

**Terri Gilleece**

**CoRIPS Research Grant 139**

**£9,944 awarded**

**Title:** Partners in Prostate Cancer: An exploration of the impact of prostate cancer on intimate relationships from a partners' perspective.

### **Principle Aim**

To explore the impact that a diagnosis of prostate cancer (PCa) has on the partners of men diagnosed with the condition.

### **Primary research question**

What impact does prostate cancer have on the partners of those diagnosed with the condition?

### **Secondary research question**

Can the quality of life of partners of prostate cancer survivors be improved by addressing the impact side effects of treatment for the condition have on relationships?

### **Outcomes**

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

### **Review of literature and identification of current gap in knowledge**

Prostate cancer (PCa) is the most commonly diagnosed cancer in men across the UK. It is currently estimated that 1 in 8 men in the UK will develop PCa (Cancer Research UK 2012). As with most cancers the risk of developing PCa is related to increasing age; it is rare under the age of 40 and the risk rises rapidly over the age of 70. Although the number of PCa diagnoses between 1979 -2010 has doubled, the survival rates of those diagnosed have demonstrated an upward trend and currently over 80% of men live for 10 years beyond their diagnosis (Symonds and Walter 2012). The majority of patients will experience at least one of the common side effects: erectile dysfunction (ED), urinary incontinence, urinary retention, bowel problems and feminisation (gynaecomastia, hot flushes) and general loss of libido, or a combination of those listed and other less frequent but possible sequelae (Clark and Talcott Oct 2001, Katz Jul-Aug 2007, Sanda *et al.* Mar 2008).

Given the litany of possible side effects, it is well documented that PCa can have a profound impact on all aspects of relationships between men diagnosed with the condition and their partners. . There are a number of intertwined factors relating to PCa that can impact on all aspects of relationships of those with the condition and their partners.

Sexual dysfunction is the biggest cited side effect of prostate cancer treatment. For the purposes of this study we have adopted Cleary and Hegarty's (2011) neo-theoretical framework of sexuality that takes a holistic view of intimacy rather than just viewing intimate relationships in the context of sexual interaction and so all aspects of relationships will be examined.

PCa can be classed as a chronic illness because of the high survival rates and any form of cancer or chronic illness can have an impact on relationships (Checton *et al.* Jun 2012, Lim *et al.* May-Jun 2015, Scott *et al.* Dec 2004, Ussher *et al.* Nov-Dec 2013).

Current literature documents the experiences of people with cancer (PWC). The partners of those diagnosed with cancer have different experiences, emotions and needs to PWC (Dagan *et al.* Apr 2011, Ervik *et al.* May-Jun 2013, Harden *et al.* Mar-Apr 2013, Langer *et al.* Sep 2007, Ussher *et al.* 2015). Literature also shows that partners are the main source of emotional care for these men (Ervik *et al.* May-Jun 2013, Langer *et al.* Sep 2007) and because of this PCa is recognised as a 'couples' disease and interventions have been developed in the context of the 'dyad' in recent years; however, these interventions have been developed without fully understanding the needs of the partners. (Chambers *et al.* 2012, Harden *et al.* 2002, Li and Loke Mar-Apr 2015, Li and Loke Mar-Apr 2015, Nelson and Kenowitz 2013, Northouse *et al.* Dec 2007).

On examination of the currently available literature it is possible to conclude that there are complex issues relating to couples experiencing life after a prostate cancer diagnosis: age (of both partners), treatment related sequelae, psychological impact of a cancer diagnosis, and possible co-morbidities in both partners. Couples are highly likely to encounter a change in their relationships that affects communication and impacts on quality of life (Hughes 2000, Tierney 2008). Recent research has

