness of sex (Ervik et al., 2013).

Female partners' positioning in their experiences of PCa

Women positioned themselves in four key ways when discussing their experiences of PCa: *As part of a couple*; *provider of support to their male partner*; *resilient*; and *guided by faith and spirituality*.

As part of a couple

Positioning themselves as part of a couple was a prominent response for some women. Women positioned themselves as facing PCa as a couple through use of the pronoun 'we' when discussing their experiences (Bottorff et al., 2008; Ervik et al., 2013; O'Brien, 2017; Rossen et al., 2016; Street et al., 2010; Tanner et al., 2011). Self-positioning as part of a couple could be motivated by an unconscious assumption or expectation that it is normative behaviour in a couple (Ervik et al., 2013; Evertsen & Wolkenstein, 2010).

Positioning as part of a couple was evident in descriptions of mutual decision-making throughout the survivorship journey. These included decisions to adhere to scientific facts (Rossen et al., 2016), to reduce the influence of PCa on everyday life (Bruun et al., 2011), and that the relationship, rather than sex, was of most importance (Ka'opua et al., 2005; Street et al., 2010). Self-positioning in this way was also evident in discussions around joint coping mechanisms. These included couples' use of humour around managing incontinence and prognosis (Ervik et al., 2013; Ka'opua et al., 2005), sharing joint experiences with other couples facing PCa (Ka'opua et al., 2005), taking an active approach in dealing with the impact on daily life (Rossen et al., 2016; Tanner et al., 2011), joint maintenance of a positive attitude (Street et al., 2010; Tanner et al., 2011), joint faith, and the strengthening of relationships by length of marriage (Ka'opua et al., 2007; Tanner et al., 2011).

Dealing with PCa as part of a couple could positively impact daily life. For example, the provision of practical care improved communication through working together (Ervik et al., 2013). Facing a cancer diagnosis positively influenced joint philosophies on life (Tanner et al., 2011). For other women, the impact of treatment side effects on daily life as a couple limited the ability to socialise and participate in activities outside the home (Bruun et al., 2011; Evertsen & Wolkenstein, 2010; Street et al., 2010; Tanner et al., 2011).

Provider of support to male partner

Women also positioned themselves as the provider of support to their male partner (O'Brien, 2017; Rossen et al., 2016; Street et al., 2010). Perceptions of the role of women as provider of support included being a natural instinct to care for others (Bruun et al., 2011; O'Brien, 2017), feeling it was their duty (Ervik et al., 2013), and that levels of support increased with illness severity (Ervik et al., 2013; Tanner et al., 2011). Some women contextualised their role in relation to the level of support provided by their male partners for their own health issues. While some male partners reciprocated support (Street et al., 2010; Tanner et al., 2011), others took a more individual approach to dealing with their partners' health issues in contrast to a collaborative approach (Evertsen & Wolkenstein, 2010).

Women provided support in a range of ways. These included practical support such as managing their partner's diet (Williams et al., 2014), encouraging their partner to exercise (Rossen et al., 2016), keeping the household running (Wootten et al., 2014), and providing medical care at home (O'Brien, 2017). Women also provided support through attending medical appointments with their partner (Ervik et al., 2013; Evertsen & Wolkenstein, 2010; O'Brien, 2017; Rossen et al., 2016), and assisting with translation if their partner had limited English proficiency (Ka'opua et al., 2005). Women played a significant support role for their partners in PCa support groups. This included being the 'glue' that kept support groups together, being a silent supporter during group discussions, and facilitating socialisation at gatherings (Bottorff et al., 2008).

Resilient

Being resilient was a valued characteristic for some women who positioned themselves as proactive and strong in their experience of dealing with PCa. Actively deciding not to dwell on PCa helped to mitigate psychosocial distress (Rossen et al., 2016; Street et al., 2010), with women making conscious decisions to take an active approach, particularly in learning about PCa (Bottorff et al., 2008; Ka'opua et al., 2005; Tanner et al., 2011), and focusing on moving forward (Ka'opua et al., 2005; Rossen et al., 2016; Street et al., 2010; Tanner et al., 2011; Williams et al., 2014). Being resilient also involved making decisions to focus on looking after their own health and well-being (Tanner et al., 2011) and choosing to maintain positivity through the survivorship experience (Rossen et al., 2016; Street et al., 2010; Tanner et al., 2011). Being strong and calm in the face of adversity was important (Ervik et al., 2013; Williams et al., 2014), and was influenced by strength modelled by their own mothers as well as having experienced past adversity (Ka'opua et al., 2005).

Guided by faith and spirituality

Women also positioned themselves as guided by faith and spirituality in dealing with PCa particularly around sexual dysfunction (Ka'opua et al., 2007), treatment decision-making (Ka'opua et al., 2005), and their approach to life after a diagnosis (Williams et al., 2014). Faith and spirituality played a significant role as coping mechanisms for women who positioned themselves in this way. Women drew on their faith and spirituality to maintain positivity (Ka'opua et al., 2007; Ka'opua et al., 2005), sought reassurance through prayer (Bamidele et al., 2019; Bruun et al., 2011; Ka'opua et al., 2005; Williams et al., 2014), and were comforted by belief in something greater than themselves, in life after death, and an end to suffering

(Bruun et al., 2011; Ka'opua et al., 2005). Religious values and ideals around the sanctity of marriage and looking after each other also guided women to take up the support role (Ka'opua et al., 2007). Religious communities congregated around places of worship were an important source of support (Ka'opua et al., 2007; Tanner et al., 2011).

Male responses to PCa

Women were positioned by whether their male partner responded with distress or coped well with PCa. They became either the *manager of their partners' psychological distress* or *strengthened by their partner' positive response*.

Manager of male partner's psychological distress

Dealing with their male partners' psychological distress was a significant aspect of some women's experience of PCa. Women struggled to cope with volatile changes in their partners' moods as they could often be angry (Evertsen & Wolkenstein, 2010; Street et al., 2010; Tanner et al., 2011; Williams et al., 2014) and emotionally distant (Street et al., 2010). Challenges around dealing with their partners' distress were exacerbated by not knowing how to help (Pinks et al., 2018) and lack of recognition of their own distress (Bamidele et al., 2019). The manifestation of distress was linked to the impact of PCa on masculinity (Evertsen & Wolkenstein, 2010), particularly around experiencing sexual dysfunction and incontinence as side effects that influenced their partners' sense of manhood (Ervik et al., 2013; Evertsen & Wolkenstein, 2010; Williams et al., 2014).

