Long Title: **Prostate Cancer and the impact on couples: a qualitative metasynthesis.**

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Short Title: Couples and the prostate cancer experience

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Abstract

Purpose: To review and interpret existing qualitative literature on the experiences of couples affected by prostate cancer (PCa).

Methods: A metasynthesis was carried out which included a systematic search of seven databases between 2000-2016. A modified version of Noblit and Hare's meta-ethnographic approach was used to synthesise qualitative study findings and inform overarching interpretations.

Results: Thirty-seven studies focusing on the experiences of the dyad (men with PCa and their partners) were included, producing seven interconnected constructs. The construct *Accepting change vs seeking continuity* reflects the range of ways individuals within the dyad and couples adjust to the diagnosis. *Cultivating connection versus disengaging* illustrates how couples seek to manage the impact of PCa and its treatment on their relationship, which may lead to a *Threatened identity,* including sexual insecurities. *Shielding me, you, and us* reflects ways in which couples strive to protect themselves as individuals and/or each other from the impact of PCa. *Being a partner and its challenges* highlights the responsibilities partners assume and the impact of their supporting role. Yet, partners sometimes report *Feeling unsupported and side-lined* both by the man they are caring for and by healthcare professionals. Couples often recognise *The value of facing PCa together.*

Conclusions: PCa affects both members of the dyad as individuals, as well as the couple's relationship. How best to support couples and how to overcome difficulties in expressing their concerns to one another requires further consideration. Healthcare professionals should endeavour to employ a couple-focused approach where appropriate.

Key words: prostate cancer, qualitative metasynthesis, partner experience, couples, dyad, oncology

Background

Prostate cancer (PCa) is the second most common cancer worldwide in men, with more than 1.11 million men estimated to have been diagnosed in 2012 [1]. Mortality rates have been decreasing in developed countries as a result of increased use of PSA testing and the improved, broad range of treatments available [2, 3]. Consequently, an increasing cohort of men are living with and beyond their cancer diagnosis, posing a challenge to health and social services in providing the most effective support to meet their needs [4].

Both the diagnosis of prostate cancer, and the side effects of treatment, which can include urinary incontinence, erectile dysfunction and fatigue may impact on the quality of life and dynamics of the relationship for both the man with PCa, and his partner [5–7]. It is frequently reported that the primary source of support for men with PCa is their intimate partner [8, 9].

Studies suggest that there is a reciprocal influence on how members in a relational dyad adjust to cancer, i.e. the person with cancer's diagnosis and treatment side effects may impact on the emotional and physical wellbeing of the partner, and in turn partners' support may influence the adjustment of the person with cancer [7, 10–12].

It is important to understand how couples live with a diagnosis of prostate cancer and manage the effects during various phases of this process in order to further understand the relational processes and the support that couples need.

There is a large qualitative literature exploring experiences of PCa. Synthesizing the findings from qualitative studies in order to enhance understanding of a topic area has been shown to be a useful and accepted methodology in health care research [13–15]. We have therefore conducted a comprehensive metasynthesis of qualitative studies to address the post-diagnosis PCa experience [16]. We made an a priori decision to undertake a subsynthesis, presented here, on the post-diagnosis impact of PCa on couples. To the best of our knowledge no previous systematic qualitative review has addressed this topic. Schumm et al [17] have previously conducted an evidence synthesis which focussed on the barriers and facilitators that influenced the patients' and their partners' treatment decision making for PCa and two additional reviews have focussed specifically on sexual adaptation following diagnosis and treatment [18, 19]. The aims of our synthesis are broader, and we seek to build upon collective knowledge of the impact of PCa on couples including the relational impact and managing treatment side effects, in order to identify relevant clinical implications and future research priorities.

Methods

Full methods of the overarching metasynthesis are detailed elsewhere [20]. Herein we report on methods applicable to the couples' sub-synthesis. The term 'overarching metasynthesis' pertains to the synthesis of studies with themes relevant to heterosexual men from non-minority groups who have partners, as the most typical profile of men with PCa.

