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Living with Chronic Illness: Experiences of diagnosis and treatment

By

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This thesis is submitted in partial fulfillment of the requirements for the
degree of Doctorate in Clinical Psychology

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List of Abbreviations

ACT Acceptance and Commitment Therapy

APA American Psychiatric Association

BD Bipolar Disorder

BPS British Psychological Society

CINAHL Cumulative Index to Nursing and Allied Health Literature

DCP Division of Clinical Psychology

GP General Practitioner

IPA Interpretative Phenomenological Analysis

NHS National Health Service

NICE National Institute for Health and Care Excellence

ONS Office for National Statistics

PRISMA Preferred Reporting Items for Systematic Reviews and
Meta- analysis

PCA Prostate Cancer

PSA Prostate-specific antigen

QA Quality Assessment

QOL Quality of Life

UK United Kingdom

USA United States of America

WHO World Health Organisation

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Thank you to my research supervisors Jo Kucharska, Magda Marczak and Tom Barker for your patience, persistence, support and guidance. To my family and friends that have given me the hope to continue when I have struggled, I have really appreciated it.

Declaration

This thesis has not been submitted for a degree at any other University. It has been produced under the academic supervision of Jo Kucharska (Clinical Director, Coventry University) and Magda Marczak (Lecturer in Clinical Psychology, Coventry University) and the clinical supervision of Tom Barker (Clinical Psychologist, Worcester Health and Care NHS Trust). This thesis is my own work apart from the collaborations already stated. It is intended that chapter one will be submitted to the Journal of Psycho-Oncology and chapter two will be submitted to the Journal of Affective Disorders.

Summary

The experience of living with a chronic illness can impact on both the person receiving a diagnosis and those close to them. Experiences of diagnosis and any subsequent treatment are important as it allows individual, lived experiences to be better understood. Through exploring these experiences, it is hoped that services, treatment and support could be developed and improved. This paper consists of three chapters.

Chapter one focuses on the experiences of partners of men with prostate cancer. A review of the literature identified twenty-two papers that are reviewed and synthesised into four overarching themes. Changes to the relationship and the unmet needs of partners are explored. Further ways in which services and professionals can support partners are identified.

Chapter two involves a qualitative study exploring the experiences of seven men living with a diagnosis of Bipolar Disorder. Interpretative Phenomenological Analysis is utilised to understand men's lived experiences. One theme identifies the battles men experience internally and externally in relation to vulnerability, masculinity, medication and stigma. Clinical implications and research directions are identified.

Chapter three is a reflective account of the overall research process. It spans from the development of the research proposal through to conducting and reflecting on the research undertaken. Consideration is given to the role of a Clinical Psychologist in the research process.

Overall word count: 22864

CHAPTER 1: Literature Review

Partners' experiences of prostate cancer: A review of the Literature

In preparation for submission to *Journal of Psycho-Oncology*
(See Appendix A for Author Guidelines)

Word count: 10948 (Exclusive of figures, tables, footnotes and
references)

1.1 Abstract

Providing emotional and practical support to men with prostate cancer (PCA) is shown to result in higher levels of distress for partners, which impacts on their own health and well-being and causes changes to the intimate relationship. This review aimed to focus on the experiences of partners of men with a diagnosis of PCA and any subsequent treatment. An electronic database search involving PsychINFO, CINAHL, Medline and Web of Science was conducted. Twenty-two studies were identified that satisfied the inclusion criteria and were subject to a quality assessment. A meta-ethnographic approach was taken to synthesise the findings which highlighted four main themes: *'Making sense of cancer'*, *'What about us?'*, *'Changes to the intimate relationship'* and *'The role of caregiver'*. Partners were shown to put the man with PCA first before their own needs by providing emotional and physical support following diagnosis and any subsequent treatment. The result of treatment related changes impacted on the intimate relationship, specifically in relation to communication and sexual intimacy. A need for further support from professionals was identified in order to provide emotional support, inclusion in medical appointments and opportunities for partners to receive information for caring with someone with PCA. Further to this, interventions that promote communication within the relationship and support the unmet needs for partners of men with PCA are suggested.

1.2 Introduction

This section will introduce PCA and the different treatment options available in the UK. Following this, the impact of PCA on men and their partners will be explored. Previous literature review papers will be acknowledged and finally a rationale for the focus of this paper will be put forward.

1.2.1 Prostate cancer

PCA is the second most common form of cancer in men worldwide (World Health Organisation [WHO], 2015) and the most common form of cancer in men in the UK (Office for National Statistics [ONS], 2016). In 2014, PCA accounted for 26.4% of all new diagnoses registered for men with cancer in the UK and this incidence rate has increased by 6.8% over the last ten years (ONS, 2016).

The introduction of the prostate-specific antigen (PSA) blood test in the 1980s has not only enabled PCA to be recognised at an earlier stage of development (NICE, 2014) but also led to a growing number of cancer 'survivors' (Bell & Kazanjian, 2011) living with PCA and the effects of treatment (Couper et al., 2006a). A PSA test, together with a digital rectal examination, is usually performed when PCA is suspected (NICE, 2015). In addition to this, some men undergo a prostate biopsy (NHS, 2015) or MRI, CT or bone scan investigations (Prostate Cancer UK, 2014) before receiving a diagnosis of PCA. Factors such as medical history, prior and current PSA levels, age, ethnicity, physical examinations and any co-morbidities are considered when making a decision to perform a biopsy (Dunn & Kazer, 2011). PCA can be diagnosed at varying stages and is known as localised, locally advanced or metastatic PCA respectively (NICE, 2014).

Localised PCA is contained within the prostate, whereas locally advanced PCA may include the surrounding areas or organs. Metastatic PCA involves the spread of cancer to other parts of the body (Prostate Cancer UK, 2014).

There are a number of treatment options available in the UK for localised or locally advanced PCA; however, this is more limited for metastatic cancer where the treatment aim is to manage symptoms through contact with palliative care teams and to provide information and support (NICE, 2014). Clinical guidelines for localised PCA specify that treatment options include active surveillance, radical prostatectomy, radical radiotherapy, hormone therapy, brachytherapy (a type of radiation therapy where radioactive seeds are implanted in the prostate) or watchful waiting (NICE, 2014). For locally advanced PCA, treatments offered may include radiotherapy, hormone therapy or watchful waiting (Prostate Cancer UK, 2014). Hormone therapy or bilateral orchidectomy are recommended for metastatic cancer (NICE, 2014). However, for hormone-refractory metastatic PCA, chemotherapy may be considered (Dunn & Kazer, 2011).

1.2.2 Impact of prostate cancer

Radical treatment for PCA is reported to have adverse effects for men, such as sexual dysfunction, urinary incontinence and radiation-induced enteropathy which should be considered prior to engagement in treatment (NICE, 2014). Other side effects reported by men on hormone therapy include hot flushes and fatigue (Ervik et al., 2010). Both the experience of being diagnosed with PCA and treatment related changes, have been reported to leave men feeling overwhelmed (Ervik et al., 2010) and affecting men's physical, mental and social well-being (Weber & Sherwill-Navarro,

2005). The concept of survivorship may be used to describe the physical, psychosocial and economic experiences of cancer from being diagnosed, through possible treatment, until end of life (Goonewardene et al., 2015). For men adjusting to life after treatment, significant deterioration has been shown in relation to social and leisure activities, illness-related sexual functioning, as well as in relationships within the family unit and with extended family (Ezer et al., 2012).

Lack of sexual desire and erectile dysfunction are highlighted as key experiences after treatment for PCA, which have been shown to impact not only on a man's sexuality but also on his masculinity (Ervik et al., 2010). Sexuality is considered to have an important role in good quality of life (QOL) (Dahn et al., 2004; Katz et al., 2007) and sexual performance is closely linked with the hegemonic understanding of masculinity, which provides a template for how men are expected to be (Gray et al., 2002; Wall & Kristjanson, 2005). Further to this, some men have been shown to avoid discussions or disclosure of their PCA to people other than their spouse and were uneasy with the notion of needing support, especially emotional support (Gray et al., 2000). Some men did not want to appear vulnerable as a result of their illness, as it could be perceived as harmful to their masculine values of being strong and not needing help (Ervik et al., 2010).

1.2.3 Partners of men with prostate cancer

Spouses have been shown to be the closest source of support for men with PCA and the most likely to deal with the repercussions of illness (Ezer et al., 2012). Caring for someone with cancer impacts on emotional well-being, physical health, employment, finances, continuing with a social life and relationships (Macmillan, 2012). Many carers

have to reduce their working hours and spend less time with family and friends to fulfil their caring role. This can lead to isolation and loneliness, and for some carers also stress, anxiety and depression (Macmillan, 2012). Carers who provide daily support are shown to put the needs of the cancer patient first which can mask the practical implications of caring and their own emotional needs are often not recognised (NICE, 2004). Cancer patients and health care professionals can underestimate the level of a cancer patient's unmet needs in comparison to the carer's perspective of a patient's unmet needs (Sharpe et al., 2005). Further to this, caregiver burden and poorer caregiver health are often associated with carers reporting a high level of patient unmet needs (Sharpe et al., 2005).

Caregivers of PCA patients have shown difficulties with the strain associated with fulfilling a caring role and the negative effects on their own well-being due to multiple role responsibilities between family and work (Harden, 2005). Spouses often fulfil the role of caregiver and experience distress in relation to their caregiving roles which spans through cancer diagnosis, treatment and beyond (Resendes & McCorkle, 2006). The long-term effects of localised PCA treatment on spouses' QOL identified how spouses continued to experience negative appraisals (general stress, perceived threat and perceived benefit) in relation to their caregiving role at twenty-four months post treatment when their partner had experienced either radical prostatectomy, radiation therapy or brachytherapy (Harden et al., 2013). Further to this, spouses who were younger than sixty-five years old had a more negative view of care-giving, had lower sexual satisfaction and lower QOL, as they experienced more stress and perceived more threat in relation to their caregiving role. Those spouses in the study who had partners with treatment difficulties related to urinary, sexual and hormonal function

were reported to experience more stress and worse QOL twenty-four months post treatment.

Whilst a number of studies highlight how spouses have reported greater psychological distress than their husbands with PCA (Heyman & Rosner, 1996; Herr, 1997; Phillips et al., 2000), Eton et al. (2005) reported the level of distress for spouses was the same as the male patients. Research on wives has shown they exhibit more distress in relation to QOL after their husband received treatment for PCA than the male patients themselves (Kornblith et al., 1994). Higher distress has also been shown in partners at the time of a man's PCA diagnosis and which had reduced six months later, however partners reported to be less satisfied with their relationship over this time (Couper et al., 2006b). There is limited literature on the experiences of same sex partners who have PCA (Wootten et al., 2014). Only two qualitative case studies involving same sex couples (Filiault, Drumond & Smith, 2008; Hartman et al. 2014) and one mixed-design study focusing on erectile dysfunction and sexual changes for men and partners were identified (Ussher et al., 2016).

1.2.4 Impact of prostate cancer on the intimate relationship

PCA and any subsequent treatment can impact on the couple, particularly with regard to communication, sexual functioning and intimacy (Gailbraith, Fink & Wilkins, 2011). The impact of treatment related changes such as urinary incontinence and sexual impotence may strain the relationship between partners resulting in a need to explore new ways to be sexually intimate (Harden, 2005). Intimacy needs in older adults with chronic illness can often be overlooked by healthcare providers (Steinke, 2005; Wallace, 2003), even though sexual intimacy is considered important as it contributes

to the desire to experience physical pleasure and emotional intimacy (Sanders, Pedro, Bantum & Galbraith, 2006). Feelings of loss and sadness were expressed by long-term same sex partners in relation to the impact of erectile dysfunction on sexual intimacy and pleasure (Ussher et al., 2016). However, other male partners within the same study reported ways to renegotiate sexual intimacy by focusing on non-penetrative sex, cuddling and stroking, which for some partners made the sexual connection stronger (Ussher et al., 2016).

