

**Title:**

Partners in Prostate Cancer: An exploration of the effects of prostate cancer on female partners of men living with and beyond the condition

**Background to the project:**

The treatment of men with prostate cancer (PCa) is one of the largest portions of the case mix in oncology departments. Much work has been done to mitigate the long-term side effects for men by improving treatment methods, but given the excellent survival statistics, where 80% of men treated for PCa live 10 years beyond diagnosis (1), there are large numbers of men who are surviving, but enduring quality of life issues from their treatment. It is well established that these men experience high levels of erectile dysfunction, urinary leakage and bowel problems as a result of treatments (2-4). Such side effects are known to have an impact on all aspects of relationships between these men and their partners.

It has been documented that partners provide the greatest source of emotional and physical care for men with PCa, which can put a strain on relationships (5). Couper et al. (6) state that partners report experiencing much higher levels of stress than the cancer survivor. The literature suggests that there is also a level of protective buffering (7) when couples are dealing with cancer, with partners feeling they need to protect those who have been ill, putting aside their own needs to support the person who has been unwell. This can be maintained for a limited period of time, but given the excellent survival statistics for PCa, it may be difficult to sustain such altruistic behaviour in the long-term. Research by Cassidy (8) found that although spouse caregivers initially found benefit in caring, this oscillated before declining at around two years post diagnosis. Additionally, some partners of cancer sufferers reported feeling disloyal by discussing problems that are caused by the long term side effects of PCa (9,10).

In recent years, it is commendable that the extent of side effects for men with PCa has been recognised and interventions developed to support couple partnerships. However, such interventions have been developed as a result of exploring the needs of the men with PCa, without autonomously examining the impact of diagnosis and long-term psychological side effects of treatment on partners. Invitations for female partners to participate in such research have always been made via men with the condition. No literature has reported studies where female partners have been recruited independently of their partners. Hence, previous research may be biased, in so much as men who are unwilling to take part in research themselves, are unlikely to pass on information or encourage female partners to participate in studies. It is thought that some men might be too embarrassed by the induced physical side-effects to be comfortable with the prospect of partners disclosing these to a researcher, clinician or other support person (11,12)

**Hypotheses, aims and objectives:**

To understand the impact of prostate cancer from the perspective of the female partners of men living with and beyond a diagnosis of prostate cancer.

**Objectives:**

- To assess the impact of diagnosis/treatment/side-effects on the partner's life
- To gain insight into the 'experiences' of the female partners of men who have had or who are undergoing treatment for prostate cancer
- To explore the type of support partners have accessed (if any) and how useful this has been
- To determine if there are gaps in the provision of support for partners and if so, make recommendations for improvement in service provision to this group

**Preliminary data:**

Eleven interviews have been conducted and initial coding has identified a much broader range of issues that have been reported in dyad studies. This is consistent with feedback provided by the three women who reviewed the initial proposal for the study.

Preliminary categories show that female partners feel there is a lack of communication in a number of areas from health-care professionals: Long-term side effects; who to contact for advice and support; what services (and aids such as incontinence products) are available. There are issues with health literacy and interpreting 'health speak'.

Women have identified 'Isolation' as impacting on their lives through husbands/partners discouraging or preventing women from discussing their experiences of PCa or seeking support from others. Isolation has also been felt if a partner's ill-health required the woman to give up work or limit time previously spent with hobbies or social activities. Isolation was felt within the relationship due to loss of intimacy, rippling outwards impacting on other areas of closeness that previously led to intimate relations.

Although 'Intimacy' has emerged as a category from data, it has a different locus of concern in this female study, compared to previous male or dyad studies. Women focused more on the concepts of sharing, togetherness, touch and affection rather than coitus.

Feelings of inadequacy permeated for some in respect of participants not being able to either provide solutions to deal with partners' long-term side effects, nor to bring the relationship back to what they perceived as normality.

There appears to be a strong feeling that their husband/partner's survival has an associated cost: losing their relationships, losing 'normality', fear of losing their husband/partner and an overall a feeling of losing themselves.

Much deeper analysis is still required and concepts that need to be examined further are length of time since diagnosis, social expectations attached to women's peer groupings, age-related expectations of possibility of ill-health.

There are parallels between findings by Cassidy (2018) that carers find benefit in their role for a period of approximately two years before decline and participants reported feelings of stress when partners have been experiencing side-effects for prolonged timeframes.

When older female participants describe their role in caring for their partner, they use words such as 'duty' and 'expectation' and describe it as an extension of their role as mother/family carer. Younger participants did not use this terminology.

There also appears to be a difference between younger women in the study and those over 60; exploration is required as to whether this is due to expectations of age-related ill-health by older women.

Pinks, Davis and Pinks (12) explored women's coping with PCa and found they felt ignored by the medical profession, participants in the current study have also demonstrated reluctance to seek medical advice on coping with their partner's PCa. Interesting of the four who did seek GP advice, anti-depressants were immediately prescribed without full exploration of the sources of stress felt by the women, only one of these women accepted this medication.

**Potential impact of the project:**

Literature on the effects of breast, prostate and colorectal cancers show that despite demonstrating psychological strain equal to, or sometimes in excess of that of cancer patients,

partners are unwilling to seek help and support from primary care providers or cancer charities. Research has illustrated that partners/spouses of men with PCa felt ignored by the medical profession (8,10), the current study will highlight the unmet needs and issues faced by this 'unseen' population and suggest support information and interventions to relieve emotional distress due to losses in self-identity, feelings of inadequacy and help promote quality of life.

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