Searches

The search for the overarching metasynthesis encompassed the inclusion criteria for this subsynthesis for efficiency (Box 1), with papers subsequently allocated to the different analyses [16]. A search was conducted of seven electronic medical, sociological, and psychological databases: MEDLINE, CINAHL, PsycINFO, Web of Science, SSCI, AHCI, ProQuest IBSS. This also included backward and forward citation tracking of all included papers. Articles included in the main metasynthesis were

dated 2000-2015 to reflect the most current health care experiences in PCa. A further search for the year 2016 was carried out for the subsynthesis by NC. Terms for PCa and keywords; *couples experience*, *partner* and *dyad* were combined with an adapted version of the search strategy for published qualitative studies provided by Saini and Shlonsky [21].

Primary inclusion criterion:

- Qualitative studies in which at least 50% of analytical themes consider and include an example of the PCa illness or management experience for adult men (aged 16 and over) with PCa and/or their partners or caregivers

Secondary inclusion criteria:

- Published in English language due to interpreting meanings across languages
- Published articles post-1999
- Empirical qualitative studies (stand alone, secondary, or discrete components of mixed method studies) employing qualitative methods for both data collection and analysis
- With original data extracts
- Peer reviewed published articles or reports

Exclusion criteria:

- Men not diagnosed with PCa prior to participation in the research
- Data on diagnosis experiences (explored in detail by others [17])
- Book chapters, dissertations, grey literature
- Papers that focus upon dietary and lifestyle interventions
- Experiences prior to or at the time of diagnosis, including decision-making, although consideration of the impact of such decisions included.

Additional inclusion criteria for the couples subsynthesis:

- Studies focusing on the dyad, i.e. man with PCa and partner. Partners are defined as someone in an intimate relationship with the man with PCa and may be of any gender or sexual preference. This also includes the term 'spouse', or 'wife/husband'.
- Studies considering partner-only interviews, however with a focus on the impact of PCa on the relationship.

Additional exclusion criteria for the couples subsynthesis:

- Studies in which the experience of the man with PCa is the focus. These are included in the overarching metasynthesis (Rivas et al. *In prep*).

Box 1: Inclusion and exclusion criteria

Screening

Initial screening of identified titles was undertaken by the lead reviewer of the main metasynthesis (CR), leaving 711 papers requiring independent assessment of abstracts by CR and LM, and full texts where relevant to determine eligibility. The papers that met the inclusion criteria for the subsynthesis on the experience of couples were confirmed by NC. Disagreement of the papers to be included was resolved through discussion with authors CR/EW/RW/LM. One additional article, published in 2015, was found in 2016 [22] (see Online Resource 1).

Two papers included participants with mixed cancers, however relevance to PCa only was referenced [23, 24]. Three mixed methods studies were also included, taking into consideration qualitative data only [25–27].

Data Extraction & Management

A data extraction form was used to record publication details, study design, as well as demographic and treatment information. Full replication of two key types of data was also extracted in accordance with Noblit and Hare's [28] meta-ethnographic approach:

1. Participants' (man with PCa and partner) verbatim quotes about their actual experiences *(first order constructs).*

2. The original authors' interpretations of the study data, representing their conceptualisation and understandings of men with PCa and partners' experience *(second order constructs).*

Extraction of the study data was carried out by NC. Reviewers LM, CR and JN double extracted 30 out of the 37 studies included in the sub-analysis to improve rigour. Any differences in data extraction were discussed and resolved between NC, CR and LM.

Q*uality Assessment*

Included studies were appraised for quality using an existing scoring system, adapted by CR [16, 29, 30]. This took into account credibility, methodological congruence, analytical precision, transferability and heuristic relevance or applicability. Categorisations of studies were 'good' (score: 18-24), 'fair' (score: 12-17) or 'poor' (score: 1-11). Papers which scored as 'poor' were still included [31] as even if the methods are weak or poorly reported, the content and utility of findings can still be rich and thus pertinent to the sub-synthesis' aims [13] (see Online Resource 2). However, a sensitivity analysis was undertaken, whereby poor quality studies were removed to check the impact of the quality of the study on the constructs formed [13, 32].