Where there is open communication surrounding the potential impact of PCA, a man and his partner cope more effectively with the stressors associated with PCA and subsequent treatment (Jones et al., 2008). This can be more difficult where couples feel unable to discuss sexual functioning or intimacy. In one study looking at male patients and their female partners, similarities and differences were explored in relation to their individual experiences of living with PCA following treatment (Sanders et al., 2006). Partners reported a lack of romance in the intimate relationship following treatment, feelings of being unattractive and that sex had become clinical due to the preparation and planning involved as a result of sexual dysfunction. Male patients within the same study found it hard to depend on others, although valued their wives support, they described difficulties with communication with their partners. Men and their partners agreed there was a need for more information focusing on how to manage the impact of PCA as a couple. However, they showed differences in the way they wanted to receive this information, with partners preferring support groups and male patients preferring reading materials (Sanders et al., 2006). Facilitation of communication between partners by healthcare providers is crucial to assess and affirm sexuality and intimacy needs, especially where partners may have different

preferences in terms of the information needed (Sanders et al., 2006). It is highlighted that with the increasing survival of men with PCA, developing appropriate family-relational-psychosexual interventions to meet unmet needs is important to address sexual and psychological needs in order to provide supportive care to partners as well as men with PCA (Paterson et al., 2015).

1.2.5 Support for partners

Professional, informational and emotional support for spouses is not as advanced as it is for patients with PCA (Resendes & McCorkle, 2006). The type of support offered to spouses is shown to reflect either a focus on improving the proficiency of caregivers in order to address the needs of the patient or on psychological interventions focusing on alleviating distress. In a review of psychosocial interventions for partners of men with PCA, only one out of eleven intervention studies was solely for the partner alone (Wootten et al., 2014). Further to this, educational, psycho-educational, and skill building strategies are usually aimed at the couple (Resendes & McCorkle, 2006). Psycho-education includes topics such as medication, nutrition, stress, coping, social support, survivorship, marital communication (Manne et al., 2004), behavioural strategies for sexual intimacy (Hampton et al., 2013), symptom management, family involvement, optimism and uncertainty reduction (Northouse et al., 2007). Psychosocial interventions often focus on the man with PCA even if they are designed for the couple, highlighting how the partner's needs may be missed. With the introduction of the Care Act (2014) in April 2015, carers have the same legal right to receive a needs assessment and support as the patient they are caring for. Further to this, local authorities have a duty to provide these assessments and support. Unmet

needs of partners of men with PCA include a lack of understanding of the best way to support their partner with coping with changes to their relationship, lack of confidence in being able to support their partner and being unsure of where to access help (Paterson et al., 2015). Where partners feel supported in their caring role, there is more satisfaction with their relationship and an increased ability to cope with the emotional impact of care-giving (Couper et al., 2006a). Therefore, it is imperative to find strategies to promote positive coping and lessen the negative self-appraisal of care-giving (Harden et al., 2013).

Little research has focused on caregivers within the PCA population. Most research has focused on the effects of living with and being treated for PCA from the perspective of the man and from the perspective of the couple, but little has focused on partners of men with PCA and the difficulties they face (Harden, 2005). Resendes and McCorkle (2006) highlight the need for further research on providing emotional and practical support to alleviate spousal distress, which could then be beneficial to the patient. This is particularly relevant where partners are considered to be important interlocutors between patients and professionals (Ervik et al., 2010). A number of existing review papers and their specific focus involving partners of men with PCA are listed below:

- relatives' experiences (spouses and children; Bruun et al., 2010),
- sexual intimacy in heterosexual couples (Beck et al., 2009),
- psychosocial adjustment of female partners (psychosocial distress, coping patterns, effect on couple's relationship, psychosocial interventions; Couper et al., 2006),
- the effects on intimate relationships (Couper et al., 2007),

- developmental life stages and couples experiences (developmental age and disease specific issues, quality of life and adapting; Harden et al, 2005),
- psychosocial responses of spouses whose husbands have undergone prostatectomy (responses to diagnosis, treatment, and side effects; Resendes et al., 2006),
- influences on patients' and partners' treatment decision making (barriers and facilitators; Schumm et al., 2010),
- experiences of how care was organised and delivered (screening, diagnosis, treatment decision, treatment and post-initial treatment; Sinfield et al., 2009)
- psychosocial interventions for partners (both solely and as a couple) focusing on emotional distress and sexual intimacy (Wootten et al., 2014).

According to the existing reviews on partners of men with PCA listed above and the literature highlighted throughout the introduction, it has been shown that focusing on the experiences of partners alone would be valuable in order to further understand their unmet needs. A rationale for this paper is provided below.

1.2.6 Rationale for this literature review

PCA diagnosis and treatment impacts on partners when they experience high levels of emotional distress, are relied on by partners for vital physical and emotional support, and subsequently expected to fulfil a new role of caregiver. This has life changing implications in areas of employment, social and leisure activities and within their intimate relationship. Further to this, partners are also a source of emotional support for family members, focusing on other people's needs rather than their own, resulting in a number of unmet needs, impacting on their own health and wellbeing. If partners'

needs and experiences are better understood and appropriate support is offered to them then this reduces carer burden and allows them more availability to support the man with PCA. Much of the research into PCA has focused on the patient and the partner as a couple and little research has focused exclusively on the experience of the partner alone. This paper will review articles focusing solely on partners' experiences of living with a man diagnosed with PCA. When synthesising qualitative articles, preservation of meaning and key concepts within the studies is important and therefore this will be adopted within this review (Britten et al., 2002). The aim of this review is to gain an in-depth understanding of the experiences of partners of men receiving a diagnosis of PCA and any treatment offered. Partners include married couples, cohabiting couples or those in a civil partnership such as wives, spouses, male partners and husbands. Experiences of partners will include aspects such as how the partner responded to the diagnosis, any treatment or support received and experiences of the intimate relationship.

1.3 Methodology

A robust systematic search of the literature was undertaken between April and August 2016. Electronic databases were chosen in order to include journals with psychological and medical literature.

1.3.1 Database search

Four databases were used in the electronic search: PsychINFO, CINAHL, Medline and Web of Science. No date restriction was used. Search terms were chosen by considering the main concepts and aim of the review and included PCA, diagnosis, treatment, partner and experience. Additional variations for each concept were used to enable a thorough search of the literature (see Table 1.1). The boolean 'AND' was used to combine research terms while 'OR' was used between additional variations of a particular search term. For example, (cancer* OR neoplasm* OR tumo?r*) AND diagnos?s. Searches were restricted to title and abstract only.

Table 1.1: Concepts, search terms and additional variations of search terms used in the electronic searches.

Concept	Search Terms	Additional Variations
Cancer	cancer*	neoplasm*, tumor, malignan*, carcinoma*
Diagnosis	diagnos?s	
Partner	partner*	carer*, caregiver*, spouse*, husband*, wives, wife*, "same sex", "same-sex", "male partner*"
Experience	experience*	impact*, adjust*, attitude*, view*, opinion*
Prostate	prostat*	
Treatment	treat*	intervention*, surgeon*, operat*, medicat*

a truncation was used in order to capture all variations of a word. For example, malignan could represent malignancies or malignant.

1.3.2 Manual Search

Reference lists were checked manually for any other relevant papers that fit within the search criteria in order to include as many relevant papers as possible.

1.3.3 Inclusion/ Exclusion criteria

Table 1.2 shows the inclusion and exclusion criteria for the articles that were screened.

Table 1.2: Inclusion and exclusion criteria used

Inclusion	Exclusion
<ul style="list-style-type: none">• Peer reviewed• Written in English• Partner of a man with a diagnosis of prostate cancer• Partner's experiences of a diagnosis and/ or treatment of prostate cancer• Qualitative study design• Mixed study design if the qualitative section includes a partner's experience of diagnosis and/ or treatment	<ul style="list-style-type: none">• Not written in English• A review, commentary, book chapter, letter, editorial, conference proceeding, discussion piece, legal paper, non-published thesis, not peer reviewed• Includes other forms of cancer• Quantitative study design and mixed study designs where the qualitative section does not focus on experiences of the partner• Focus is on men with prostate cancer and their experience, rather than the experiences of the man's partner• Feedback/ evaluation of a clinical trial or intervention rather than the experiences of the intervention or clinical trial

1.3.4 Search results

The database search identified a total of 361 articles. 182 of these were duplicates, therefore 179 articles were screened at the title and abstract level and 152 were excluded due to the inclusion/ exclusion criteria. 33 full text articles were assessed for eligibility. This included 27 from the database search and six additional papers when the reference lists were hand searched. 11 of these were excluded on the inclusion/ exclusion criteria. 22 articles met the eligibility criteria (Figure 1.1).

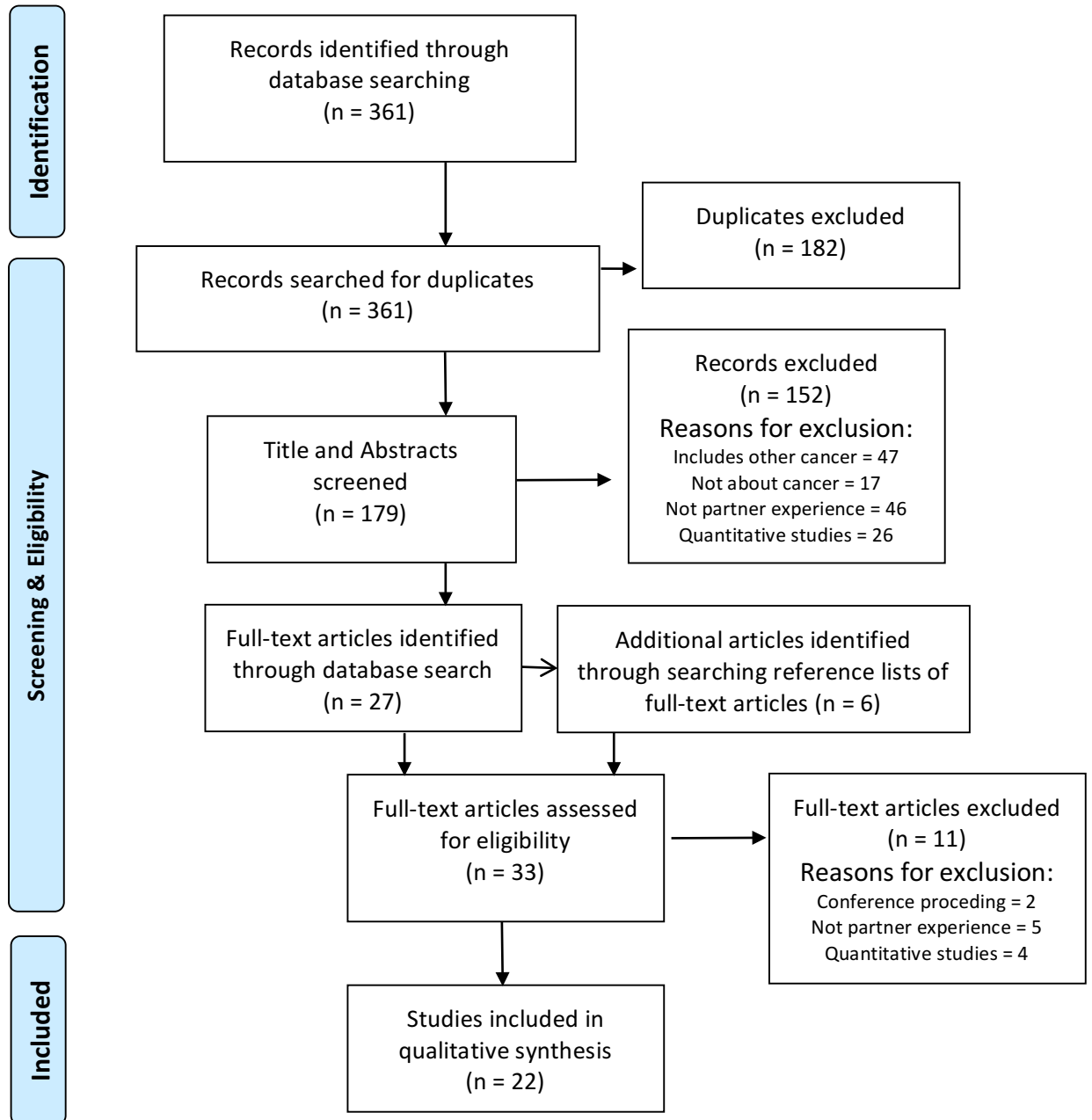


Figure 1.1: Systematic Review and Meta-analysis (PRISMA) flow diagram (Moher, Liberati, Tetzlaff & Altman, 2009).