Opening up communication channels was difficult with partners who responded to distress by shutting down communication (Bruun et al., 2011; Tanner et al., 2011; Wootten et al., 2014). The decision to 'keep the illness inside themselves' (Bruun et al., 2011; Pinks et al., 2018; Wootten et al., 2014) could be emotionally hurtful (Bamidele et al., 2019), with lack of help-seeking from men identified as driven by denial (Evertsen & Wolkenstein, 2010).

Reluctance to share feelings by men was compared to women being more open to sharing (Bottorff et al., 2008). Gendered differences in the willingness to communicate openly with others meant some men hindered their partners’ communication with social networks by explicitly mandating non-disclosure, against women’s natural instinct and need to seek social support (Bamidele et al., 2019; Pinks et al., 2018; Wootten et al., 2014).

Women in this situation were positioned as the manager of their partners’ psychological distress. A prominent response was the suppression of their own emotions and needs to focus on managing those of their partner (Bamidele et al., 2019; Bottorff et al., 2008; Bruun et al., 2011; Ervik et al., 2013; Williams et al., 2014; Wootten et al., 2014). Other methods included moderating conversation to avoid hurting their partners’ feelings (Ervik et al., 2013), being patient (Rossen et al., 2016; Street et al., 2010; Williams et al., 2014), being positive (Ka'opua et al., 2005; Williams et al., 2014), and maintaining sensitivity in addressing issues such as sexual dysfunction (Ervik et al., 2013; Ka'opua et al., 2005; Pinks et al., 2018; Williams et al., 2014). Couple therapy with an ‘outsider’ was identified by women as a potential support to both managing the man’s response to PCa as well as drawing attention to the needs of the woman (Bamidele et al., 2019).

Strengthened by male partner’s positive response

If men coped well with PCa, women were strengthened by their partners’ positive response. Women coped well if their partner took a proactive approach to dealing with PCa (Rossen et al., 2016), was positive in his outlook (Wootten et al., 2014), maintained calmness (Street et al., 2010), and openly communicated his emotions (Wootten et al., 2014). These women described PCa as having strengthened their relationship and having brought them closer to their partner (Bruun et al., 2011; Ervik et al., 2013; O'Brien, 2017; Street et al., 2010; Williams et al., 2014).

Family members and social networks

Family members, informal social networks, and formal networks such as peer support groups, positioned women in various ways. Support from family members as part of a family unit framed the experiences of some women (Bruun et al., 2011; Williams et al., 2014). The wider family unit became involved with lifestyle changes such as diet and exercise (Rossen et al., 2016; Williams et al., 2014) and contributed to treatment decision making (Ka'opua et al., 2005). Involvement in the care of grandchildren could also assist in coping with PCa (Williams et al., 2014). Simultaneously caring for other ill family members as well as their partner, however, caused distress for some women (Street et al., 2010).

While informal social networks were an important source of support for some women (Bruun et al., 2011; Rossen et al., 2016), other women identified that friends either lacked the knowledge to be able to provide support or were concerned only for the well-being of their male partners (Bottorff et al., 2008; Ervik et al., 2013). Peer support groups for female partners were more formal networks that provided consistent support for women. Women attended these groups to seek support from other partners, accessing information about PCa as well as solidarity in hearing other women’s journeys (Bottorff et al., 2008). Female peer support groups allowed women to communicate openly about sensitive intimate relationship issues they couldn’t share anywhere else, as well as privately held concerns over treatment options (Bottorff et al., 2008; Ervik et al., 2013).

Clinicians and the health system

Women described being positioned on the periphery of the wider health system, feeling that their own needs were ignored by clinicians (Ervik et al., 2013). Being overlooked by clinicians during consultations was difficult to cope with in light of the significant levels of support women provided as partners (Ervik et al., 2013; Pinks et al., 2018). Lack of concern from clinicians about the psychosocial well-being of female partners (Evertsen & Wolkenstein, 2010; Rossen et al., 2016) resulted in a lack of psychosocial support (Evertsen & Wolkenstein, 2010; Pinks et al., 2018; Williams et al., 2014). This was despite the identified role clinicians could potentially play in supporting female partners (Rossen et al., 2016). Limited English proficiency was a particular barrier to psychosocial support in health systems where English was the dominant language (Williams et al., 2014).

Women identified a lack of partner-specific information from clinicians on the practical caregiving role (O'Brien, 2017; Wootten et al., 2014) which impeded their ability to know what to expect and how best to assist their partners. There was also a lack of information from clinicians on how to interpret prognosis (Evertsen & Wolkenstein, 2010; Rossen et al., 2016), the impact of certain treatment types on intimate relationships (Bamidele et al., 2019; Pinks et al., 2018; Wootten et al., 2014), and the reality of side effects and recovery from surgical treatment (Evertsen & Wolkenstein, 2010). Women valued open communication (Evertsen & Wolkenstein, 2010; O'Brien, 2017; Rossen et al., 2016) and feeling they were able to ask questions of clinicians (Evertsen & Wolkenstein, 2010; Rossen et al., 2016), yet, they expressed uncertainty over timing of and types of questions they could ask (Wootten et al., 2014). Home visits by nurses were identified by women as an avenue to ensure questions from both women and men were answered, and that advocacy from prominent public figures about the "long road after treatment" could increase access to information (Evertsen & Wolkenstein, 2010).

Cultural values and customs

Women were also positioned by cultural values and customs in their experiences of PCa. Cultural values and customs were a source of strength to draw upon in the face of adversity for some women (Ka'opua et al., 2007; Ka'opua et al., 2005), however, cultural taboos around discussing death and dying impeded the ability of other women to seek help for their own psychosocial concerns (Bamidele et al., 2019). Cultural ideals that married couples should persevere through good times and bad influenced the way women approached PCa (Bamidele et al., 2019; Ka'opua et al., 2005), and cultural ideals around masculinity were perceived to influence the way men coped with PCa (Bamidele et al., 2019; Ka'opua et al., 2005).