Data Analysis

The data synthesis drew on a modified version of Noblit and Hare's meta-ethnographic approach [21, 28, 33, 34]. Accordingly, becoming familiar with the context and detail of the studies was the first stage, and establishing considerations of the common concepts and relationships. First and second order constructs were identified, and then third order constructs developed (the views and interpretations of the researchers from all the studies synthesised) and recorded on an Excel spreadsheet. In order to be explicit about first and second order constructs, a grid was created in which the constructs were separated. This aided in the development of the third order constructs.

Studies were translated into one another based on similar or recurring concepts [35]. This process involved distinguishing whether concepts correlated ('reciprocal synthesis'), contradicted or adopted competing ideological perspectives ('refutational synthesis') or identified divergent components of the topic under study that integrated similarities and differences between concepts ('a line of argument synthesis) [21, 36].

Sub-constructs of the 1st and 2nd order constructs were developed, for example, constructs relating to the relationship were subdivided into 'communication', 'reassurance', 'renegotiation' and so forth. This helped to inform the third order constructs and directed the line of argument explorations and development of a new understanding through synthesising and interpreting first and second order constructs. NC developed preliminary overarching third order constructs and discussion with CR, LM, EW, RW, and OA aided the refinement and finalisation of the third order constructs (see Online Resource 3 to view development of one such third order construct).

Results

Thirty-seven studies met our inclusion criteria [8, 22–27, 37–66]. Studies were identified as good (n= 15), fair (n= 20) or poor quality (n= 2) (see Online Resource 2). The poor quality studies lacked methodological congruence, dependability and confirmability [57, 60]. However, the sensitivity analysis showed that removal of the poor quality studies did not make a difference to the constructs developed and therefore they were still included. Twenty-eight were interview studies, five studies employed focus groups, three used a combination of both, and one study used observation in addition to semi-structured interviews. The majority of studies were conducted in Canada *(n*=12*)* and America (*n*=12), the others in Australia (*n*=6), continental Europe (*n*=4) and the UK (*n*=3). Two papers were part of a larger mixed methods study [23, 24]. Five papers drew on the results of a longitudinal qualitative study of men with PCa and their spouses [47–51]. Two studies were each represented by two papers [41, 42, 58, 59]. The 37 included studies were heterogeneous with regard to treatment type and age. Only six studies recruited same sex couples [23, 25, 38, 53, 65, 67], of which the sample sizes were small. A commonly reported limitation was the lack of ethnic diversity in participants recruited.

The process of capturing meaning of participants' views of their experiences (first order constructs) and primary authors statements about the study data (second order constructs), in addition to researcher interpretations (third order constructs) are presented in Table 4 (see Online Resource 4). Seven key third order constructs emerged from the papers on couples' experiences of PCa. The third order constructs developed from the studies are described below with exemplar extracts provided.

Accepting Change versus seeking continuity

This core construct highlights how couples learned to deal with change and is also reflected in the subsequent constructs.

Reaching acceptance was a pivotal process for some couples, particularly in relation to altered sexual activity with couples actively grieving the loss of sexual activity [25, 58, 59, 66]. Partner acceptance of loss of sexual activity sometimes aided the man with PCa to normalise and integrate this impact of PCa [8, 39, 49, 52, 53, 61, 65]. Furthermore, for both men and their partners, linking changes in sexual activity to the ageing process, menopause, other medical conditions, and the length of time they have been together helped with acceptance [23, 25, 26, 38, 40–43, 49, 52, 56, 58, 59, 66]: *'I mean when you get older anyways, the sex, the sex aspect of marriage is deteriorating actually. I think it's different from when you're younger' (Patient) [58]*. This concept of acceptance was also reinforced in three studies which reported that couples who developed realistic expectations were better able to accept feelings about their current and future sexual relationships [44, 58, 65].

Couples who were unable to accept loss of sexual activity often exhibited poorer adjustment [44]; *''... I feel like I've lost the rest of my sexual life because of (man's) operation. It has been very hard to accept. […] It seems a large part of our life is missing. It's been very hard for both of us to accept.''(Partner) [64]*. Two studies highlighted that younger men may struggle to accept PCa [52, 66]. Older men (≥ =75years) appeared to be more accepting of illness, which was also highlighted in another study in which acceptance of changes to sexual experiences was attributed to advancing age [38].