1.3.5 Assessment of Quality

In order to interpret the quality of the 22 papers identified for inclusion, an assessment framework was utilised (Caldwell, Henshaw & Taylor, 2005). This framework was considered suitable as it can be applied to qualitative research. There

is deliberation over whether quantitative and qualitative studies can be assessed using the same assessment criteria (Mays & Pope, 2000), however the current framework takes into account the differences between qualitative and quantitative research studies. Each study was marked against 18 criteria questions using a 3-point scale. If the criterion was fully met then it was given a score of 2, if the criterion was partially met it was given a score of 1 and if the criterion was not met, it was given a score of 0 (see Appendix B). The total rating for each article was calculated by adding the scores of the 18 criteria together, to produce a score of between 0 and 36. A higher score reflected a better quality paper. A score below the midpoint of 18 indicated the article did not meet a satisfactory level of quality. Scores were converted to a percentage. To check for reliability in the application of the quality assessment, another researcher used the same framework to review five of the papers which resulted in consistent scoring. The Kappa statistic (0.7) showed moderate inter-rater reliability.

1.3.5.1 Assessment of Quality Results

The results of the quality assessment (QA) ranged from 25 (69%) to 34 (94%) with a mean of 31 (85%). The assessment highlighted that studies varied in their quality, however all studies were above 18 (the mid-point cut off) and thus included within the review (Caldwell, Henshaw & Taylor, 2005). The 22 studies all provided a clear rationale for undertaking the research, identified major concepts, stated aims and outlined the context of the studies. All but two studies (O'Shaughnessy et al., 2013; Street et al., 2010) described data collection that was systematic.

The method of participant sampling was not stated in 11 of the studies (Bruun et al., 2011; Ervik et al., 2013; Evertsen & Wolkenstein, 2010; Gray et al., 1999; Gray et al., 2000; Lavery & Clarke, 1999; Maliski et al., 2002; O'Shaughnessy et al., 2013; Street et al., 2010; Tanner et al., 2011; Wootten et al., 2014). However, nine studies used purposive sampling (Butler et al., 2000; Harden et al., 2002; Ka'opua et al., 2005; Ka'opua et al., 2007; McCaughan et al., 2015; O'Callaghan et al., 2014; Petry et al., 2004; Rossen et al., 2016; Sinfield et al., 2007), while the remaining two utilised convenience (Boehmer & Clark, 2001) and non-random sampling (Docherty et al., 2007). Purposive sampling in qualitative research is common due to the need for a homogenous group of participants who can provide breadth and depth on a topic (Cleary et al., 2014). Even though the sampling method was not stated in 11 of the studies, the selection of participants was described which gives a little insight in to the way the participants were invited to take part.

All studies apart from five (Boehmer & Clark, 2001; Docherty et al., 2007; Ka'opua et al., 2005; Street et al., 2010; Rossen et al., 2016) reported the study design, however only two studies (Ervik et al., 2012; McCaughan et al., 2015) gave a justification for the chosen design. Three of the reviewed studies identified the philosophical background which included a stance of critical realism (Sinfield et al., 2008) and a phenomenological-hermeneutic approach (Bruun et al., 2011; Ervik et al., 2012). Only Ervik et al. (2012) justified the chosen approach by describing it as a way to obtain rich information from participants, in order to understand experiences. This highlights a lack of quality throughout the papers in terms of the epistemological backgrounds and the justifications for the qualitative research designs that were chosen.

All studies described the method of data collection. Fifteen of the studies used interviews (Bruun et al., 2011; Butler et al., 2000; Ervik et al., 2012; Gray et al., 1999; Gray et al., 2000; Ka'opua et al., 2005; Ka'opua et al., 2007; Lavery & Clarke, 1999; Maliski et al., 2002; McCaughan et al., 2015; O'Callaghan et al., 2014; Petry et al., 2004; Rossen et al., 2016; Sinfield et al., 2007; Street et al., 2010), six studies used focus groups (Boehmer & Clark, 2001; Docherty et al., 2007; Evertsen & Wolkenstein, 2010; Harden et al., 2002; O'Shaughnessy et al., 2013; Wootten et al., 2014) and one study used narrative data (Tanner et al., 2011). The method of data analysis was harder to determine as even though the type of data analysis was stated in most studies, there was limited explanation of the exact procedures:

- six studies stated the use of grounded theory (Boehmer & Clark, 2001; Gray et al., 2000; Maliski et al., 2002; O'Callaghan et al., 2014; Petry et al., 2004; Rossen et al., 2016),
- three used content analysis (Butler et al., 2000; McCaughan et al., 2015; Tanner et al., 2011),
- three used thematic analysis (Docherty et al., 2007; O'Shaughnessy et al., 2013; Wootten et al., 2014),
- two used a combination of grounded theory and content analysis (Ka'opua et al., 2005; Ka'opua et al., 2007),
- two stated qualitative data analysis (Lavery & Clarke, 1999; Sinfield et al., 2007),
- two used phenomenological techniques (Ervik et al., 2012; Harden et al., 2002)
- one did not state the analysis used (Gray et al., 1999).

Very few studies provided a detailed account of the process of analysis and therefore it made it harder to understand exactly how this was conducted.

It is worth noting that the same samples were used within Gray et al. (1999) and Gray et al. (2000), however one study reported experiences prior to treatment (Gray et al., 1999) and the other covered experiences both pre and post treatment (Gray et al., 2000). Ka'opua et al. (2005) and Ka'opua et al. (2007) also used the same samples, however one focused on adaptive processes to long-term prostate cancer and the other focused on spiritually based resources in coping and adapting to prostate cancer. It therefore appeared relevant to include each of these studies as they provided different perspectives that were relevant to partners' experience of PCA.

1.3.6 Characteristics of studies

The focus of this review is on the qualitative experiences of partners of men who have a diagnosis of PCA and any subsequent treatment (if they received treatment). Only the qualitative data and results of the 22 reviewed studies have been reported in the summary table (see Table 1.3).

Table 1.3: Characteristics of included studies

Author, date, title, country of origin	Study Design, Aims	Sample size, strategy description and recruitment location	Data collection and method of data analysis	Participant details (age, ethnicity, relationship status)	Time since diagnosis or treatment, type of prostate cancer, treatment type	Key Findings & Summary	Quality Rating (Total Kappa= 0.7)
Boehmer, U. & Clark, J. A. (2001) Communication about prostate cancer between men and their wives USA	Qualitative study Objective: explored the perceptions of men who have been treated for metastatic prostate cancer and the views of their wives regarding the changes that were caused by prostate cancer and its treatment	Convenience sample 27 participants Recruited from a larger investigation/ study	Retrospective focus groups (men and wives separately) Grounded theory	20 Men (11 white, 9 African American) 7 wives (5 white, 2 African American) 20 married men Men aged 60-82 (mean 69 years)	All men had metastatic prostate cancer Men had experienced the following treatments: 13 men had an orchiectomy and 7 men had monthly hormone ablation	Findings: Physical changes, Coping with Physical Changes, Perceptions of changes in spouse, Sexuality Summary: Physical changes occurred after treatment. Variations in couple's communication was highlighted and emotions were hidden to protect the other, although humour was sometimes used to voice important emotions. Changes were noticed in men's moods and social networks. Changes to sex lives were reported where women attempted to reassure men in terms of threats to their masculinity and paid little attention to their own needs. Communication about sexual losses were discussed pre-treatment but then this communication discontinued post-treatment.	86%
Bruun, P., Pedersen, B. D., Othser, P. J. & Wagner, L. (2011) The Lonely Female Partner: A	Qualitative, Longitudinal, phenomenological-hermeneutic approach Objective: to focus on life with incurable prostate	Sampling strategy not stated 5 participants Recruited through having a husband who had recently been diagnosed with	Qualitative Interviews (2 interviews, 7 months in between) Analysis and interpretation	5 female partners Age 54 – 73 years 4 married, one co-habiting	3 and 10 months after the male partner's diagnosis	Findings: 1 theme Coping: 1) Aspects of loneliness, 2) Informal Care, 3) The significance of relationships Summary: Loneliness was experienced in a variety of ways including the result of the male partner not talking about his illness, not telling others outside the family about the illness and	78% (Kappa: 0.684)

Central Aspect of Prostate Cancer Denmark	cancer from the perspective of the female partner with the intent of better understanding female partners' everyday experiences	incurable prostate cancer and attended a Urology Centre at a Hospital	based on Ricoeur (1979)			endeavouring to carry on life as normal. There is a duty and a wish to provide care to their partner and the family which resulted in their own needs being put aside. Having love and care in daily life was significant within the couple relationship and the relationship with family in order for the female partners to manage. Having a religious faith was also considered important as a way of managing loneliness.	
Butler, L., Downe-Wamboldt, B. Marsh, S., Bell, D. & Jarvi, K. (2000) Behind the scenes: partners' perceptions of quality of life post radical prostatectomy Canada	Exploratory descriptive study Objective: to determine the effects of the experience of a radical prostatectomy on the partners of men with prostate cancer	Purposive sample 21 participants Approached through their husbands who attended a Urology Clinic of a large tertiary hospital	Semi structured interviews Content analysis to categorize emergent themes	21 Caucasian females Aged 43-75 years (mean = 59) Married 0.5-54 years (mean = 34) 13 retired, 5 currently employed	Husband treated by Radical prostatectomy during previous 24 months	Findings: The diagnosis of prostate cancer Sources of information for treatment decision Acquiring needed information Urinary incontinence Sexual relationship Quality of Life Summary: the themes focused on partners wanting (and needing) to be involved in all phases of the experience (diagnosis, decision-making, treatment and recovery) due to the impact it has on their lives. A lack of support and information made this experience more difficult especially in the area of practical support (incontinence) and recovery expectations (sexual relationships). Partners are heavily involved in assisting men in their adjustment/ recovery after treatment.	81%
Docherty, A., Brothwell, C. P. D. & Symons, M.	Qualitative Thematic Approach	Non-random sample 12 participants	In-depth focus groups (joint patient and partner)	9 men, 3 women	6 months to 5 years since prostate cancer diagnosis	Findings: 4 categories: 1) initial experience, 2) patient involvement, 3) health judgement, 4) coping	94%