Discussion

This thematic synthesis of qualitative data describes the substantive psychosocial impact of PCa on female partners and their lived experiences of PCa at the individual, dyad, social, health system, and cultural levels through a gender lens. The different ways that women are positioned have implications for levels of psychological burden and coping mechanisms as well as for the design and delivery of services to support their needs. While major advancements in treatments for PCa have been made over the 15 years covered by the included studies, men still experience adverse treatment side-effects for a longer time due to increased survival rates. Despite changes in treatments and diagnostic practices, female partners have consistently identified the substantive psychosocial impact of PCa for over a decade. The impact of different treatment and diagnostic choices on female partners should be acknowledged in policy and practice, and considered when forming individualised approaches to psychosocial care for these women.

Research on femininities (feminine practices), in the context of the female partners of PCa survivors, is emergent at best, and part of a wider movement in psycho-oncology research recognising the influence of gender roles, relations, and identities on cancer caregivers (Kim et al., 2019). Research on how PCa survivors manage and respond to their illness has consistently found that masculinities (masculine practices) play a central role (Mróz et al., 2011; Oliffe, 2009). In particular, research in this area has been informed by Connell’s (1995) masculinities framework, which conceptualises men enacting complicit, subordinate, marginalised, and protest masculinities in response to the dominant Western hetero-normative ideal of hegemonic masculinity (Connell, 1995). The masculinities framework was expanded by Howson (2006) to include consideration of specific femininities in recognition that work in this area had been under-emphasised (Howson, 2006). In Howson's schema, femininities are conceptualised in relation to how women enact emphasised femininity (total compliance with hegemonic masculinity), ambivalent femininity (combinations of compliance, resistance, and cooperation), or protest femininity (challenging the hierarchy of the gender order) (Howson, 2006). These femininities are evident in some of the diverse ways women position themselves, and perceive they are positioned by their male partners, in their experiences of PCa. For example, emphasised femininity may be seen in the way some women positioned themselves as part of a couple wherein they dutifully embodied the primary provider of support to men reflecting normative womanly instincts to loyally care (irrespective of self-cost). Also evident was a resilient sense of duty often guided by faith and spirituality in adhering to religious ideals around the sanctity of marriage and the wife's role in the partnership. Ambivalent femininity may be seen in women who positioned themselves as managers of their partner's psychological distress which was enacted and operationalised both as compliance and resistance to hegemonic masculinity through an awareness that it was problematic for their own well-being to give entirely or take responsibility for all that the man felt (and expressed). PCa survivors have also positioned their wives as 'selfless supporters' without explicitly recognising their wives' own needs for emotional support (Arrington, 2005). Protest femininity may be seen in the self-positioning of women as resilient, employing an active focus on moving forward and in some cases making the decision to triage their own well-being after thanklessly trying, but failing *"to be the perfect wife"* in the face of PCa. The dyadic relationships, and how women enact femininities in response to hegemonic masculinity, evidently influences women's experiences of PCa. This is reflected in quantitative research which has found that men's psychological distress and sexual bother most strongly relates to their female partner's mental health status (Chambers et al., 2013).

The findings of the current review also demonstrate that women's experiences of PCa are not solely confined to their relationship with their male partner. The influence of broader contextual factors in how women perceive that they are positioned by their social networks, the health system, and cultural values and customs are important considerations. Framing the experiences of women through positioning theory allows for the conceptualisation of femininities to expand to include the influence of structural contexts and norms as well as their dyadic relationship with their male partner. Consideration of what might be termed 'contextualised femininities' in the tailoring of services and support through conceptualising the influence of gender roles, relations, and identities within the wider life course contexts of women may assist in ensuring that they address the holistic needs of female partners. It may also help to avoid reductionist approaches to gender. The recently released Prostate Cancer Survivorship Essentials Framework (Dunn et al., 2020) places men and their families firmly at the centre as active agents in their survivorship care, with consideration of masculinities and men-centred care a key component. Gender considerations should extend to meeting the contextualised life course needs of female partners to improve the PCa survivorship experience for these women.

Social networks are a key contextual factor influencing the experiences of PCa for female partners. Informal support networks of family and friends are an important source of support for women, although some women find that the level of support is variable. A study of informal cancer caregivers similarly found that avoidance behaviour from friends could lead to greater distress for caregivers (Stamataki et al., 2014). As informal social networks do not always provide consistent support, formalised female partner-specific peer support groups may provide reliable supports for women and are an important component to developing models of care (Hyde et al., 2018).

The positioning of female partners on the periphery of the health system is driven by the perception that clinicians ignore their needs as well as a lack of partner-specific information. Identification of the need for more partner-specific information provided by clinicians is a long-term issue (Lavery & Clarke, 1999) in urgent need of addressing. Clinicians have a key role in facilitating the involvement of female partners in consultations, addressing their information needs, as well as assessing their psychosocial needs and providing support if required, rather than focusing entirely on the patient (Collaco et al., 2018; Feltwell & Rees, 2004; Hammond & Montgomery, 2018). Provision of emotional support for female partners by clinicians is associated with lower levels of distress and can assist women in feeling a greater capacity to support their partners with PCa (Lehto et al., 2018). Provision of information and support from clinicians to female partners should be tailored to the specific preferences of individual partners rather than assuming a one-size-fits-all approach (Rees et al., 2003). There are growing calls to increase the involvement of clinicians in addressing the needs of female partners through conducting regular screening and assessment to identify partners at risk of distress, and referral to appropriate psychosocial supports, as part of PCa survivorship care (Hyde et al., 2018). Prostate Cancer Specialist Nurses (PCSNs) are uniquely placed to play an important role in coordinating survivorship care for these women (Ralph et al., 2020). Workforce training that includes education around the psychosocial needs of female partners may help support PCSNs to bring female partners in from the periphery of the health system.

The influence of cultural values and norms on the experiences of female partners is an important consideration for some women. African American women play a key role in promoting the health-seeking behaviours of African American men, addressing late-stage PCa diagnosis and subsequent inequities in outcomes (Blocker et al., 2006; Okoro et al., 2018). African American female caregivers of men with PCa are more likely to use faith-based coping and look to their communities for assistance than female caregivers from Caucasian backgrounds (Vines & Demissie, 2013). Just as research with PCa survivors identifies the need for clinicians to engage in culturally sensitive and patient-centred communication (Palmer et al., 2018), so too should care be extended to female partners. Further research with female partners from culturally and linguistically diverse backgrounds is required to tailor and target support to meet their needs.