Studies which focused on the impact of PCa in ethnically diverse couples highlighted the importance of culture and value systems in supporting one another and in reaching acceptance of their situation.

Faith in a higher spiritual power strengthened in time of illness and was a coping mechanism for female spouses [39, 42, 43]. This was also reported in one study outside of ethnic specific studies, in which faith became more significant in the period of men's illness [60].

Strategies used by couples to *seek continuity* included humour, carrying on as normal by not focusing on cancer, being positive, putting things into perspective, in addition to accepting support from family and friends which facilitated burden management for partners of men with PCa [8, 21, 25, 26, 37, 38, 40, 42, 43, 45, 47–52, 54, 56–61, 63–65].

Information and support was important in enabling couples to seek continuity in their situation. Couples reported receiving a mixture of levels of support/information from healthcare professionals [50, 54, 61–63]. Studies highlighted that couples were not always receiving the right type of information or information delivered in the right way. Participants valued a model of care that was tailored to their needs, including couple focused support comprising sexual and self-care information [8, 22, 26, 27, 37–39, 41, 42, 45, 53, 54, 56, 57, 62, 63, 66]. However, some studies [8, 53] reported that discussions with clinicians about sexual functioning were not felt to have been well-conducted, perhaps reflecting the difficulties healthcare professionals and couples encounter in finding a mutually acceptable lexicon for discussing sex and intimacy. Other concerns included limited opportunities offered for couples to talk about their sexual needs and not being given enough information about the possible impact and use of sexual aids [8, 37, 41, 53]: *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, […] 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* [53].

Cultivating Connection Vs Disengaging

PCa treatment can often cause erectile dysfunction, and therefore may affect the psychosexual aspect of the relationship. For couples who adjusted well to their situation, integration of change was established through a renegotiation or redefining of a new sexual paradigm between both members of the dyad in which non-coital practices were positioned as sexual connection [8, 23, 24, 38–40, 44, 45, 47–49, 51–53, 56–59, 64–66]. For example, mutual genital touching, massage, kissing, hugging, and oral sex highlighted how connection was cultivated. One participant described this as *'engaging in outercourse not intercourse''* (*Patient*) [24]. Embracing relational intimacy (emotional closeness) became the foundation for well-adjusted relationships and was considered more satisfying as both members in the dyad engaged in focusing on other parts of the relationship than sex [39, 44, 49, 58, 59]. Other attributes that were associated with positive adjustment were both members of the dyad being interested in engaging in sex [26, 27, 44, 53, 58, 65], and being open to experimenting with the use of erectile aids as an approach to engaging in sexual activity [23–25, 40, 44, 47, 49, 50, 58, 59, 64–66].

Another way that connection was cultivated amongst couples was through the use of open communication to express their feelings and needs [8, 24, 37, 38, 44, 48–50, 56, 58, 59, 64, 65]: *"I emphasize open and honest communications, […] I really think you have to express your true feelings so that the other person in your life really understands what you're going through" (Patient) [38]*. Communication was highlighted as an important action in positive adjustment, and for some couples this connection could be achieved through non-verbal communication [37, 38]. Emotional support through reassurance cultivated connection between members of the dyad as it was often used by couples in relation to their future together and love for one another, in addition to dealing with challenges [50, 59–61, 65].

However, loss of the sexual relationship sometimes led to distancing and disengagement between members of the couple [22, 25, 37, 38, 56, 58, 59], and this may also reflect those unable to *accept* this change. Lack of sexual desire was also reported by men on hormone treatment and post-surgery [38, 58, 59]. Unbalanced initiation of sex caused withdrawal in the relationship [25, 58, 59], as an example of those that are *'disengaging'*: "*I started to avoid touching her, because she would think I would be interested when I'm really not. And then [she] would get all hot and bothered, and I'm not […].''* [59] Couples frequently reported lack of spontaneity in sexual activity following treatment, which for some couples resulted in feelings of unhappiness and frustration [25, 38, 57]. Studies suggested that couples who struggled and were sexually dissatisfied had negative expectations about sexual activity which therefore hindered successful sexual outcomes [23, 44, 59].