<p>(2007)</p> <p>The Impact of Inadequate Knowledge on Patient and Spouse Experience of Prostate Cancer</p> <p>UK</p>	<p>Objective: to describe the impact of patient and spouse knowledge and awareness on their experience of prostate cancer from initial symptoms to subsequent treatment</p>	<p>Recruited via an independent prostate cancer support group</p>	<p>Qualitative thematic approach</p>	<p>Most married, 2 single, 1 widower</p>	<p>Treatments included radiotherapy, orchiectomy and hormonal tablets</p>	<p>Summary: Men waited before seeking initial help due to lack of awareness of the potential seriousness of their symptoms until the pain became unbearable or they were encouraged by a partner to seek medical advice. Treatment options were given and a key influence was the impact on sex life and using the support of medical staff, where spouses were often the ones to contact and obtain further information. Physical well-being was used to determine health in relation to cancer along with the PSA level and the trust of medical professionals. Dealing with the cancer diagnosis quickly via treatment followed by acceptance and reliance on medical staff was a common coping technique.</p>	
<p>Ervik, B., Norday, T. & Asplund, K. (2012)</p> <p>In the Middle & on the Sideline: The Experience of Spouses of Men with Prostate Cancer</p> <p>Norway</p>	<p>Qualitative - phenomenological hermeneutic approach</p> <p>Objective: to explore how the daily life of female spouses is affected by their husband's prostate cancer</p>	<p>Sampling strategy not stated</p> <p>9 participants</p> <p>Invited through their husbands who attended either an outpatient department of Endocrinology and Urology at a University Hospital, a learning and coping seminars by the University Hospital or a local meeting arranged by PROFO</p>	<p>In-depth interviews</p> <p>Analysed within a phenomenological hermeneutic framework and presented as a stepwise research method</p>	<p>9 female spouses</p> <p>Aged 52-68 years</p> <p>Married 23-48 years (8) <5 years (1)</p> <p>5 working 1 retired, 2 disabled, 1 housewife</p>	<p>2-48 months since husband's prostate cancer diagnosis</p> <p>Husband treated by Radical Prostatectomy (6), radiation therapy (1) or a combination of radical prostatectomy and endocrine or radiation therapy (2)</p>	<p>Findings: 4 themes a) strong and optimistic versus vulnerable and overstrained b) maintaining the partner's sense of manhood, c) being on the side line, and d) the need for relationships outside of the immediate family</p> <p>Summary: The themes showed that spouses strived to achieve a balance between their own needs and meeting their husband's needs (providing emotional support and practical support). Initially their husband's needs were put before their own needs (suppressing their own anxieties) and later attempts were made to address their own needs without compromising their husbands needs. Spouse's needs were not recognized by professionals, family or friends</p>	<p>94%</p>

		(a national prostate cancer organisation)				and a need for someone to discuss these with, outside the family was recognised.	
<p>Evertsen, J. M. & Wolkenstein, A. S. (2010)</p> <p>Female partners of patients after surgical prostate cancer treatment: interactions with physicians and support needs</p> <p>USA</p>	<p>Pilot study</p> <p>Objective: to explore the interaction of the female partner with the patients physicians (primary care and urologist) and her support needs associated with treatment of & recovery from prostate cancer</p>	<p>Sampling strategy not stated</p> <p>14 participants</p> <p>Recruited through their male partners who were seen at a large Midwest Urology clinic</p>	<p>Focus groups using open-ended trigger questions (7 participants in each focus group)</p> <p>Analysis used the framework approach of familiarization, identifying thematic framework, indexing, charting and interpretation</p>	<p>14 female partners</p> <p>Aged 47-77 (mean 61.6)</p> <p>13 married, 1 not married</p> <p>Ethnicity: non-Hispanic white (12), black (1), unknown (1)</p>	<p>1-18 months since prostate cancer diagnosis</p> <p>All male partners had received surgical prostate cancer treatment prior to the focus group for partners</p>	<p>Findings:</p> <p>3 themes</p> <p>1) support issues and needs, 2) role of physicians (primary care and urologist) and 3) changes to the couple's relationship</p> <p>Summary: Changes within the couple's relationship were apparent through diagnosis and treatment where women became increasingly involved and took on a role of primary caregiver and provider of emotional support. Roles of primary and secondary care professionals were unclear which resulted in difficulties for women who were communicating on behalf of their partners. Emotional and informational support needs were identified as partners entered into an unfamiliar role of caregiver where there was not enough information available and a lack of opportunity to gain support from someone.</p>	86%
<p>Gray, R. E., Fitch, M. I., Phillips, C., Labrecque, M. & Klotz, L. (1999)</p>	<p>Longitudinal qualitative study</p> <p>Objective: to describe the experiences of</p>	<p>Sampling strategy not stated</p> <p>64 participants</p>	<p>Interviews separately and simultaneously</p> <p>No specific data analysis stated</p>	<p>34 men, 34 women</p> <p>Ages: men 50-68 years (mean 60.6), women</p>	<p>Chosen prostatectomy as treatment but at pre-surgery stage</p>	<p>Findings:</p> <p>6 themes</p> <p>1) Shock of diagnosis, 2) Connecting with each other, 3) Getting informed and making decisions, 4) Communicating with Others, 5) Carrying on as normal, 6) Dealing with anxiety</p>	<p>78%</p> <p>(Kappa: 0.658)</p>

<p>Presurgery experiences of prostate cancer patients and their spouses</p> <p>Canada</p>	<p>men with prostate cancer and their spouses between diagnosis and surgery</p>	<p>Referred by 16 urologists across a geographical area</p>		<p>42-72 years (mean 57.1)</p> <p>Married for 12-41 years (mean 30)</p> <p>Employed: 44% men 61% women</p>		<p>Summary: Initial shock and then acceptance of the prostate cancer diagnosis is highlighted followed by a re-established commitment within the couple where wives openly communicated love and support. It was critical to learn about prostate cancer, available treatments and a medical specialist they trusted. While waiting for surgery couples continued to live their lives normally, while deciding who else to tell and how much to say. Worries were kept from each other at times, while at other times it was seen as important to share anxieties to re-assure each other.</p>	
<p>Gray, R. E., Fitch, M., Phillips, C, Labrecque, M. & Fergus, K. (2000)</p> <p>Managing the Impact of illness: The experiences of men with prostate cancer and their spouses</p> <p>Canada</p>	<p>Longitudinal qualitative study</p> <p>Objective: to investigate support, coping and experiences associated with diagnosis and surgical treatment for men with prostate cancer and their spouses</p>	<p>Sampling strategy not stated</p> <p>64 participants</p> <p>Referred by 16 urologists across a geographical area</p>	<p>Interviews separately and simultaneously (3 time points, pre-surgery, 8-10 week's post-surgery and 11-13 month's post-surgery)</p> <p>Grounded theory</p>	<p>34 men, 34 women</p> <p>Ages: men 50-68 years (mean 60.6), women 42-72 years (mean 57.1)</p> <p>Married for 12-41 years (mean 30)</p> <p>Employed: 44% men 61% women</p>	<p>Pre and post prostatectomy treatment</p>	<p>Findings:</p> <p>Core category: Managing the Impact of Illness. Expressed through five major domains: dealing with practicalities, stopping illness from interfering with everyday life, keeping relationships working, managing feelings and making sense of it all</p> <p>Summary: Managing emphasised a sense of having control through gathering information, preparing for surgery or finding practical solutions as well as a sense of agency in that their reactions played a part in how prostate cancer influenced their lives. Psychological and social strategies were utilised to allow the couple to live as normal life as possible, facing the illness as a team, managing feelings and helping to make sense of it all.</p>	86%

<p>Harden, J., Schafenacker, A., Northouse, L, Mood, D., Smith, D., Pienta, K., Hussain, M. & Baranowski, K. (2002)</p> <p>Couple's experiences with prostate cancer: focus group research</p> <p>USA</p>	<p>Qualitative, descriptive study</p> <p>Objective: to explore the experiences of couples living with prostate cancer, the impact of the illness on their quality of life, their ability to manage symptoms and their suggestions for interventions that would help them to improve their daily experiences</p>	<p>Purposeful sampling</p> <p>42 participants</p> <p>Recruited from 2 cancer centres</p>	<p>Focus groups (6 focus groups: 2 men only (n=14), 2 spouses only (n=12) and 2 couples (n=8)</p> <p>Qualitative phenomenological techniques to produce themes</p>	<p>22 men 22 spouse-caregivers</p> <p>Men: average age 63.7 64% Caucasian 32% African American, 4% Native American 86% married 55% retired</p> <p>Caregivers: Average age 60.5 years, 75% Caucasian, 25% African American, 65% retired or homemakers, 35% working</p>	<p>Three phases of illness: Newly diagnosed, post primary treatment (18%) Post-primary treatment with a rising PSA (biochemical recurrence) (23%), metastatic (59%)</p> <p>Treatment: Prostatectomy (46%), radiation therapy (41%), hormone treatment (46%), other types (23%). No watchful waiting.</p>	<p>Findings: Themes 1) Enduring Uncertainty (struggling with choices, interruption in life, emotional roller coaster), 2) Living with treatment effects (losing urinary control, sexual dysfunction, hormonal alterations, overwhelming fatigue), 3) Coping with change (drawing together, shifting roles, facing anger, controlling the situation, sharing with others), 4) Needing help (professional caring, tailored information, peer reassurance)</p> <p>Summary: Themes reflected the physical and psychological impact of living with prostate cancer. From making treatment decisions, to having treatment and living with the physical changes/ side effects, there was a need for help and information to gain a sense of control over the changes and varying different emotions associated with these.</p>	94%
<p>Ka'opua, L. S. I., Gotay, C. C., Hannum, M. & Bunghanoy, G. (2005)</p> <p>Adaptation to long-term prostate cancer survival: the perspective of</p>	<p>Qualitative study</p> <p>Objective: to explore the adaptive process to long-term prostate cancer survival in elderly Asian/ Pacific Islander wives</p>	<p>Purposive sample</p> <p>26 participants</p> <p>Identified through their participation on a longitudinal study on quality of life</p>	<p>Semi-structured interviews, (2 interviews with 6 months in between)</p> <p>12 stage analytic procedure that combined elements of</p>	<p>26 women of Asian or Pacific Islander ethnicities</p> <p>Aged 60-86 years (mean 73.82)</p>	<p>Average of 8.3 years since husband's prostate cancer diagnosis</p> <p>Treatment: 50% radiation therapy 38% prostatectomy</p>	<p>Findings: Challenges Adaptation through Continuous Learning Adaptive Work: promotion of husband's health, continual affirmation of the marital bond, normalization of stress and adversity in life participation in meaningful acts</p> <p>Summary: Women adapted to the physical and psychological challenges of their husband's</p>	83%

elderly Asian/Pacific Islander wives Hawaii			grounded theory & content analysis	81% married for more than 45 years	12% combination	cancer diagnosis and treatment by continuous learning (formal and informal). Wives promoted their husband's health by navigating the medical system, affirming the marital bond (especially in response to changes in sexual function), drawing on previous experiences of adversity and participating in meaningful activities.	
Ka'opua, L. S. I., Gotay, C. C. & Boehm, P.S. (2007) Spiritually based resources in adaptation to long-term prostate cancer survival: perspectives of elderly wives Hawaii	Longitudinal interview study Objective: identify wives' challenges of long-term prostate cancer survivorship and aging, describe the function of spiritually based resources (SBR) in coping and describe common themes in adaptation among wives using SBR	Purposive sample 28 participants Identified through their participation in a survey for a larger study on quality of life	Semi-structured Interviews (2 interviews with 6 months in between) 12 stage analytic procedure that combined elements of grounded theory & content analysis	28 women Aged 55 to 86 years old (mean 72.6) Ethnicity: white 28.6%, Japanese 28.6%, Chinese 21.4%, Filipina 10.7%, Native Hawaiian 10.7%	6-15 years (mean 8.5) since husband's prostate cancer diagnosis Treatment: 46.4% radiation therapy 42.8% prostatectomy 7.1% both, 1 person received no treatment	Findings: Challenges Women's Spirituality SBR in Adaptation: Core Areas and Characteristic Actions Summary: Women relied on spiritual beliefs and practices to cope with the challenges of their husband's cancer treatment. Although the spiritual traditions were diverse, a sense of connection and collaboration with the sacred source was common. Nurturing an embracing spirit was important in adaptation in the areas of marriage preservation and couple intimacy, personal growth and continuous learning, health related attitudes and behaviour, and in sustaining meaningful community connections.	86%
Lavery, J. F. & Clarke, V. A. (1999) Prostate cancer: patients' and spouses' coping	Qualitative study Objective: (1) describe the coping strategies patients and spouses adopted; and (2) the impact of the prostate	Sampling strategy not stated 24 participants Recruited through two urologists in private practice	Interviews (separately) Qualitative analysis	12 men and 12 female partners Married 17-50 years (mean 33) Men: Aged 41-74 years (mean	5-42 months since prostate cancer diagnosis (mean 24) 9 undergone surgery, 4 radiotherapy in addition to	Findings: Coping Issues: a) individual coping (direct action, intrapsychic, information seeking), b) interpersonal coping (direct action, intrapsychic), c) impact on marital relationships – general and sexual changes Summary: Both individual and interpersonal ways of coping were highlighted. Direct action	78%