Limitations of this review

Stringent application of established eligibility criteria excluded a study (Butler et al., 2000) on the basis that one participant in a sample of 21 women was interviewed with her male partner. While the synthesis of qualitative data from individual qualitative studies remains an ongoing area of debate (Thorne, 2019), the rigorous process of this review is evident in its systematic and transparent thematic synthesis method that involved the use of multiple analysts in the development of descriptive and analytical themes.

The lack of studies exploring the experiences and needs of female partners of men at the end-of-life, and those whose partners have died, highlights an area requiring further research. Female partners can experience an elevated risk of psychological distress if the patient is anxious in the immediate period approaching death, or if they have not had enough time to prepare for their partner’s death (Couper et al., 2006). Distress and complicated grief can continue for a long period after their partners’ death for some women (Couper et al., 2006).

Family members of men with advanced PCa have identified the need for increased access to knowledgeable clinicians and the development of family resource centres (Carter et al., 2010). The lack of focus on this group of female partners, combined with the potentially ongoing psychosocial impact of this stage, suggests a need to broaden the definition of PCa survivorship for female partners to extend beyond the death of their partner. This reflects growing calls, more broadly, for research to focus on survivorship with incurable cancer (Langbaum & Smith, 2019). Given potential delays in diagnosis caused by the Covid-19 pandemic, clinicians should be aware of the psychosocial support female partners may require related to late stage diagnosis. This review also found a lack of studies investigating the experiences and needs of younger female partners, indicating a focus for future research. While the average age of men diagnosed with PCa is around 66 years (American Cancer Society, 2021), the incidence of PCa in younger men is increasing, potentially due to diagnostic-related factors such as under/over-diagnosis and use of prostate-specific antigen screening (Bleyer et al., 2020). Recent research with younger couples affected by PCa suggests age-specific challenges around when/if to initiate conversations around diagnosis with children, concerns around the potential hereditary nature of PCa, and the impact of treatment side effects on fertility (Collaço et al., 2019), with a need for tailored supports (Collaco et al., 2020). In general, future research should be designed to specifically focus on primary research questions related to female partners.

Conclusion

Qualitative studies for over a decade consistently emphasise the substantive psychosocial impact of PCa on the female partners of PCa survivors, yet research has largely focused on the psychological and physical effects of PCa survivorship on men. The interplay of factors related to the ways women are positioned at the individual, dyadic, social, cultural, and health system levels in their experiences of PCa, should drive the design and delivery of services to understand and address their unmet needs. Incorporation of ‘contextualised femininities’ encompassing the wider life course contexts of female partners will yield dividends to both women and their partners.

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Figure 1 Data synthesis process

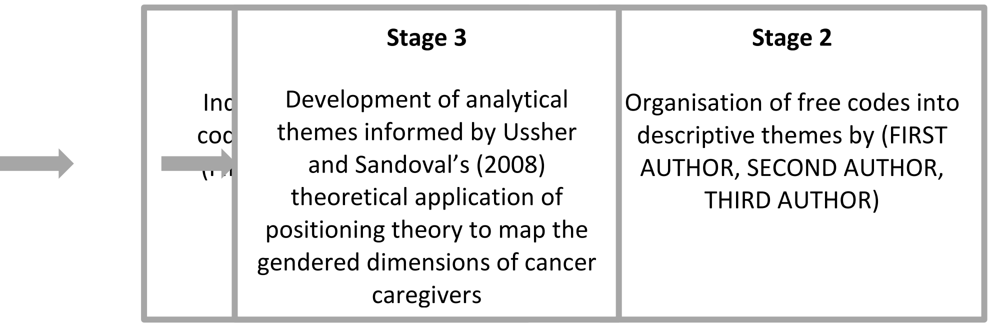
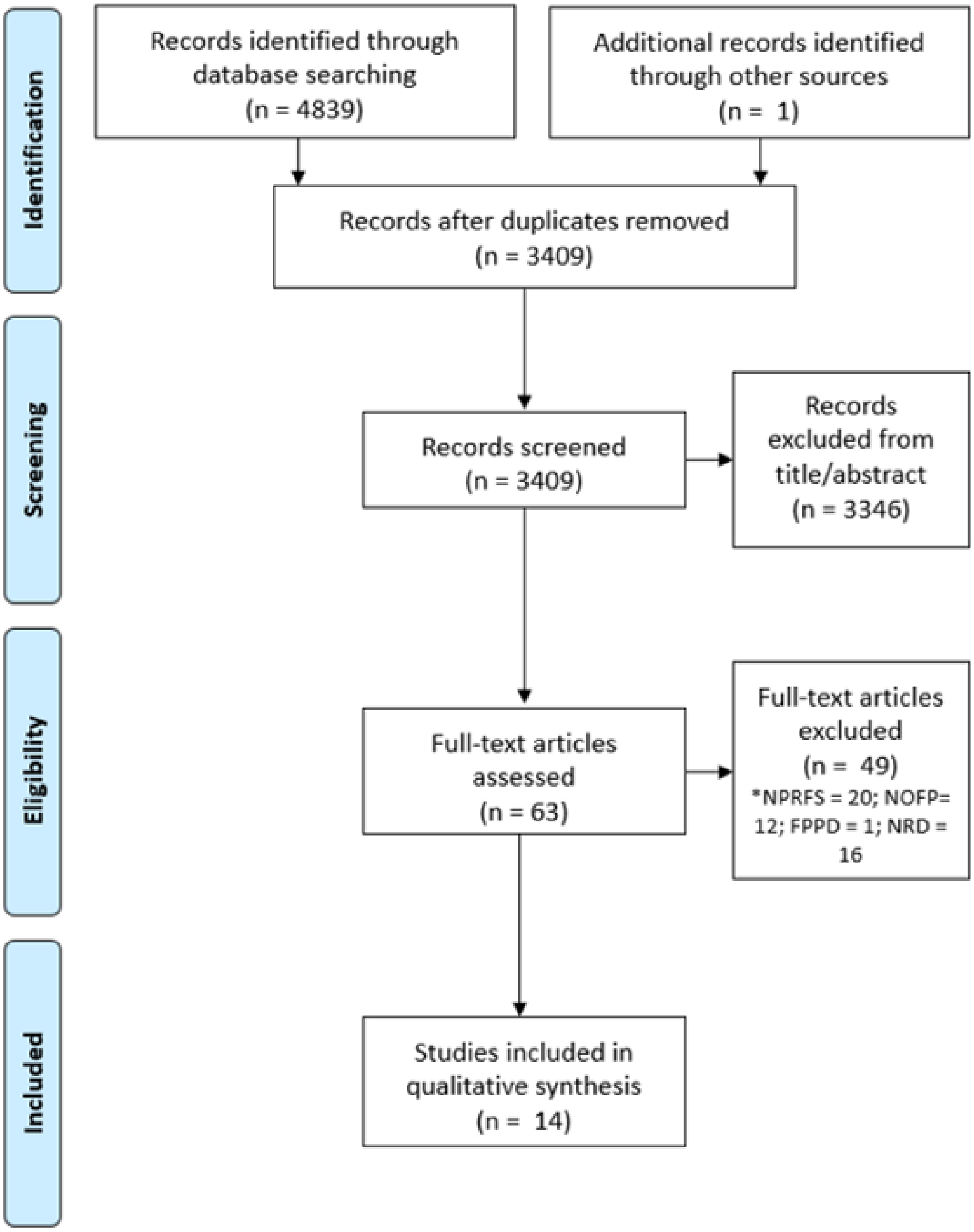