Threatened identity

The construct '*threatened identity* refers to ways in which individuals in the dyads' identity were threatened by feelings of insecurity due to PCa and/or its impact. For some, sexual impairment posed a significant *threat* to their masculine identities and therefore on the relationship [8, 23, 25–27, 37, 38, 41, 43, 47, 49, 51, 58, 59, 63, 64, 66], as some men felt insecure about the possibility of their partner leaving them and uncertainty about the trajectory of the relationship[56, 59, 65, 66]. *Threatened identity* was also reflected in some partners who described a decrease in self-esteem due to loss of sexual affection from their husband [8, 27, 57, 59, 61]. Sexual insecurities were also related to diminished satisfaction or distress in the use of sexual aids [24, 25, 38, 41, 47, 49, 50, 64, 65]. This was due to the loss of normality in the process of using sexual aids [49, 61], and mechanization of sexual activity as sexual pleasure was replaced with managing the technical aspects of the sexual aid [38]:*''[…] It's not the same sort of satisfaction. It relieves the pressure, but it's not that sort of sense of fulfilment, and bonding.'' (Patient) [49]*. Negative perceptions of using biotechnology/medication were also a barrier to use [25, 26, 37, 41, 42, 49] and for some women, led to frustration over men's attempts at the use of failing biotechnology [49]. In addition, role changes as a consequence of the impact of PCa may threaten the identities of both members of the dyad as wives/partners carry out activities the husband/partner would have normally done [8, 48, 51, 52, 57]: *"My wife tries to do too much. It's physically exhausting for her and very, very difficult. But at the same time, I don't know how to change it. I think that's her way of coping.''*[8]. Furthermore partners may feel *threatened*, through fear of losing their husband/partner which also caused disengagement with the man with PCa [8, 42, 43, 60–62, 64]: *"I was crying all the time at first and he was trying to get his head round focusing on living and he used to say it's like walking on eggshells round here, you know, look at you with your miserable face...and once we realised well actually the crux of this is that he's focusing on living, and I'm focusing on him dying and the future and it's just not the same [. . .] that was quite painful for quite a long time"* [62].

Shielding Me, You, and Us

This construct represents how couples attempt to shield each other, their selves and others when faced with challenges related to the prostate cancer. Couples often hid their feelings from each other, for example as a coping mechanism, or as a way to *seek continuity*. This could also be to shield the other and avoid causing more distress to one another [8, 22, 37, 41–43, 47, 48, 54, 61]. Authors of two studies suggested that women suppressed their feelings so as not to interfere with men's coping efforts [37, 48]. In contrast, some women viewed their husbands' concealment of feelings as antagonistic to their own coping ability [48]. *'.... I [knew] he was protecting me and that upset me even worse—that he was feeling much sicker than he would let me know.... He didn't want to worry me [but] instead of protecting me, it made me feel like I was dying inside, it just broke my heart ...." (Partner)* [48]. Couple's absence of communication toward each other often created discord and also made mutual support difficult [22, 24, 25, 37, 38, 41, 42, 49, 57–59].

Shielding was also used in relationships when women were challenged in their ability to maintain and express physical intimacy due to their desire to protect men with PCa feeling inadequate about an inability to meet their sexual needs [38, 43, 47, 49, 58]. On the other hand, men with PCa feared getting their partner aroused and not meeting their expectation to sexually perform, therefore failing to try and sometimes leading to tension and withdrawal within the relationship [8, 25, 49, 52, 57–59, 65]:*'I think she's afraid of making me feel incompetent. And I'm afraid of getting her aroused and not being able to complete things. And this tension builds up. I'm afraid to try too much and maybe she's afraid to suggest it too much for fear of disappointment on both our sides..."(Patient) [49]*.