and marital adjustment Australia	cancer experience on marital relationships			62.4), 6 retired, 6 employed Spouses: Aged 38-69 years (mean 57), 8 spouses employed, 4 home-makers.	surgery, 3 of which were also receiving monthly hormone injections 2 men metastatic cancer	involved diversionary activities, work and exercise for an individual and the active engagement of communication, expression of emotions and working as a team at the interpersonal level. Information seeking was particularly important for spouses. Some coping responses proved more difficult where there was avoidance or denial. Changes to relationships (mainly positive in bringing them together) and changes to sexual functioning (mainly negative) were acknowledged by men and their spouses.	
Maliski, S. L., Heilemann, M. V. & McCorkle, R. (2002) From 'death sentence' to 'good cancer': couples' transformation of a prostate cancer diagnosis USA	Qualitative cross-sectional approach Objective: To describe the experience of men who are diagnosed with prostate cancer and their wives, from the time of diagnosis through staging to the completion of radical prostatectomy	Sampling strategy not stated 40 participants Recruited from a nationally noted urology practice in a large university-based medical centre	Interviews individually but with the other present Grounded theory techniques	20 couples (19 white, 1 black) Ages: men 51-71 years (mean 58.97), spouse 28-70 years (mean 54.3) All married, in middle-upper socioeconomic group	Between 3 – 11 month's post prostatectomy (Mean 6.9 months)	Findings: Cancer as a loss of control, "crash course", Prostate Cancer as a "Good Cancer", Quest for the best: treatment, Quest for the best: Surgeon, Preparing for Surgery, The Surgery: Turning over Control Summary: Initially feelings of fear and shock were described which resulted in men and their wives gathering as much information as possible on prostate cancer. Prostate cancer was perceived to be 'good' as it could be controlled and cured. Time was spent making decisions about the best treatment and surgeons. Test results and preparing for surgery were anxiety-provoking times and surgery was identified as the point at which control was given to the medical staff.	83%
McCaughan, E., McKenna, S, McSorley, O. & Parahoo, K.	Qualitative Design Objective: To explore the	Purposive sample 22 participants	Semi-structured interviews (joint)	11 couple dyads (11 female partners, 11 male patients)	Most common treatment received by males was	Findings: a) Couples experiences of CONNECT grouped into 3 themes: 1) Sharing and validation, 2) Gaining Information, 3) Couple care	86% (Kappa: 0.727)

<p>(2015)</p> <p>The experience and perception of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration</p> <p>UK</p>	<p>experience of prostate cancer survivors and their partners of the CONNECT psychosocial intervention</p>	<p>Recruited through being included in an intervention arm of a feasibility RCT investigating the CONNECT intervention.</p>	<p>Inductive content analysis</p>	<p>Ethnicity: Caucasian</p> <p>Ages (mean): Male patients 67.5 years, partners 65 years</p>	<p>hormone treatment followed by radiotherapy.</p>	<p>b) Factors influencing implementation of CONNECT: 1) role of facilitator, 2) group size and dynamics.</p> <p>c) Improvement of prostate cancer psychosocial support: 1) issue of sexual dysfunction, 2) role of partners and barriers to engaging them, 3) delivery of CONNECT, 4) intervention fidelity</p> <p>Summary: Couples perceived benefits and potential areas for improvement of the intervention were identified.</p>	
<p>O'Callaghan, C., Dryden, T., Hyatt, A., Brooker, J., Burney, S., Wooten, A. C., White, A., Frydenberg, M., Murphy, D., Williams, S. & Schofield, P. (2014)</p> <p>'What is this active surveillance thing?' Men's and partner's</p>	<p>A qualitative descriptive research design</p> <p>Objective: to examine men's and partner's experience of treatment decision making following localised prostate cancer (LPC) diagnosis and their experience of active surveillance (AS) when active surveillance was</p>	<p>Purposive sampling</p> <p>35 participants</p> <p>Recruited from a private urology practice, an integrative cancer centre and a public hospital's oncology service. Men invited partner's to participate if available.</p>	<p>Semi-structured telephone interviews (separately)</p> <p>Techniques associated with grounded theory: inductive, cyclic, and constant comparative data analysis</p>	<p>21 men and 14 partners (1 male partner)</p> <p>Relationship length 0-50 years</p>	<p>Men had been or were on active surveillance for 3 – 96 months (mean 22 months)</p> <p>Treatment decisions: 11 on AS, 7 had radical prostatectomy after AS, 1 radiation therapy after AS, 1 brachytherapy after AS, 1 radical prostatectomy</p>	<p>Findings:</p> <p>3 themes and 7 categories:</p> <p>1) LPC treatment decisions are affected by information gathered and varied emotional and relational reactions: a. information was satisfactory, contradictory, stressful, and/or misunderstood, b. decision making: difficulties, assistance and rationales.</p> <p>2) Men and partners both experience and often cope with AS: a. Partners shared experience of AS and its advantages, b. pre-existing strengths, informal supports and maintaining 'normal' life assist coping with AS, c. cancer monitoring and confidence in health professionals assist coping with AS.</p> <p>3) AS stressors are endured or inform radical treatment decision: a. AS stressors encompass illness uncertainty, monitoring stressors and</p>	<p>86%</p>

<p>reactions to treatment decision making for prostate cancer when active surveillance is the recommended treatment option</p> <p>Australia</p>	<p>the recommended treatment option.</p>				<p>immediately after diagnosis.</p>	<p>inconsistent information, b. ceasing AS is informed by personal and medical factors.</p> <p>Summary: Prostate cancer information was described as contradictory, confusing and stressful. Treatment decisions were based on varied reactions to prostate cancer information. AS was commonly misunderstood by men and partners, although the monitoring procedures could be described. Coping was at times influenced by treatment decision-making memories, conflicting information, painful biopsies and unanswered medical questions.</p>	
<p>O'Shaughnessy, P. K., Ireland, C., Pelentsov, L., Thomas, L. A. & Esterman, A. J. (2013)</p> <p>Impaired sexual function and prostate cancer: a mixed method investigation into the experiences of men and their partners</p> <p>Australia</p>	<p>Mixed methods study</p> <p>Objective: to explore issues related to sexual function and relationships, for men and their wives or partners following a diagnosis and treatment for prostate cancer</p>	<p>Sampling strategy not stated</p> <p>32 participants</p> <p>Referred from local prostate cancer support groups via flyers and direct contact with the researcher</p>	<p>Focus groups (2 just men n=5, n=5 and 2 with partners n=7, n=9), interviews (3 couples)</p> <p>Thematic analysis</p>	<p>Doesn't specify how many men and partners.</p>	<p>Men diagnosed and treated for prostate cancer</p>	<p>Findings:</p> <p>Primary theme: Unique sequel of symptoms at identifiable key stages of the cancer journey. Secondary themes: Emotional responses to cancer of men, physical responses to cancer, supportive care needs of men. Third-order themes: Emotional responses to cancer of wives/partners, emotional responses to change in sexuality men, supportive care challenges for wives/ partners and relationship challenged by changes to men's sexuality.</p> <p>Summary: The cancer journey was the overall theme; men and partners had different needs depending on disease progression. Secondary themes related to sexuality and sexual function including emotional and physical responses. Sexual dysfunction and changes to masculinity were significant in all secondary themes.</p>	<p>69%</p> <p>(Kappa: 0.708)</p>

<p>Petry, H., Berry, D. L., Spichiger, E., Kesselring, A., Gasser, T. C., Sulser, T. & Kiss, A (2004)</p> <p>Responses and experiences after radical prostatectomy: perceptions of married couples in Switzerland</p> <p>Switzerland</p>	<p>Cross-sectional Qualitative study</p> <p>Objective: to explore the responses and experiences of a sample of Swiss men after radical prostatectomy and their intimate partners</p>	<p>Purposive sample</p> <p>20 participants</p> <p>Recruited through 2 University Hospitals, informed by a surgeon.</p>	<p>Interviews (separately or together – patient’s choice)</p> <p>Grounded theory</p>	<p>10 men 10 women</p> <p>Men had an average age of 64.6 years</p>	<p>4-12 weeks since radical prostatectomy</p>	<p>Findings: “Getting a grip on it” describes the efforts participants used to deal with diagnosis, surgery and complications in order to “return to normal life”</p> <p>Men: regaining control (setting priorities, managing urinary incontinence, dealing with sexual activity). Women: Being there (dealing with burdens, taking on, placing erectile function into perspective).</p> <p>Summary: For men it was about regaining control over their lives, mainly their urinary and erectile functions, increasing control was perceived as an indicator in the success of recovery. Wives played a vital role in re-establishing normal life by being there for their husbands through being physically present, actively supportive and emotionally accessible.</p>	<p>92%</p>
<p>Rossen, S., Hansen-Nord, N. S., Kayser, L., Borre, M., Borre, M., Larsen, R. G., Trichopoulou, A., Boffetta, P., Tjonneland, A. & Hansen, R. D. (2016)</p> <p>The Impact of Husbands' Prostate</p>	<p>Qualitative study</p> <p>Objective: to explore how the prostate cancer diagnosis and the participation in their partners’ intervention influenced the spouses’ life, their relationship with their partner, and how they handle the situation</p>	<p>Purposefully selected sample</p> <p>8 participants</p> <p>Recruited through the Nordic Lifestyle Intervention Study among men with prostate cancer (NILS). Spouses of men who had completed a 6-month intervention phase. Enrolled by clinicians</p>	<p>Semi-structured Interviews</p> <p>Grounded theory approach by applying constant comparative analysis</p>	<p>8 women</p> <p>Aged 55-68 years</p>	<p>Men were diagnosed with early-stage prostate cancer or diagnosed within the last 3 years if already diagnosed.</p> <p>Interviews took place 3 to 9 months after the end of the follow-up on the NILS study</p>	<p>Findings:</p> <p>3 major themes:</p> <p>1) Feeling insecure: a. lack of information, b. anxieties</p> <p>2) Coping: a. seeking information, b. setting information aside, c. active support, d. communication</p> <p>3) Feeling reassured: a. active support, b. confidence/ hopefulness, c. communication.</p>	<p>92%</p>

Cancer Diagnosis and Participation in a Behavioral Lifestyle Intervention on Spouses' Lives and Relationships with Their Partners Denmark		in a Urology department at a University Hospital.			where men were on active surveillance, offered a patient education program regarding vigorous activity, healthy diet and monitored by clinical examinations.		
Sinfield, P, Baker, R. Agarwal, S. & Tarrant, C. (2008) Patient-centred care: What are the experiences of prostate cancer patients and their partners UK	Qualitative study Objective: To gain an in depth understanding of the experiences of care of men with prostate cancer and their partners	Purposive sample 45 participants Identified from hospital's patient registers and urology outpatient clinics at two hospitals and two cancer charities. Patients requested to pass information to partners.	Semi-structured interviews (separately) Qualitative data analysis	35 men and 10 female partners Men aged under 55 (5), 55-70 (13), over 70 (4), white (26), south Asian (4), Afro-carribean (5) Female partners white (8), south Asian (1), afro-carribean (1)	Tested or treatment within last 6 months Treatment: 17 prostatectomy or radiotherapy, or a combination of radiotherapy and hormone therapy, 8 hormone therapy, 7 actively monitored, 3 newly diagnosed (prior to treatment)	Findings: Patients experiences of information provision and communication Patients experiences of making decisions Experiences of partners Summary: The themes highlighted a variation of experiences. Shock at diagnosis initially as men either did not associate the symptoms with cancer or were asymptomatic. Difficulties with communication with professionals and the provision of information to understand the diagnosis and treatment, made it hard to make informed decisions (if the opportunity was given). The role of the urology nurse as a source for information was highly valued. Partners were keen to support patients and valued written information, however felt there was no space for their questions and that their own needs were often unmet.	94% (Kappa: 0.625)