Figure 2 PRISMA flowchart of study inclusion/exclusion



*NPRFS = not peer reviewed full study; NOFP = not only reporting female partners; FPPD = female partners participated as a dyad = 1; NRD = no raw data.

Figure 3 Factors influencing the gendered experiences of female partners of PCa survivors

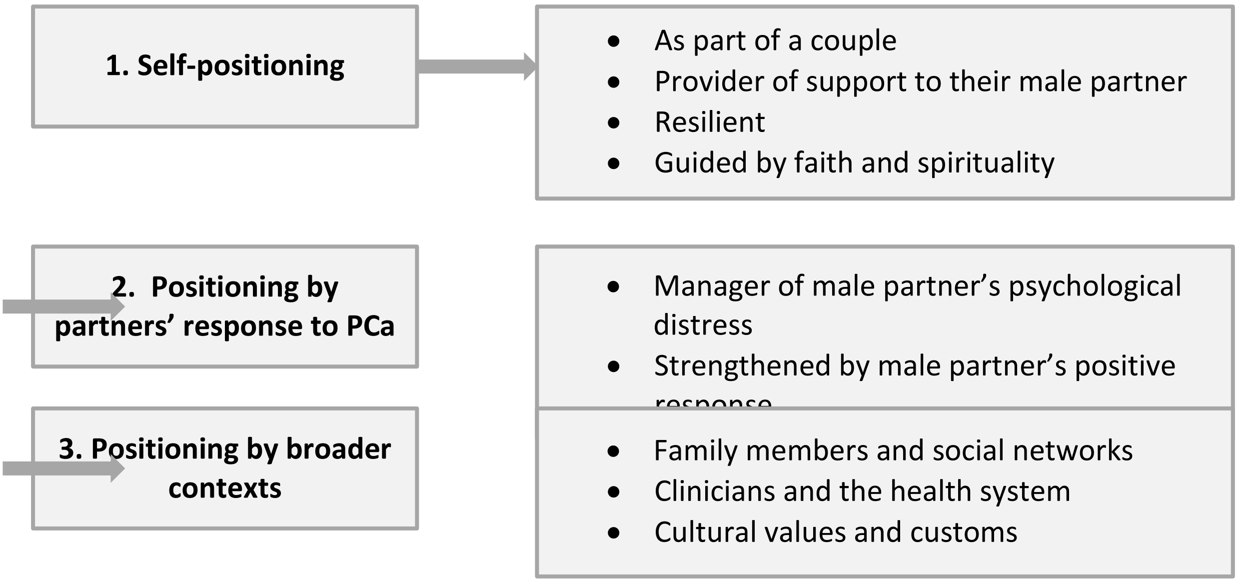


Table 1 Example search strategy

Search terms for Medline
Key search concept 1: Prostate cancer
1. Prostatic Neoplasms.mp. or exp Prostatic Neoplasms/
2. Prostate.mp. or exp Prostate/
3. exp Neoplasms/ or Neoplasms.mp.
4. 2 and 3
5. (prostat* adj3 (cancer* or carcinoma* or malig* or tumo?r* or neoplas* or metastas* or adeno*)).mp.
6. 1 or 4 or 5
Key search concept 2: Perspectives and experiences
7. Qualitative research.mp. or exp Qualitative Research/
8. Focus groups.mp. or exp Focus Groups/
9. survey.mp. or exp "Surveys and Questionnaires"/
10. Health Knowledge, Attitudes, Practice.mp. or exp Health Knowledge, Attitudes, Practice/
11. exp Attitude/ or Attitude.mp.
12. interview.mp.
13. experience.mp.
14. qualitative.mp.
15. views.mp.
16. perspectives.mp.
17. beliefs.mp.
18. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
Key search concepts 3: Partners
19. Caregivers.mp. or exp Caregivers/
20. Family.mp. or exp Family/
21. Spouses.mp. or exp Spouses/
22. partner.mp.
23. partners.mp.
24. carer*.mp.
25. spous*.mp.
26. wives.mp.
27. wife.mp.
28. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
Combined search concepts and limits
29. 6 and 18 and 28
30. limit 29 to English

Table 2 Study characteristics (n=14)