Studies often alluded to the conflict between seeking and avoiding information either due to some partners' need for more information compared to the man with PCa, or by partners censoring themselves in consultations to avoid causing anxiety to the person with PCa, thus highlighting how partners protect their husbands. For some partners, information was avoided in order to reduce fear and feelings of uncertainty and anxiety, thus protecting themselves: *"The least you know the better."*[46] This was connected to their attempt, discussed above, to *seek continuity* in their lives [37, 46, 57, 62, 63]. Partners had to be careful in finding ways to support men without impinging on men's need for autonomy [47–50, 55, 57, 61].

The shield also appeared to be used to protect people outside of the relational dyad. Censorship of talking about health concerns between family members/friends was sometimes due to differences in readiness to tell or so as not to distress others [50, 60].

Being a partner and its challenges

Partners appeared to play a fundamental role in supporting their husband/partner to integrate the changes posed by PCa and in facilitating his recovery: *"The wife in something like this is very much involved. It changes your life afterwards, not only the husband's, but yours"(Partner)* [63] Some of the responsibilities partners assumed included providing information about PCa for the men they are caring for and family members [37, 40, 48, 55–57, 65], being the communication conduit between men and healthcare professionals [8, 25, 62], and providing practical support [8, 22, 48, 52, 54, 57, 60, 63]. In addition they helped men work out their care routines [8, 40, 43, 51, 56] and juggled with the emotional caretaking of their husbands/partners as well as managing their own [25, 43, 47, 50, 56, 57, 61, 63, 65]:*''I was extremely afraid of hurting 'man's name', 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)''(Partner) [61]*. *Challenges* occurred where partners/wives experienced difficulties in balancing the demands of caring and work/family roles [22, 25, 26, 37, 43, 50, 52, 61, 62, 64, 65]. As a result, conflict and tension could arise in couples [22, 43, 51, 56, 63]. Partners' caregiving also resulted in the development of physical ailments or feelings of being overstrained [37, 43, 61–64]. Sometimes this was because partners disregarded their own needs as less important [22, 38, 47, 49, 60, 61, 65].

Feeling Unsupported and Side-lined

Some partners felt unsupported in healthcare settings and felt they were relegated to the side-line in consultations, with their needs not addressed [22, 53, 56, 61–63]: *''In the hospital, the patient is the focus; it feels a bit hard when I do so much'' (Partner) [61]*. Partners also often felt isolated and unsupported at times when men emotionally and physically withdrew, possibly highlighting a barrier to being able to *seek continuity* in their lives However, some partners understood that their partner needed to retreat in order to adjust to their situation [37, 45, 47, 48, 51, 59, 63–65]. Some men restricted their partner's disclosure of PCa [8, 30, 42, 61], which was difficult for some partners as

they found benefit in talking to others to gain support, and sometimes encouraged men to speak with others in order to ease the situation for themselves [8, 37, 56, 60–63]: ‘’*My husband didn’t want me to talk to anyone else...So it was difficult when I couldn’t share it. I realize he was having to process this himself, but it was difficult for me because I really needed to talk about it with somebody.’’(*Partner*) [51].* As one author suggested ‘imposed loneliness’ occurred when a family/social network pretended that illness did not exist and therefore was not discussed, which could also happen if men did not want to discuss their situation with their partner [22, 60, 64]. Some women chose ‘self-inflicted loneliness’ as a strategy to avoid questioning from others about their husband/partners’ health [60].

The value in facing PCa together

In contrast to the constructs *feeling unsupported and sidelined and Shielding me, you and us*, the literature often reported that couples spoke of PCa in terms of the ‘WE’ disease and facing PCa as a team, because the impact of the illness and its management affects both members of the dyad (20,40,41,43,46–49,53,54,56,58,59): *‘I think you have to have the feeling that you’re going through it together. […], you have to do it as a team. And that’s been a wonderful thing for us’[50]*. PCa presented a situation whereby the value in *accepting change* was reflected by couples who were able to spend more time together, and for some couples strengthened relationships within the family and with their partner [8, 23, 25, 39, 40, 43, 45, 47–50, 52, 59, 61, 64, 65, 67]. Other ways *the value in facing PCa together* was highlighted was through couples embarking on new ventures together, valuing each day, and having a new perspective on their relationship and as individuals [8, 39, 40, 47, 48, 50–52, 61, 64]: ‘’*…we’re closer than ever emotionally. It’s very good for you in some ways as you learn to forget a lot of the crap in life. You don’t put up with it. It just gives you a different insight into yourself and into your partner’’ (Partner) [64]*.