<p>Street, A. F., Couper, J. W., Love, A. W., Bloch, S., Kissane, D.W. & Street, B. C. (2010)</p> <p>Psychosocial adaption in female partners of men with prostate cancer</p> <p>Australia</p>	<p>Mixed methods study</p> <p>Objective: to explore the psychosocial adaptation of female partners living with men with a diagnosis of either localised or metastatic prostate cancer</p>	<p>Sampling strategy not stated</p> <p>50 participants</p> <p>The first consecutive 60 women partners of men recruited into a multi-site study were invited to participate</p>	<p>Semi-structured qualitative interviews (2 time points: before or just after treatment and 6 months later)</p> <p>NVivo7 computer program for analysis</p>	<p>50 women</p> <p>Aged 43-78 years (mean 62)</p>	<p>Male partners: 34 diagnosed with localised prostate cancer, 16 with advanced disease</p> <p>Treatment: 17 watchful waiting, 20 on hormone treatment, 8 had radical prostatectomy, 4 had radiotherapy, 1 chemotherapy.</p>	<p>Findings: Emotional adaptation, Appraisal of impact: threat, loss or challenge, Adaptive coping: processes and strategies: coping well, staying calm, acceptance. Re-appraisal – relational meaning: impact on sexuality, social impact. Spiralling downward: the distressed subset of women: somatic and emotional responses, isolation.</p>	72%
<p>Tanner, T., Galbraith, M. & Hays, L. (2011)</p> <p>From a Woman's Perspective: Life as a Partner of a Prostate Cancer Survivor</p> <p>USA</p>	<p>Qualitative study</p> <p>Objective: to understand the effects of prostate cancer on the female partners of prostate cancer patients</p>	<p>Sampling strategy not stated</p> <p>113 participants</p> <p>narrative data was collected from 2 longitudinal survey studies on quality of life issues for couples who were survivors of prostate cancer over 8 years</p>	<p>Narrative data generated from 2 open-ended questions</p> <p>Content Analysis</p>	<p>113 women</p> <p>87% white</p> <p>Aged 65 years (average)</p>	<p>Partner followed or treated for prostate cancer</p>	<p>Findings: 3 themes</p> <p>1) coping with life in the face of cancer, 2) encountering difficult emotions related to a partner's illness, 3) learning to live with relationship changes</p> <p>Summary: It was acknowledged that cancer was an added difficulty to already complicated lives and that there were a number emotions associated with this including fears of death, and the unknown. This created changes in the women's lives including day to day activities, their sex lives and communication with their partner.</p>	89%

<p>Wootten, A. C., Abbott, J. M., Osborne, D., Austin, D. W., Klein, B., Costello, A. J. & Murphy, D. G. (2014)</p> <p>The impact of prostate cancer on partners: a qualitative exploration</p> <p>Australia</p>	<p>Qualitative, focus group design</p> <p>Objective: to explore the experiences of intimate spouses or partners of men diagnosed and/or treated for prostate cancer to better understand the personal impact of prostate cancer on the partner</p>	<p>Sampling strategy not stated</p> <p>27 participants</p> <p>Recruited through their partner who received treatment at a hospital department (2 sites) or through support groups (3 sites)</p>	<p>6 focus groups (26 participants), 1 in depth interview (1 participant)</p> <p>Thematic coding</p>	<p>27 female partners</p> <p>Aged 43-76 years old (mean 61.6)</p> <p>Intimate or married partner</p>	<p>10 months to 2.75 years since treatment</p> <p>Treatments: radical prostatectomy only (11), radiotherapy only (7), combination of prostatectomy plus radiotherapy +/- hormone therapy (9)</p> <p>3 partners undergoing investigation and required further treatment</p>	<p>Findings:</p> <p>6 themes</p> <p>1) the influence of the man's response to prostate cancer on the partner, 2) the need to be involved in treatment and medical decision making, 3) supporting a man who is experiencing a loss of masculinity, 4) degree of congruence between each partner's coping responses, 5) constrained communication, 6) changed roles and increased practical management</p> <p>Summary: The themes highlighted how men cope with their diagnosis impacts on the partner as well as whether the couple have congruent coping responses. Difficulties with communication was highlighted within relationships and with professionals where there was a lack of support and involvement in treatment and decision-making. Women neglected their own self care while maintaining the management of the family. There was a significant need to access support, information and knowledge to better understand how to support a man who is experiencing a loss of masculinity.</p>	<p>89%</p>
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1.3.7 Analysis

In order to synthesise the included articles, a meta ethnographic approach was utilised based on Britten et al. (2002), and the steps advocated by Noblit and Hare (1988). This approach was chosen as it encouraged the preservation of meaning when comparing the key concepts and explanations across different studies and translated them into each other (Britten et al., 2002). Studies related to each other by being directly comparable (reciprocal translations), by conflicting with each other (refutational translations) or by complementing each other to form a line of argument (Noblit & Hare, 1988). The included studies were read and key concepts were identified. These key concepts were then pinpointed within each study, taking into account the way in which each study related to another in order to create themes. These themes were then synthesised together to form overall themes. In studies involving both partners and the male patient with PCA as participants, only concepts that were identified as being experiences of both the patient and the partner or those that were stated as specifically experienced by partners were extracted to contribute to the overall themes.

1.4 Results

Four overall themes were identified from the reviewed papers: *Making sense of prostate cancer*, *What about us?*, *Changes to the intimate relationship* and *The role of caregiver*. Each theme was made up of sub-themes as shown below:

Making Sense of prostate cancer

- ***A mixture of emotion***
- ***Searching for and gaining information***
- ***Own needs put aside***

What about us?

- ***The need for support***
- ***Not enough information***

Changes to the intimate relationship

- ***Role changes***
- ***Communication and Feeling Alone***
- ***Sexual changes***

The role of caregiver

- ***Emotional support***
- ***Practical support***
- ***Coping***

Each theme will be explored in more detail to show how concepts from each study were incorporated and synthesised together.

1.4.1 Making sense of prostate cancer

1.4.1.1 A mixture of emotion

A number of different emotions were highlighted within the studies and were summed up in one of the better quality studies as an emotional rollercoaster (Harden et al., 2002). The studies reflected that upon finding out about the diagnosis of their

partner's PCA, emotions such as being scared, concerned, worried, nervous and angry as well as feelings of emotional turmoil and devastation (Butler et al., 2000) or insecurity (O'Shaughnessy et al., 2016) were highlighted by partners. Shock was acknowledged in a number of the studies (Gray et al., 1999; Gray et al., 2000; Harden et al., 2002; Maliski et al., 2002), as was fear or anxiety (Ervik et al., 2012; Gray et al., 1999; Gray et al., 2000; Lavery & Clarke, 1999; Maliski et al., 2002; Street et al., 2009; Tanner et al., 2011; Wootten et al., 2014). A number of sources of anxiety were highlighted. These included the illness itself (Ervik et al., 2012), how the partner would deal with it (Ervik et al., 2012; Maliski et al. 2002; Wootten et al., 2014), disease progression (Rossen et al., 2016) and the potential future loss of their partner (Ervik et al., 2012; Harden et al., 2002; Street et al., 2009). Fears revolved around death, pain and the unknown of what would happen next (Tanner et al., 2011) and for some partners these anxieties diminished over time (Ervik et al., 2012). However, in contrast to this, a couple of lower quality studies reported that partners expressed acceptance of the diagnosis quite early on (Butler et al., 2000; Lavery & Clarke, 1999), whilst others were grateful that their husband could receive medical treatment (Tanner et al., 2011), showing variance in the emotions experienced. One good quality study highlighted how some partners directed anger at themselves for not knowing that screening could be performed (Harden et al., 2002). In addition, feelings of isolation (Street et al., 2009) or loneliness were experienced by partners in a range of areas related to living with a man's PCA diagnosis (Bruun et al., 2011).

Emotions were also experienced in relation to decision-making and treatment for PCA. Feelings of being overwhelmed and confused were reported in relation to treatment options (Harden et al., 2002) and information (Gray et al., 2000; Maliski et al., 2002;

O'Callaghan et al., 2014), as well as feeling unclear and ignored during consultations (Sinfield et al., 2008). Waiting for test results, biopsy results (O'Callaghan et al., 2014; Rossen et al., 2016) or for surgical operations to finish was anxiety provoking (Maliski et al., 2002), as was the uncertainty of the illness trajectory where partners were also having to manage family anxiety (Petry et al., 2004). Despair was described in relation to changes in men's physical health after treatment (Boehmer & Clark, 2001), as was loss and uncertainty in relation to changes within relationships and sexual intimacy (Ka'opua et al., 2005). Partners' felt unprepared and stressed in relation to their role after treatment (Evertsen & Wolkenstein, 2010) and surprised by the length of time recovery took (Wootten et al., 2014). In a higher quality study, where partners had received a psychosocial group intervention, their experiences of emotions such as irritation or feeling drained were validated by others which helped them to recognise they were not alone and reduced any feelings of guilt (McCaughan et al., 2015).

1.4.1.2 Searching for and gaining information

Partners tried to learn as much as possible about PCA and the potential treatment options available (Gray et al., 1999; Street et al., 2009) in order to help their diagnosed partner decide on the best treatment (Butler et al., 2000) or best surgeon (Maliski et al., 2002). This was highlighted in the studies as a need to gather information (Gray et al., 2000; Harden et al., 2002; Lavery & Clarke, 1999; Maliski et al., 2002) through a variety of sources (Wootten et al., 2014). Gathering information involved searching the internet, cancer societies, magazines, leaflets, libraries or bookstores, (Butler et al., 2000; Gray et al., 2000; Maliski et al., 2002). For others, it was primarily through healthcare professionals (Docherty et al., 2007; Ervik et al., 2012; Evertsen &

Wolkenstein, 2010), from family members (Butler et al., 2000; Petry et al., 2004) or women who had husbands with PCA (Maliski et al., 2002). Being advised by surgeons (Butler et al., 2000), urologists (Evertsen & Wolkenstein, 2010) and specialists (Gray et al., 2000), as well as the clinical nurse specialists (Maliski et al., 2002; Sinfield et al., 2008) was reported as important. However, the studies showed that for other women seeking out information in addition to that provided by doctors enabled them to feel more involved in the decision making process (Lavery & Clarke, 1999) and helped when there were opposing choices (Harden et al., 2002). Partners expected physicians and urologists to give balanced information on PCA including both positive and negative aspects, in order to feel prepared for what could happen (Evertsen & Wolkenstein, 2010). It was described by partners that information gathered could seem overwhelming (Gray et al., 2000; Maliski et al., 2002).

Information was also gained from healthcare professionals in relation to the effects of treatment such as urinary incontinence (Butler et al., 2000), impotence (Ervik et al., 2012) and in the form of information hand-out sheets during a psychosocial intervention (McCaughan et al., 2015). Ka'opua et al. (2005) highlighted how women who had lived with the diagnosis of their husband's PCA for an average of eight years described that there is continuous learning associated with it, showing the long-term nature of the information needed. Interestingly, in a higher quality study in which the findings were more robust, the variety of information obtained was considered to be related to the patient and partner's levels of emotional well-being, where those who were not emotionally distressed by the diagnosis accessed information from a variety of sources (Wootten et al., 2014). This highlights a role distress may play in relation to being able to seek out information.