First Author (year)	Country of origin	Sample	Demographics	Partners type and stage of PCa and treatment	Design	Aim	Quality appraisal score
Bamidele et al. (2019)	England	11 women in intimate/ marital relationships with Black African (BA) and Black Caribbean (BC) men	*Ethnicity(n):* BA (3); BC (4); White (4) *Age(n):* < 45 (1); 45–55 (5); 56–65 (2); 66–75 (2); > 75 (1) *Years married(n):* < 20 (4); 21–30 (2); 31–40 (3); > 40 (2) *Education level(n):* Below graduate (3); Graduate (4); Post graduate (4)	BA and BC men who had undergone at least 3 months' active treatment *Treatments:* Robotic surgery, Brachytherapy, Surgery + radiotherapy, Radiotherapy + hormone therapy, Cryotherapy + hormone therapy *Time since treatment(n):* Ongoing long term treatment (3); < 1 year post treatment (5); 1–5 years post treatment (3)	Qualitative design using constructivist grounded theory. Semi structured interviews	Explore partners' experience and support needs as influenced by impacts of PCa, treatment side effects and socio-cultural context	22/32††
Pinks et al. (2018)	Australia	16 women	*Ethnicity(n):* Caucasian (16)	Initial treatment for localised PCa	Qualitative exploratory design using inductive	Obtain understanding of partner experiences of PCa	16/32††

			Age range(M, SD): 48 to 88 (69, 11) *Length of relationship(M, SD):* 3 to 67 years (36, 19)	completed at least 12 months prior to study *Treatments:* Radical prostatectomy, Radiotherapy, Hormone therapy *Years of survivorship(M, SD):* 1 to 11 (5, 3)	thematic analysis. Focus groups, interviews	survivorship to inform healthcare service providers	
O'Brien et al. (2017)	United States of America	20 women	*Ethnicity(n):* Caucasian (19); African American (1) *Average age(range):* 67.6 (41-87) *Average years married(range):* 36 (3-63) *Average years of education (range):* 16.5 (13-24)	*Treatments:* Radical prostatectomy, Radiation therapy, Combination therapy – incl. hormone therapy, chemotherapy, and radiation therapy	Triangulation design that included quantitative, nonexperimental, and a collective case study methodology. Demographic data sheets, close-ended interview schedule of the Appraisal of Caregiving Scale with an open ended question	Explore effects on wife caregivers of patients diagnosed with PCa cared for in the home	11/32††
Rossen et al. (2016)	Denmark	8 women	*Age range:* 55-68 years *Education level(n):*	Men with early stage PCa *Treatment:*	Qualitative sub-study of the Nordic Lifestyle Intervention feasibility study using	Explore how the PCa diagnosis and participation in their partners' behavioural	16/32††

			Vocational (5); College training (3) *Working status:* Full-time employed (5); Retired (3)	Active surveillance	a grounded approach applying constant comparative analysis. Semi-structured interviews	lifestyle intervention influenced their life, dyadic relationship, and handling of the situation	
Wootten et al. (2014)	Australia	27 women	*Age range(M, SD):* 43–76 (61.6, 8.99)	*Treatments:* Radical prostatectomy, Radiotherapy, Combination of prostatectomy plus radiotherapy and/or hormone therapy *Time since treatment(M):* 10 months-2.75 years (2.5 years)	Qualitative focus group design. Focus groups, structured interview	Explore the experiences of partners of men diagnosed and/or treated for PCa to better understand the impact of PCa on the partner	11/32[††]
Williams et al. (2014)	United States of America	28 women	*Ethnicity(n):* Latina (28) *Age range(M):* 36-63 (55.1) *Working status(%):* Homemakers (71.4); Caretakers for children or the disabled (21.4);	*Treatment:* Radical prostatectomy within the previous 6 months	Qualitative longitudinal study design (interviews at 3 time points). In-depth, semi-structured interviews at 3 time points 3-6 months apart	Describe the longitudinal experiences of low-income Latinas as their husbands recovered from radical prostatectomy, develop a framework for strategies used	19/32[††]

			Worked outside the home in other capacities (10.7) *Country of birth (%):* Mexico (78.6); Central America (10.7); South America (10.7) *Years of U.S. residence(M):* 1-40 (7.2)			when caring for their husband and coping with his illness and side effects	
Ervik et al. (2013)	Norway	9 women	*Age range:* 52-68 *Years married(n):* 23-48 (8); <5 (1) *Working status(n):* Full time (3); Part time (2); Retired (1); Disabled (2); Housewife (1) *Months post-diagnosis at time of interview(n):* 2-4 (4); 24-36 (4); 48 (1)	*Treatments:* Radical prostatectomy, Radiation therapy, Radical prostatectomy + additional endocrine therapy, Radical prostatectomy +additional radiation therapy	Phenomenological hermeneutic. In-depth interviews	Explore how the daily life of female spouses is affected by their husband's PCa	19/32††
Bruun et al. (2011)	Denmark	5 women	*Age range:* 54-73 *Relationship status(n):*	Men recently diagnose with incurable PCa, terminal phase was excluded	Qualitative longitudinal design with a phenomenological-	Better understand the everyday experiences of the female	14/32††

			Married (4); Cohabitating (1) *Maternal status(n):* Mothers (5)		hermeneutic approach. Semi-structured interviews at 3 and 10 months post-diagnosis	partners' of men with incurable PCa	
Tanner et al. (2011)	United States of America	113 women from 2 follow-up longitudinal survey studies focused on quality of life issues for couples	Not reported for the specific sample	Men who decided to obtain treatment for stage I or II PCa and men who had received treatment at a tertiary facility *Treatments:* Conventional external beam radiation, Proton beam radiation, Surgery, Mixed beam radiation (a combination of conventional external and proton beam radiation), Watchful waiting	Qualitative content analysis of open ended survey questions. Qualitative content analysis of responses to 2 open ended questions in 2 longitudinal surveys	Understand the effects of PCa on the female partners of PCa patients	17/21[†††]
Evertsen et al. (2010)	United States of America	14 women	*Ethnicity(n):* Non-Hispanic white (12); Black (1); Unknown (1) *Average age(range):*	*Treatment:* Surgical PCa treatment *Time since diagnosis:* 1-18 months	Pilot focus group study design	Explore the interaction of the female partner with the patient's physicians (primary	20/32[††]