Discussion

This metasynthesis highlights how PCa impacts on both the individuals in the dyad and their shared life; psycho-emotionally, physically, socially and practically [69], and suggests what is unique to the experience of couples.

From a dyadic perspective, high relationship functioning during or after treatment may be dependent on how well couples integrate cancer and side effects of treatment into their lives [70, 71]. The constructs developed highlighted the tension in couples’ use of different strategies to *accept change versus seeking continuity*, which converged with other constructs that reported adjustment strategies associated with the impact on the relationship. It seemed that being unable to accept changes posed by PCa and its impact or being unable to find continuity led to a form of disengagement or withdrawal and therefore difficulties in adjusting as a couple. Withdrawal and avoiding communication seemed to be a theme common to some constructs, for example in relation to the impact to masculine identities as a result of sexual dysfunction (see constructs *cultivating connection vs disengaging and threatened identity)*. Here, as in the main metasynthesis (Rivas et al., *in prep)*, as well as metasyntheses on younger, unpartnered and gay men [72] and BME men [73], loss of sexual activity was found to impact men’s sense of manhood and sometimes led to feelings of inadequacy and avoidance behaviours [8, 23, 25, 37, 38, 41, 43, 47, 49, 51, 58, 59, 63, 64]. In relation to the construct *shielding me, you, and us*, challenges in navigating physical intimacy sometimes led to couples withdrawing from each other or avoiding communication, In the wider cancer literature, withdrawing or avoiding communication is revealed to be dysfunctional and related to lower relationship functioning [10, 74–76].

Conversely, couples that adjusted well to the impact of PCa renegotiated sexual experiences, reached a level of acceptance about their situation and were able to openly communicate with each other; as

strategies highlighted in the core construct *accepting change versus seeking continuity*, and in the construct *cultivating connection vs disengaging*. Previous studies have also suggested that mutual communication is associated with successful adjustment [10, 77–79]. In couples affected by breast cancer, helpful communication was characterised by high partner empathy and low withdrawal, which were related to positive psychological adjustment [80–82]. Therefore, it could be advantageous if healthcare professionals advised about or signposted to support services that included interventions to help couples in communicating honestly with each other.

Benoot et al's qualitative metasynthesis [18] with focus on the sexual adaptation process during cancer, developed three key constructs to highlight the pathways of sexual adjustment which included grief, restructuring and rehabilitation. The pathways of restructuring and rehabilitation in which the person with cancer and partner adjust through means of redefining their sexual experience and employing specific attitudes/behaviours and practical ways to adjust are similar to the constructs in our subsynthesis termed as *cultivating connection vs disengaging and accepting change vs seeking continuity* thus adding to the validity and credibility of our subsynthesis. Since Benoot et al's metasynthesis focused on the links between the studies' theoretical approaches and the interpretation of the sexual adaptation process, there was a prominent focus on gendered aspects of the sexual adjustment process.

Across the studies there was evidence of gaps in clinical support, specifically in relation to the impact on the sexual relationship. Numerous studies reported the need for an approach tailored to the needs of the couple, including interventions to maximise sexual functioning and communication about their grief and sexual losses [8, 24, 25, 45, 52, 53, 57, 65].

Six intervention studies sought to address relational and sexual intimacy following PCa treatment. [78, 83–87]. Specifically, four of the studies that focused on sexuality and erectile dysfunction (ED) treatments [83–86] reported that whilst men with PCa reported an increase in sustained ED treatment use and benefit, there were no significant outcomes for partners. In comparison, the two relational focused intervention studies that addressed concerns regarding relationship factors such as intimacy and communication, found that men with PCa reported fewer benefits than partners [78, 87]. Whilst these studies suggest that men with PCa and their partners may benefit from different types of interventions, it can be argued that couple's lack of engagement in support that embraces both the physical and relational aspects may hinder their adjustment in sexual recovery, as incorporation of both aspects may be needed to truly work as a team and move forward as a couple. The significance of developing empathy in order for couples to work as a team and adjust positively has predominantly been highlighted in the breast cancer literature but is also highly relevant to PCa [80]. Empathy development coexists with active listening and open communication which has been further emphasised as a way to provide effective support for couples' post PCa treatment in other areas of this discussion.

