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College of Radiographers Doctoral Fellowship 016

£15,055 awarded

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

Principle Aim

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

Outcomes

The study is being conducted using a recognised type of analysis (Grounded Theory) that does not predict findings, it allows the findings to develop from information participants disclose during the interviews. As some interviews have already been conducted, preliminary findings have shown that women feel they are not receiving enough information about PCa, they feel isolated, and are experiencing changes in their relationships. Importantly they report that while they are grateful that their partners have survived, normality has changed with some feeling they have lost their own identity. These and other issues will be explored further with future participants.

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).

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 be 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, loosing '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.

Methodology

Ethical approval for semi-structured interviews with female participants was granted in July 2017 (REC/16/0099). A revision in March 2018 allowed the widening of recruitment and contact with the only identified all female support group in the UK or Ireland. A further amendment (REC/16/0099 Amendment No.2) was granted 22 Nov 2018 to allow expansion of recruitment to include leaflet distribution at named Bingo Halls and in local newspapers. Participants to date have all been from middle class backgrounds and a broader cross-section of society would be welcome.

Access N.I. approval has been granted.

Prior to beginning full recruitment three females, whose husbands/partners had previously been diagnosed with the condition, provided feedback on the proposed study. All three had been approached independently and unanimously agreed that they were uncomfortable with the proposed title and the emphasis on psychosexual issues. All reported that although there were sometimes problems with intimacy, there were a much wider array of issues associated with a spouse/partner with PCa. Having taken their comments on board, the title was amended, and interview schedule/prompts adjusted.

Mason (13) undertook research to determine the ideal sample size for qualitative research involving interviews and determined that 31 was optimal. Mason's research paper has been used as an estimation of the sample size required for this qualitative study and ethical approval was sought in line with her recommended sample size. However, given the study employs a grounded theory approach, it is more important to consider theoretical saturation and it is possible that fewer numbers might prove sufficient or indeed that additional participants might be required (14).

To date 19 ladies have requested information, of these 15 agreed to participate and provided written consent. Three ladies later withdrew consent before interview. In line with ethical requirements, potential participants had been clearly informed that they could withdraw at any time without giving any reason, however two of those withdrawing did freely offer an explanation; their husbands were not comfortable with them taking part. This endorsed the possible bias in previous research literature. The male partners' reluctance for wives to speak about issues arising as a result of prostate treatment side effects was also mentioned by two women who have taken part in the study.

Eleven individual interviews have already been conducted. The interviews were digitally recorded and analysed on a line-by-line basis following a constructivist grounded theory approach (14). Provisional categories are emerging: finding information, feeling inadequate, being isolated from partner and social groups, and losing intimacy. The provisional categories appear to be wider than those previously identified in the dyad focused research studies. Whilst participants in this study identified physical relationships as challenging, they also identified other aspects of everyday life such as finances, isolation and knowledge as being of equal or more significance.

In the UK, there is only one support group specifically for female partners, this was developed as an adjunct to a male support group. An invitation to 'sit in' on the female support group monthly meeting was accepted by the researcher. Nine female members were in attendance at the meeting, the proceedings were not recorded, as the purpose of attending the group was to see how it functioned, how they had organised the group and consider whether this might be something that should be expanded upon in other locations.

Recruitment continues and further individual participants will be sought to strengthen the work. To this end, a second amendment to the recruitment strategy has been approved (REC/16/0099 Amendment No.2), this was due to the already

recruited sample being mainly from higher socioeconomic groupings. It is hoped that through broadening the recruitment pool with the addition of advertisements in community newspapers and distribution of flyers at Bingo Halls that women from lower socioeconomic groups can be recruited.

In an ideal world, recruitment will continue with analysis progressing in tandem until theoretical saturation is reached, however given the time restraints afforded with a PhD study, time for writing up the findings will necessitate closing recruitment in April 2020. Rich data has already been collected, however with further participant input, a deeper understanding of the female perspective can be added to the current knowledge base on living with and beyond prostate cancer.

Work is underway with a scoping review of the literature. This will follow the protocols defined by, and is registered with, the Joanna Briggs Institute. Two reviewers will independently search and evaluate works pertinent to this study. Discrepancies will be arbitrated by a third researcher.

A scoping review has been chosen in preference to a standard systematic review because research on the impact of a cancer journey on female partners of prostate cancer survivors is an under-researched field. Previously identified literature does not examine the perspectives of independently recruited females, current literature tends to take a dyad approach, and there is limited research exploring the impact of cancer (of any anatomical site) on independently recruited partners. Preliminary literature searches identified intimacy as the main focus of concern, yet public/service-user input during protocol development in this study brought this into dispute. Ussher and Sandoval (15), Broady (16) and Pinks, Davis, and Pinks (12) have examined issues and needs of spouses from the perspective of the gender of the caregiver, so dyadic investigation and intervention is unlikely to provide the full picture of the experiences and needs of these female partners. Although research has led to the development of interventions for 'couples' (17-21) female partners' psychological morbidity is still poorly understood. A scoping review allows incorporation of a range of study designs, published literature and grey literature that would add insight to this study (22-24).

Potential impact

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

Dissemination Strategy

Opportunities have already arisen to publish articles aligned to the current study;

- “No Sex Please, We’re ... Embarrassed” was published in *Imaging and Therapy Practice* (25)
- “Choosing an Appropriate Review Typology: Looking Beyond the Systematic Review,” has been accepted (January 2019) for publication in *Imaging and Therapy Practice* (26).
- Initial findings were presented at UK Annual Radiotherapy Conference 2019 (27).
- Oral presentation was delivered at Early Career Researchers pre-meeting of BPOS 2019
- A poster at BPOS conference 2019
- An abstract has been accepted for oral presentation at the NIBPS meeting in April 2019.

As work progresses abstracts will be submitted to appropriate national conferences/journals related to Psychosocial Oncology and/or Radiography. The researcher also hopes to present at International Psychosocial Oncology Society’s conference in the future.

To enhance dissemination ORCID, Researchgate and LinkedIn are also being utilised.

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