			61.6 (47-77) *Relationship status(n):* Married (13); Not married (1)			care and urologist) and her support needs	
Street et al. (2010)	Australia	50 women	*Age range(M):* 43-78 (62) *Sub-sample of 11 women experiencing clinically relevant distress(n):* Anxious (5); Depressed (4); Depression and Anxiety (2)	*Disease stage:* Localized, Advanced *Treatments:* Watchful waiting, Hormone treatment, Radical prostatectomy, Radiation therapy, Chemotherapy	Mixed methods. Two questionnaires completed 6 months apart, semi-structured interviews at 2 time points before the start of definitive treatments and 6 months later	Explore the psychosocial adaptation of female partners living with men with a diagnosis of either localized or metastatic PCa	19/32††
Bottorff et al. (2008)	Canada	20 women	*Ethnicity(n):* Anglo-Canadian (14); Northern European (6) *Age range(M):* 54-84 (68.5) *Working status:* Retired (15); Working (5) *Length of time attending PCa Support Groups(M):*	Men currently receiving, or had previously received, treatment for PCa	Qualitative ethnographic design. Fieldwork, participant observation, semi-structured interviews	Explore women's self-perceptions and commentaries about the roles of women who attend PCSGs	14/32††

			6 months-13 years (6.5 years)				
Ka’opua et al. (2005)[†]	United States of America	26 women	*Ethnicity(n):* Native Hawaiian (3); Chinese (7); Filipino (3); Japanese (13) *Age range (M):* 60-86 (73.82) *Education level:* High school diploma (24); College (6) *Country of birth:* U.S. (21); Asian nation (5) *Years married(n):* >45 (22)	Men at least five years post-diagnosis *Treatments:* Radiation therapy, Prostatectomy, Combination of treatments *Average years since diagnosis:* 8.3	Qualitative interview study. Semi-structured interviews at 2 time points 6 months apart	Explore the adaptive process to long-term PCa survival in a cohort of elderly Asian or Pacific Islander wives	22/32[††]
Ka’opua et al. (2007)[†]	United States of America	28 women	*Ethnicity(%):* White (28.6); Japanese (28.6); Chinese (21.4); Filipina (10.7); Native Hawaiian (10.7) *Age range(M):* 55-86 (72.6)	Men at least five years post-diagnosis *Treatments:* Radiation, Surgery, Both, None	Qualitative interview study. Semi-structured interviews at 2 time points 6 months apart	Identify wives’ challenges at the nexus of long-term PCa survivorship and aging, describe the function of Spiritually Based Resources (SBR) in coping, and describe common	18/32[††]

	Religion(n): Buddhist (2); Christian (19); Taoist (2); Spiritual (5)	*Average years since diagnosis(M):* 6-15 (8.5)		themes in adaptation among wives using SBR

[†] Different sample sub-sets from same study sample of 38 women

[††] Studies that used interviews and focus groups for data collection were appraised using the COREQ tool

[†††] Study that collected data through open-ended survey questions was appraised using the SRQR tool

Table 3 Themes identified in the synthesis of 14 studies on the experience of female partners of PCa survivors and illustrative quotes

Psychosocial impact of PCa on female partners
“The wife…is very much involved. It changes your life afterwards, not only the husband’s, but yours.” (Evertsen & Wolkenstein, 2010)
“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.” (Tanner et al., 2011)
‘‘One is always anxious and afraid of being alone [when] *one is used to being two; thus, everything becomes different the day one is by oneself.’’* (Ervik et al., 2013)
“…he is a very active, strong person, he is also the main breadwinner, he’s also head of the family…he was always the strong male of the family, so it was how it would affect everybody else and that was quite, worrying for me.” (Bamidele et al., 2019)
“When he went back to work…I stayed home by myself…in the hills. And that is how I am daily: by myself…with nothing to do…thinking only bad thoughts.” (Williams et al., 2014)
“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.” (Pinks et al., 2018)
“A wife suffers silently as she watches a beloved husband lose his health and gradually his independence...It definitely saps the pep out of a girl.” (Tanner et al., 2011)
“It was difficult…I was sick from having all of those illnesses, and then his problem. Well, I got worse.” (Williams et al., 2014)
‘‘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.” (Ervik et al., 2013)
“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.” (Ervik et al., 2013)
‘‘After menopause, I lost interest (in sex) we are very close and that nearness means a lot to me.” (Ervik et al., 2013)
“It’s about adjusting around the fact that (man) doesn’t have a huge sex drive now ‘cos he always did have. But in actual fact it’s reassuring myself that he’s still attracted to me.” (Street et al., 2010)

	“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.” (Tanner et al., 2011) *“I feel like I’ve lost the rest of my sexual life because of (man’s) operation…It seems a large part of our life is missing. It’s been very hard for both of us to accept.”* (Street et al., 2010) *“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.”* (Bamidele et al., 2019) *“I’m missing that intimacy…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.”* (Pinks et al., 2018)
Female partners’ positioning in their experiences of PCa	
As part of a couple	*“People…come up to me and whisper ‘and how’s [man]?’…but we’ve been very open…we haven’t tried to cover it up or anything…we don’t find it a problem (unlike) other people who look at it as something of a disgrace. We don’t look at it like that; we just accept this is life.”* (Street et al., 2010) *“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.”* (Evertsen & Wolkenstein, 2010) *“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.”* (Bruun et al., 2011) *“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.”* (Ka'opua et al., 2005) *“But I must say that we have been very positive and a lot of our friends have said that that they can’t believe that we’re so positive about it but we’ve accepted it and we’ve given it our best shot.”* (Street et al., 2010) *“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.”* (Tanner et al., 2011)

	"My husband's cancer has had an impact on our relationship and philosophies of life…What is important has changed and how we live our life every day has become much more positive…planning and maintaining a high quality of a love-filled life has become very important." (Tanner et al., 2011) *"My husband has a lot of body pain which keeps us from social activities as a couple..."* (Tanner et al., 2011)
Provider of support to male partner	*"Once I heard he had advanced cancer and then [metastasis] to the bone, I jumped into action. It was just a natural thing for me to take over, since it was what needed to be done."* (O'Brien, 2017) *''I feel that it is my duty to support and help him in all possible ways when he is ill."* (Ervik et al., 2013) *"He deals with all the nasty stuff I hand out while I'm in pain."* (Tanner et al., 2011) *"When I had breast cancer, it wasn't 'our' breast cancer. It was my breast cancer."* (Evertsen & Wolkenstein, 2010) *"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."* (Ka'opua et al., 2005) *"I'm the refreshment lady…it could be the guys but they didn't want to do the coffee, 'How much coffee do I put in, how much water do I put in?' you know, and they'd really stress themselves out about it."* (Bottorff et al., 2008)
Resilient	*"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."* (Rossen et al., 2016) *"I just get busy and go on."* (Tanner et al., 2011) *"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."* (Tanner et al., 2011) *"I have coped by trying to look on the positive side. I guess that's the angle I have chosen. Then I don't fall into a black hole."* (Rossen et al., 2016) *"The main thing is to be strong. To be able to come out of whatever problem that can present itself. To get the family through it…."* (Williams et al., 2014)