1.4.1.3 Own needs put aside

Throughout a number of studies, it was described how partners have put their own needs aside in order to protect or support their partner with PCA. In a number of studies this involved partners restricting conversations about their feelings (Boehmer & Clark, 2001; Gray et al., 1999; Gray et al., 2000), suppressing their own feelings (Ervik et al., 2012), hiding concern (O’Callaghan et al., 2014) or refraining from sharing their emotions (Tanner et al., 2011; Wootten et al., 2014). In some studies, this was reported as a sense of duty to support their partner and the family (Bruun et al., 2011; Ervik et al., 2012) or due to having a role of responsibility to maintain the management of the family (Wootten et al., 2014). A number of studies described how partners attempted to understand PCA from the man’s point of view rather than thinking about the impact on themselves (Boehmer & Clark, 2001; Gray et al., 1999; Ka’opua et al., 2007; Petry et al., 2004), especially in regard to their sex lives (Boehmer & Clark, 2001) or their partner’s treatment decisions (Maliski et al., 2002). Partners took a philosophical stance even though they were finding it hard to adapt to changes in relation to impotency and their sex life (Lavery & Clarke, 1999). Some studies acknowledged the impact of partners not addressing their own needs which resulted in an imbalance in self-care (Bruun et al., 2011; Wootten et al., 2014), caused physical illness (e.g. shingles and high blood pressure, Evertsen & Wolkenstein, 2010), suffering in silence (Tanner et al., 2011) and partners feeling worn out, but unable to take time out (Wootten et al., 2014). On the other hand, studies showed how partners recognised the need to tend to their own needs in order to be strong for their male partners (Maliski et al., 2002) and described striving to balance regular activities in spite of the changes to their lifestyle (Tanner et al., 2011). In study focusing on a

lifestyle intervention as part of active surveillance for early stage PCA, the majority of partners did not feel the need to suppress their needs as they could initiate ways to cope and gained information which meant they did not perceive their husbands as sick (Rossen et al., 2016).

1.4.2 What about us?

1.4.2.1 The need for support

The need for further support was a common theme within a lot of the reviewed studies. In some studies, an adequate support network was described (Rossen et al., 2016) which included family, neighbours, church members (Boehmer & Clark, 2001), friends (Gray et al., 2000), professionals and support groups (Evertsen & Wolkenstein, 2010; Sinfield et al., 2008). In another study partners sought out other women who also had a partner with PCA, however this is a lower quality paper and therefore the results need to be treated with caution (Maliski et al., 2002). Support was found to be an important resource at both an emotional and practical level (Petry et al. 2004), and involved an opportunity for partners to discuss their struggles (Gray et al., 2000). Conversely, some papers described how partners had been “relegated to the sidelines” (Ervik et al., 2012 p. 5) by family, friends and healthcare professionals as the focus was on their partner which left them feeling alone (Petry et al., 2004) or that their needs were not acknowledged in medical appointments (Ervik et al., 2012; Evertsen & Wolkenstein, 2010; Sinfield et al., 2008) resulting in little ongoing support. If the man with prostate cancer did not want to share his illness with family and friends (Bruun et al., 2011), it resulted in a lack of access to support (Wootten et al., 2014) which led to unmet needs at both an emotional and practical level (Sinfield et al.,

2008). This was highlighted in a study, where men did not want their partners to ask doctors questions resulting in little opportunity to gain support especially with sexual changes (Harden et al., 2002). Women's experiences of a psychosocial intervention indicated a passive role to support their husband by listening rather than having an active part within the group (McCaughan et al., 2015). This highlights that the intervention appeared to be directed at the patient even though it was a joint intervention for both patients and partners to attend.

It was identified that further support was needed as partners are often overlooked (Petry et al., 2004). Suggestions for further support included being invited to attend specialist appointments (Sinfield et al., 2008), being more included during hospital appointments (Butler et al., 2000), the need to speak to someone outside the family (Ervik et al., 2012; Wootten et al., 2014), additional emotional support (Evertsen & Wolkenstein, 2010; O'Callaghan et al., 2014), further practical information (Evertsen & Wolkenstein, 2010), specifically in relation to dealing with the side effects of treatment (Sinfield et al., 2008) and adjustment to sexual function (Wootten et al., 2014). It was also suggested that support groups focus more on issues after surgery such as self-care needs, sexuality and psychological difficulties (Butler et al., 2000). In contrast to this, in a high quality study where the findings were more robust, the majority of partners engaging in a behavioural lifestyle intervention felt that extra support was not needed due to the intervention project providing support (Rossen et al., 2016).

1.4.2.2 Not enough information

Partners identified that not enough information was provided to them by health professionals (Petry et al., 2004; O'Shaughnessy et al., 2016) in order to meet their needs (Sinfield et al., 2008). This related to information at diagnosis to aid treatment choices (O'Shaughnessy et al., 2016; Street et al., 2009) and following surgery in order to take care of their partner with PCA at home (Butler, 2000). Specifically, this included practical information regarding the caring role (Evertsen & Wolkenstein, 2010) and catheter care (Butler et al., 2000) as a lack of information can result in an inability to prepare for treatment symptoms after surgery (Gray et al., 2000; Harden et al., 2002). One area in particular women felt unprepared for, was the impact on a man's sense of identity or masculinity (Wootten et al., 2014).

1.4.3 Changes to the intimate relationship

1.4.3.1 Role changes

Within the majority of the studies changes to relationships were expressed following diagnosis and/ or treatment for PCA. For some partners this was positive as it brought the couple closer together (Gray et al., 2000; Ervik et al., 2012; Lavery & Clarke, 1999), facilitated the re-affirmation of commitment to each other (Gray et al., 1999), enabled them to share feelings of love and concern more freely (Harden et al., 2002), and generally improved the relationship (Butler et al., 2000) due to better communication and a change in priorities (Street et al., 2009). However, it was acknowledged by some women that they had to work to affirm or deepen the marital bond to accommodate the changes within the relationship (Ka'opua et al., 2005; Ka'opua et al., 2007). For partners who were highly distressed by the man's PCA diagnosis, the relationship no

longer felt cohesive and partners felt increasingly isolated; however this particular study was of lower quality and the findings need to be treated with caution (Street et al., 2009).

Changes in roles within the relationship were identified (Wootten et al., 2014) as men became dependent on their partners (Ervik et al., 2012; Tanner et al., 2011), therefore partners took on a variety of tasks and duties (Evertsen & Wolkenstein, 2010; Petry et al., 2004). This included learning new household skills (Tanner et al., 2011), providing practical support (Ervik et al., 2012), monitoring their partner's health (Sinfield et al., 2008) and an increased sense of responsibility (Wootten et al., 2014). At times, the changes of role from companion to caregiver was reported to take its toll on the relationship which resulted in tension, arguing (Evertsen & Wolkenstein, 2010) and conflict (Butler et al., 2000). Partners also reported changes to the man with PCA's moods (Tanner et al., 2011), such as increased irritability (Gray et al., 2000), jealousy (Boehmer & Clark, 2001) and a lack of communication (Wootten et al., 2014) which impacted on the relationship. Physical limitations of their partner's illness caused changes to relationships due to travelling and socialising being more difficult (Tanner et al., 2011). Two thirds of partners in one study described reducing expectations when it came to social activities in order to match the changes in circumstances (Street et al., 2009). Partners felt socially isolated as men with PCA were increasingly isolating themselves (Bruun et al., 2011; Street et al., 2009) which resulted in a loss of intimacy and closeness in the relationship (Wootten et al., 2014).

1.4.3.2 Communication and feeling alone

Many studies reported a lack of communication identified by partners in a number of ways. Partners perceived that men with PCA had withdrawn to deal with their illness (Gray et al., 1999), did not want to share or talk about their emotions (Bruun et al., 2011; Gray et al., 2000) or had shut down (Evertsen & Wolkenstein, 2010). Partners felt that they were not included in treatment/ care decisions (Butler et al., 2000) and that men with PCA did not want to discuss the impact of treatment on sexuality (Boehmer & Clark, 2001; Wootten et al., 2014), impotence or incontinence (Ervik et al., 2012). This lack of communication was reported to leave partners feeling alone (Boehmer & Clark, 2001; Bruun et al., 2011), isolated (Butler et al., 2000), betrayed (Tanner et al., 2011) distressed and unheard (Wootten et al., 2014). In a better quality study, women took on the role of communicating for their husband (Evertsen & Wolkenstein, 2010), whereas in a study of lower quality, open communication about difficulties between the couple was avoided (Lavery & Clarke, 1999). In contrast to this, partners who had engaged in a behavioural lifestyle intervention felt able to communicate with their husbands (Rossen et al., 2016). Similarly, in a study of good quality, partners felt that communication improved after attending a psychosocial intervention as conversations were triggered which enabled more open communication (McCaughan et al., 2015).

1.4.3.3 Sexual changes

Sexual changes were reported in the majority of the studies after treatment for PCA. Changes to men as a result of treatment included impotence (Lavery & Clarke, 1999; Ka'opua et al., 2007), incontinence (Ka'opua et al., 2007), sexual dysfunction

(Boehmer & Clark, 2001; Ervik et al., 2012; Gray et al., 2000; Harden et al., 2002; O'Shaughnessy et al., 2013), or more generally changes to sexual functioning (Butler et al., 2000; Evertsen & Wolkenstein, 2010; Tanner et al., 2011; Wootten et al., 2014). For some women this resulted in no sexual activity of any form (Boehmer & Clark, 2001), for others there was an inability to engage in sexual intercourse (Ervik et al., 2012), while others described finding alternative ways to be sexually active (Gray et al., 2000) for example, by hugging or kissing (Butler et al., 2000) or being intimate by stroking, cuddling and holding (Street et al., 2009). In a study of better quality, it was reported that women mourned the loss of their sexual relationship and the automatic sexual responses that their husbands once had (Tanner et al., 2011). One wife expressed how her husband is less romantic since treatment (Boehmer & Clark, 2001) while other partners described how a lack of sexual intimacy has impacted on their relationship (O'Shaughnessy et al., 2013; Wootten et al., 2014) especially where men are avoiding sexual intimacy (Ka'opua et al., 2007) or are not expressing sexual desire (Ervik et al., 2012) resulting in feeling further apart (Tanner et al., 2011). Studies showed how at times women reported feeling distressed (Harden et al., 2002), frustrated (Ervik et al., 2012) and finding it difficult to adjust (Ka'opua et al., 2005, Lavery & Clarke, 1999) or find ways to manage the changes to sexual relations (Ervik et al., 2012; Street et al., 2009). Some women re-framed the difficulties as a part of aging (Ka'opua et al., 2005), while others modified their own expectations and sexual wishes (Street et al., 2009) in order to accommodate the difficulties. Nevertheless, women expressed that having their husband healthy and alive was most important (Petry et al., 2004) and if given the option between having sexual relations or prolonging their husband's life expectancy then they would opt to prolong his life

expectancy (Boehmer & Clark, 2001). However, the study by Petry et al. (2014) was conducted between 4 and 12 weeks after radical prostatectomy where the experience may have still been very current for the women. In one study, it was described that the changes to the sexual relationship meant that it became more like living with a best friend (Tanner et al., 2011).

1.4.4 The role of caregiver

1.4.4.1 Providing emotional support

Many of the studies highlighted the role partners played in supporting a man with PCA emotionally. Within some studies there was a duty and a wish to provide care (Bruun et al., 2011) and in others partners became the sole emotional support for their partner (Evertsen & Wolkenstein, 2010). Partners showed support through the decision-making process in order to preserve the man's self-respect (Street et al., 2009). There was a need to provide reassurance (O'Callaghan et al., 2014) that treatment effects would not impact on the relationship (Petry et al., 2004) or the amount of love for their partner (Ervik et al., 2012), specifically in relation to the possible loss of erectile function (Gray et al., 2000). Women were reported to build their husband's self esteem and morale by reassuring them that masculinity was not tied to sexual performance (Butler et al., 2000). However, in another study it was recognised that the topic of masculinity was difficult to discuss and therefore partners focused on supporting other family members (Wootten et al., 2014). It was reported that partners openly communicated love and support (Gray et al., 1999), provided a space to listen to their husband's fears (Ervik et al., 2012) and provided encouragement to seek medical support with symptoms (Sinfield et al. 2008) and

encouragement to take medication, do exercises and be patient (Petry et al., 2004). Sometimes providing emotional support was found to be difficult, however motivation to learn more about their husband's illness helped women do this (Ka'opua et al., 2005). Humour and patience were also described as tools to help partners support the man with PCA (Ka'opua et al., 2005; Tanner et al., 2011).