shown that efforts are being made to address the effects of PCa on relationships by examining the perspectives of couples and implementing interventions for these couples, but there is little research examining the perspectives and experiences of the partners of those living with or after PCa, and in particular a paucity of studies gathering views of partners independently of the person with cancer. To date partners' needs have been investigated by invitation of the men who have had PCa. The majority of the work has been conducted on dyads. The literature suggests that there is a level of protective buffering (Langer *et al.* Sep 2007) when the couples are dealing with cancer and partners feel they need to protect those who have been ill and put aside their own needs to support them; 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. Some partners of cancer sufferers feel disloyal by discussing problems that are caused by the long term side effects of PCa (Antoine *et al.* May-Jun 2013, Holmberg SK *et al.* 2001), so dyadic investigation and intervention is unlikely to provide the full picture of the experiences and needs of these partners. The impact of changes to the relationships of these individuals after the men they share their lives with are diagnosed with PCa is therefore unknown and warrants investigation. This proposal outlines research that aims to gather essential data to identify the needs of the partners of men diagnosed with PCa to assist in the development of support services to improve the quality of life of both parties.

## **Methodology**

A qualitative design is advocated as the intention is to explore how prostate cancer has impacted on the relationships of partners of those with this condition. Research with the partners of men who are living with or survived PCa is growing but to date most studies revolve around the couple as a dyad. The few studies that have examined the experiences of partners of cancer sufferers (of any organ or site) as individuals have done so at the invitation of the person with cancer (PWC). A current model of understanding of the perspectives of this group of partners recruited independently of the PWC has yet to be developed. This demands an inductive, interactive course of investigation that would be best achieved by employing a qualitative framework. Creswell (2007) defines five main approaches to qualitative research. In choosing an appropriate direction the main consideration must be fitness for purpose in relation to the current study. Given that little work exists on the topic in question a Grounded Theory (GT) approach appears the most appropriate as it allows theories to emerge from the data. The focus of GT is on understanding human experience (Licqurish and Seibold 2011). It is a method whereby data collection, analysis and theory development are performed in tandem. The constant comparative approach employs the

simultaneous collection and structured analysis of the data, providing systematic structure and rigor. The technique originally developed by Glaser and Strauss in the 1960's has seen many iterations. The three most common forms are Classical GT, Straussian GT and Constructivist GT. Limitations of Classical GT are that it suggests that the researchers approach their study in a naïve state without conducting a literature review until the analysis phase. It also hails an objectivist view of a single reality with a passive, neutral observer (Cooney 2010). Constructivist GT sees a prior examination of the literature as essential for establishing where the proposed study fits in the context of what is already known and it seeks to bring about a mutual understanding of the topic through collaboration between the researcher and the research participant. Charmaz's process of verifying the researcher's interpretations with the participant ensures trustworthiness and helps eliminate research bias (Penny 2009). For these reasons the constructivist approach appears to balance current academic requirements of 'a priori' knowledge in the field whilst still allowing the emergence of theory from the data in reciprocity with analysis.

Limited research into the effect of PCa on the partners of those surviving the disease and subsequent lack of theory on the impact on relationships of the non-cancer sufferer is evident from the current gap in the literature. Partners of men with PCa are likely to have diverse and heterogeneous perspectives and different constructions of reality that are dependent on a myriad of factors. A constructivist paradigm provides an understanding of "the world of human experience" (Cohen and Manion 1994).

### **Potential impact**

The researchers hope that by exploring and understanding the impact that the side effects of PCa treatment have on partners of those with the condition that needs of this group can be addressed. In doing this the researchers feel that this might result in improved quality of life for partners and by reducing stresses, pressures and tensions in the relationship, improving the quality of life for men surviving PCa.

### **Dissemination Strategy**

It is hoped that this research will be of a calibre that results in publications in peer reviewed journals such as 'Radiography' and other journals with a cancer care theme. As a requirement of the PhD regulations the findings will be presented at seminars within the university and further presentations are envisaged at national cancer conferences and /or radiotherapy conferences. The findings will be written-up in the form of a thesis in part fulfilment of the applicants PhD studies.

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