	“The thing that helped me most was thinking about my mom who worked her entire life on the plantation. She is my model for female strength.” (Ka'opua et al., 2005) *“Born illegitimate and during the Depression. I've had so many hardships, heartaches, but I learned to survive!”* (Ka'opua et al., 2005)
Guided by faith and spirituality	*“I mean, you stop working, you stop a lot of things, and you have rest…it’s like God gives you that opportunity to think about and to see what is good, what is bad, what you should change.”* (Williams et al., 2014) *"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 he brings with a grateful openness"* (Ka'opua et al., 2007) *“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."* (Ka'opua et al., 2007) *"My church community is an extended family. When my body was weary, the bishop visited and sent others to help."* (Ka'opua et al., 2007)
Positioning of female partners by males’ response to PCa	
Manager of male partner’s psychological distress	*“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.”* (Tanner et al., 2011) *“He has been suffering from depression for quite a few years now, I try to cheer him up and encourage him to do things… but he won’t. His life just revolves around me… I’ve had to be his backbone, it’s so exhausting.”* (Pinks et al., 2018) *“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 grasped the level of stress I was under the whole time…”* (Bamidele et al., 2019) *“He won’t ask for help, but he might accept it...there’s been a great deal of denial.”* (Evertsen & Wolkenstein, 2010) *“He became totally single minded. In my opinion feelings just closed up… went to a separate room and we’re still in separate room.”* (Wootten et al., 2014)

	“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…” (Bamidele et al., 2019) *‘‘He became impotent, which resulted in him feeling unfit as a man and therefore sexually frustrated.”* (Ervik et al., 2013) *“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.”* (Wootten et al., 2014) *“I’ll leave him, instead of saying things and getting worse, because he gets angrier. My advice would be when they want to fight, when they start fighting, it’s better to maintain silence.”* (Williams et al., 2014) *“Well yes, I think my calmness has been instrumental ...in helping him cope with his anger.”* (Street et al., 2010) *“If it comes from an outsider, it will be very effective because if it comes from me, he will say…you are always complaining and whining, but if someone else says it, if a counsellor or psychologist says that in the presence of [the] couple I think it will be very helpful…”* (Bamidele et al., 2019)
Strengthened by male partner’s positive response	*“He handles everything with ease, he’s just a dream to deal with, what I’d call the perfect patient.”* (Wootten et al., 2014) *“(Man) was not stressed. He took it calmly so I took it calmly.”* (Street et al., 2010) *“It has united us a lot, this disease…because, well, he was a man that was always alone here. And now he says, he tells the whole world, ‘My wife was with me over there in the hospital until she took me out.’ He is proud of his wifey [laughs].”* (Williams et al., 2014)
Positioning by family members and social networks	
	“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…that I shouldn’t be like I was [distressed], because there are times that with them that I’d vent.” (Williams et al., 2014)

“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.” (Ka'opua et al., 2005)

“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…All of that helps one forget things.” (Williams et al., 2014)

“There’s a lot of areas that we’re dealing with. (Man) has terminally ill children (from previous partner). Everything is snow-balling. I only started seeking psychiatric help in January.” (Street et al., 2010)

“I guess the depression has probably been something that’s been lying low but with my mother reaching a crisis and being diagnosed with dementia and on top of that (man) having been sick and everything else...I...spiralled downward.” (Street et al., 2010)

“I had a need to talk desperately, I had my friends who had empathy and caring but they had no idea what I was going through and if any of them were losing their husbands, they were losing them through divorce not this. As much as your family and friends love you and care about you, often they don’t really have the knowledge.” (Bottorff et al., 2008)

“The women in the group I learned had such different issues, their husbands were battling disease, and had the doctors to look after them. These women did not have anyone to look after them so to speak and their issues were huge. They ranged from physical, emotional, financial, sexual, the gambit and often they couldn’t talk to anyone, their families, friends, they either didn’t trust them or just didn’t feel comfortable or didn’t feel they were given support.” (Bottorff et al., 2008)

“She…took me to the lady’s group…and she gave me the lecture, ‘We’ve all been through this, we know how you’re feeling and I promise you will come out of it feeling fine. You will come out of this, but we’ve all been there, so we understand exactly how you feel and you will be fine...’ Then I relaxed. It was the best thing that could happen to me.” (Bottorff et al., 2008)

Positioning by clinicians and the health system

“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 doctors really need to treat the couple rather than the man.” (Pinks et al., 2018)

“I have never talk with my family physician...I was never asked how I felt.” (Evertsen & Wolkenstein, 2010)

"I did have the necessity to share the load, right?...But well, there was nobody [at the hospital]. Nobody spoke Spanish…[crying] I was so desperate…" (Williams et al., 2014)

"I really didn't think there was enough information for me about expectations around recovery and what I could do for him or to help him or how I can be supportive." (Wootten et al., 2014)

"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…you need to be able to talk to someone…who can help you figure out what you need to do and how to prepare." (Pinks et al., 2018)

"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…both of us would come at him with different types of questions, and we both felt very confident with the doctor." (Evertsen & Wolkenstein, 2010)

"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?'." (Wootten et al., 2014)

Positioning by cultural values and customs

"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." (Ka'opua et al., 2007)

"Well in the Caribbean to be quite honest, you just stick together…you just have to stick together, support each other...that's it…" (Bamidele et al., 2019)

"How long will he have to live…what is going to happen to me, in African set up, you dare not mention it to your husband at that time…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…" (Bamidele et al., 2019)

"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." (Ka'opua et al., 2005)

"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…" (Bamidele et al., 2019)