The construct *Being a partner and its challenges* emphasises the key role partners assume to support the man with PCa. Previous work has shown that psychological distress is experienced differently between male and female caregivers [88]. The literature suggests that partners have difficulty with coping yet there appears to be little offered by healthcare in the way of support for this [62, 89]. Studies have highlighted the need for partners to be involved in the consultation process and for healthcare professionals to be more inclusive of their needs, in addition to those of the person with cancer [52, 61]. Partners suggested that support groups for women supporting men with PCa [61], and a systematic assessment of partner's support needs [52, 60, 62, 64] would be welcomed. Therefore, it

is important to highlight support options during consultations as a way to acknowledge and address the needs of partners [90].

Whilst partner specific support is important, an increased awareness of cancer as a 'dyadic affair' may highlight the importance of dyadic coping in maintaining and possibly improving relationship functioning in couples managing cancer, particularly with regards to the sexual impact [91], and is reflected in the construct *The value in facing PCa together* and also its antithesis construct *feeling unsupported and sidelined*. The way in which both members of the couple cope may be dependent on one another's adjustment [37, 92–96]. In the context of PCa, couples often spoke of facing cancer as a team- a 'WE-disease (20,40,41,43,46–49,53,54,56,58,59), which is a concept also commonly reported with breast and lung cancers [50, 79, 97–99].

Tailoring support to the needs of the couple, including psycho-educational/psycho-sexual interventions in addition to practical and self-management support, could have potential benefits for both members of the dyad and adheres to 'patient-centred care'. This may also address policy recommendations outlined by the NHS Outcomes Framework [100] regarding the importance of *enhancing quality of life for carers* and *ensuring people feel supported to manage their own condition* in line with National Institute for Clinical Excellence guidelines for the diagnosis and treatment of PCa [101].

Limitations and Strengths

The subsynthesis has many strengths including clear, specific inclusion criteria and rigorous methods when screening for articles. This is in addition to double extraction of data and quality assessment of the studies to be included.

The studies included were heterogeneous with regard to type of treatment men had completed, and age ranges, thus strengthening the validity of the data. However, in many cases, the time since treatment and cancer grade/stage was not reported, though likely to impact on experiences and needs.

This subsynthesis was limited by the studies included. Firstly, the majority of couples recruited had been married for over 20 years, and so our findings may not reflect the experiences and needs of couples in a relationship for a shorter time. As topics discussed in the studies are highly sensitive, there may be a selection bias as couples more open to sharing their experiences may be more likely to have participated. Well-adjusted couples may also be more likely to participate, so the views of couples struggling to adjust may not be fully captured. Many of the studies were carried out in the US, Canada, Australia and Europe, with only three in the UK. Experiences of healthcare may differ within and across countries and therefore impact on the relevance and transferability of its findings, and thus clinical implications.

Clinical Implications and Conclusion

The couples' experience of PCa impacts on different aspects of their lives, functionally, emotionally, psychologically and in terms of their relationship. Since there are many challenges for couples coping with PCa, it is important that healthcare services provide support or interventions which include and address the impact on couples. Service providers should recognise that individual members of the couple may have different needs, but that it is important to employ a couple-focused approach when highlighting support services that may be useful for them to work and move forward together. The importance of communication in adjustment is well researched, therefore effective communication training programmes and how these can be implemented into the clinical pathway needs further consideration. In addition, more studies exploring experiences, needs and access to services are

needed in couples from a range of ethno-cultural backgrounds, and same sex couples, with the aim of addressing gaps in knowledge. The experience and impact of PCa when well-integrated through the couples' own resources and with support from HCPs and others, can result in an accommodation to their new situation.

Conflicts of interest

None.

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