1.4.4.2 Providing practical support

Practical support was highlighted as another area of the caregiving role. A number of studies highlighted the role which partners took in accompanying men to medical appointments (Ervik et al., 2012; Ka'opua et al. 2005; Maliski et al., 2002; O'Callaghan et al., 2014; O'Shaughnessy et al., 2016; Sinfield et al., 2008) and providing care after hospital for urinary incontinence (Butler et al., 2000), catheter and wound care (Petry et al., 2004). Other practical elements included giving opinions and discussing treatment options (Ka'opua et al., 2005; Maliski et al., 2002; Street et al., 2009), getting supplies for managing incontinence (Petry et al., 2004) and taking a lead role in monitoring side effects (Sinfield et al., 2008). It was recognised that partners took on the responsibility for the practical management of the family, communicating to others about the illness and providing support for other family members as well as the support provided to their partner (Wootten et al., 2014). Partners also took an active role in supporting their husbands in their change of diet and exercise when this was the treatment approach (Rossen et al., 2016).

1.4.4.3 Coping

The majority of the studies described ways in which partners managed or coped with the experience of PCA. For a number of studies this involved partners distracting themselves from the preoccupation of illness by keeping busy (Gray et al., 2000), doing diversionary activities such as household chores or working (Lavery & Clarke, 1999) and continuing leisure (Tanner et al., 2011) or everyday life activities (Rossen et al., 2016). Having a religious faith was important (Bruun et al., 2011; Lavery & Clarke, 1999) as were spiritual and cultural values (Ka'opua et al., 2005; Ka'opua et al., 2007) and prayer (Tanner et al., 2011). For some partners, religious faith helped with thinking about life after death and enabling peace in relation to the illness (Bruun et al., 2011). While for other partners, spirituality provided a sense of connection with a sacred source (Ka'opua et al., 2007). The need to either carry on as normal (Gray et al., 1999; Gray et al., 2000; Lavery & Clarke, 1999; O'Callaghan et al., 2014; Street et al., 2009) or wanting to return to normal life (Maliski et al., 2002; Tanner et al., 2011) was a common feature in a number of studies. For some partners this was referred to as a way of avoiding the illness (Gray et al., 2000; Lavery & Clarke, 1999) or a feature of denying the illness existed (O'Callaghan et al., 2014), however for other partners carrying on as normal was part of accepting the illness (Street et al., 2009). A number of studies described the need to be positive (Gray et al., 1999; Lavery & Clarke, 1999; Street et al., 2009) while others reported how women tried to appreciate the positive despite the uncertainty and loss (Ka'opua et al., 2005) however the results need to be treated with caution as these papers were of lower quality. Another described the use of thoughts about happy memories (Tanner et al., 2011). Jokes and humour (O'Callaghan et al., 2014) were used as a way of communicating important emotions

(Boehmer & Clark, 2001) and there was a need for love and care to be shown in daily life as well as the support needed from family (Bruun et al., 2011). The need for partners to be able to focus on their own feelings and experiences outside of the family was also important and therefore talking to other partners in support groups was found to be particularly useful (Ervik et al., 2012). One of the better quality studies, with more robust findings, reported how partners made sense of the experience by putting it into perspective, which involved being thankful that the surgery was successful and that the cancer was removed (Petry et al., 2004). Another study highlighted that PCA was a 'good cancer' (Gray et al., 2000), while other partners searched for purpose and meaning which involved helping others cope with cancer (Ka'opua et al., 2007).

1.4.5 Critical Analysis

Although all the papers included within this review met the satisfactory level of quality within the QA, it is important to consider the areas in which the papers lacked clarification and how this may influence the way in which these themes can be interpreted. The majority of the reviewed papers did not clarify an epistemological position which is particularly relevant to this review as it is focused on qualitative data. Further to this, there was limited explanation of how the data analysis was conducted, even though the type of data analysis was stated. Due to the qualitative nature of understanding the experiences of participants, it is important to ascertain the role and position of the researcher as well as a detailed understanding of the way in which the analysis was conducted within each paper. As this has not been present in a number of papers, caution must be taken when interpreting the data. More generally, the

variation in the quality ratings of individual papers has been taken into account when synthesising the information to make themes.

Within this review, the themes were synthesised from the findings of papers that focused exclusively on the partner *and* papers that incorporated partners *AND* men with PCA. This means that some of the data synthesised within this review could have been influenced by men with PCA. The data collection within the reviewed papers either involved collecting data from partners separately or jointly with the man with PCA. This is clarified further for each of the twenty-two studies in Table 1.4 below:

Table 1.4: Data collection with or without involvement of man with PCA.

Partners only	Partner and man with PCA			
	data collected separately from partner	data collected with partner present	option of data collection together or separately	separate and joint data collection
Bruun et al. (2011); Butler et al. (2000); Ervik et al. (2013); Evertsen & Wolkenstein (2010); Ka'opua et al. (2005); Ka'opua et al. (2007); Rossen et al. (2016); Street et al. (2010); Tanner et al. (2011); Wootten et al. (2014)	Boehmer & Clark (2001); O'Callaghan et al. (2014); Gray et al. (1999); Gray et al. (2000); Lavery & Clarke (1999); Sinfield et al. (2007)	Docherty et al. (2007); O'Shaughnessy et al. (2013); McCaughan et al. (2015)	Maliski et al. (2002); Petry et al. (2004)	Harden et al. (2002)

Further to this, some of the papers which included both the partner and the man with PCA reported the findings as integrated themes, whereas other papers reported a small section of findings on partners separately. Table 1.5 highlights which studies reported findings jointly with men with PCA and which studies had a separate section for partners.

Table 1.5: Ways of reporting findings for partners and men with PCA

Partner and man with PCA			
Reported findings as joint between partner and man	Reported findings as joint with small separate section on partner	Reported findings between partner and man hard to distinguish and therefore limited inclusion in review	Reported findings separate for partner and man
Boehmer & Clark (2001); Gray et al. (1999); Gray et al. (2000); Harden et al. (2002); Lavery & Clarke (1999); Maliski et al. (2002)	McCaughan et al. (2015); O'Callaghan et al. (2014)	Docherty et al. (2007) O'Shaughnessy et al. (2013)	Petry et al. (2004); Sinfield et al. (2008)

The tables highlight that ten papers included participants who were partners of men with PCA and twelve papers which involved a combination of partners *and* men with PCA. Where data was collected with partners and men together, this could have influenced the experiences that partners were able to describe. In one study, where both joint and separate focus groups were utilised, although the themes that emerged were similar, the partner only focus group was shown to express more anger about the impact of cancer on their lives than those partners in the joint male patient and partner focus group (Harden et al., 2002). This has significance when interpreting the

studies. Where male patients and their partners are included in the same focus groups or interviews, each individual may not feel able to fully explore their personal experiences for fear of the impact this may have on their partner. Within this review it was highlighted as a sub-theme that partners put their own needs to one side in order to protect a man with PCA and therefore it may be the same in an interview situation. This has been highlighted in a previous review paper focusing on relatives' experiences of living with PCA, where it was considered that individuals may be influenced by the statements or presence of their partner (Bruun et al., 2011). Further to this, the majority of the studies involving the male patient and the partner reported the results together. This made it difficult to differentiate partners' experiences from the patient and meant that within one study although it scored above the cut off for the quality check, only a small part of one (of four) themes could be incorporated into the synthesis (Docherty et al., 2007). Similarly, in a mixed-methods study, there was only a small section on the qualitative part of the study which was predominantly related to the male patient's experience rather than that of the partner (O'Shaughnessy et al., 2013) which meant it was difficult to include in the synthesis due to a lack of description. This same study also neglected to report the exact demographics for the qualitative participants, impacting on the ability to interpret these findings.

1.5 Discussion

1.5.1 Significance of the main findings

This review aimed to synthesise the experiences of partners of men receiving a diagnosis of PCA and any treatment offered. Particular consideration was paid to the partner's response to the diagnosis, the treatment or support received and their relationship with their partner with PCA. Even though the reviewed papers focused on different stages of the cancer diagnosis and/or treatment experience, the themes identified above remained consistent.

The findings highlighted the emotional distress that is faced by partners when a man is diagnosed with PCA. Distress is not only shown in relation to the emotions surrounding diagnosis but also with the adjustment to their relationship and the long-lasting impact of the results of treatment. Existing literature highlights how levels of distress in partners is often reported as higher than that of their partner with PCA (Kornblith et al., 1994; Couper et al., 2006b; Resendes & McCorkle, 2006). Further to this, distress may also be considered short and long-term due to the ongoing care-giving role, spanning from diagnosis until after treatment, associated with the chronic nature of PCA (Resendes & McCorkle, 2006). Partners within this review, not only had to manage their own adjustment to the shock of their partner having cancer, but they also had to attend to the practical care of their partner, their partner's emotional adjustment to diagnosis, family members' emotional and practical needs, as well as taking on board extra responsibilities within the household. This was often at the detriment of responding to their own needs and being able to continue with social, leisure and employment activities. Ezer et al. (2006) explored a model of family

adaption theory, highlighting the importance of family resources, personal resources, symptom distress and situational appraisal in the adaptation to PCA. More specifically, partners with a high sense of coherence (measured as comprehensibility, manageability and meaningfulness) were shown to have better overall adaptation and psychological well-being. Further to this, family resources were not utilised until after treatment was completed and the situation was more stable. This could help to explain the findings in this review, in the way partners were shown to put their partners and families needs before their own.

The physical implications of treatment-related changes to men with PCA have a huge impact on partners due to the practical support that is required after treatments and the impact on sexual intimacy. This resulted in partners becoming caregivers *as well as* losing the intimacy of a sexual relationship. According to the bio-psycho-social model of sexuality, it is not just the physical impairment of erectile dysfunction that is an issue in the sexual relationship (Beck, 2009) but also urinary incontinence which may cause psychological implications including fear of embarrassment, shame and avoidance of physical contact (Clark et al., 2003; Bertero, 2001; Phillips et al., 2000). A lack of communication between couples surrounding sexual issues is highlighted as an area that concerned partners (Sanders et al., 2006) where some women described feeling unattractive or unwanted. Further to this, if partners expect their sex life to continue after treatment through the use of assistive aids rather than a change to sexual practices (Boehmer & Babayan, 2004), then the psychosocial impact of PCA treatment may not have been fully explored with the couple prior to engaging in treatment (Beck, 2009). Communication about the intimate relationship is therefore not only important between the couple but also from professionals in relation to the

expectations and implications of treatment. Attachment theory has been shown to help professionals working with cancer patients and caregivers to better understand and support their needs (Nicholls et al., 2014) by understanding more about the dynamics of the close relationship (Pietromonaco, Schetter & Uchino, 2013).

Within this review, partners highlighted a lack of support, information and tending to their own needs. The need for further support and information for partners has been previously highlighted in review papers (Paterson et al., 2015; Resendes & McCorkle, 2006; Wootten et al., 2014) where there is a need for tailored information at appropriate times of the care pathways to understand diagnosis, treatment options and the support available (Sinfield et al., 2009). Strategies and interventions for partners living with PCA have included educational, psycho-educational, support and skill building strategies (Resendes & McCorkle, 2006). However, where interventions are aimed at the couple, there are mixed reports on the relevance for the partner (Chambers et al., 2011; Wootten et al., 2014). The development of family-relational-psychosexual interventions for PCA have been suggested (Paterson et al., 2015), as well as the need for separate interventions to meet the care-giving needs of partners.

1.5.2 Review Limitations

The purpose of this review was to synthesise the existing evidence base, by identifying themes from a number of studies in order to create new understanding (Barnett-Page & Thomas, 2009). The studies revealed few areas of conflict which suggests consistency within the experiences of partners of men with prostate cancer and the themes identified. This supports the view that qualitative studies have findings that can be transferable, and that a more comprehensive understanding can be acquired

from synthesising the research (Campbell et al., 2011). Qualitative studies do however have their limitations and therefore it could be useful for further research to include mixed designs or quantitative research. This would expand the evidence base further and include a larger pool of participants. Part of the quality analysis involved an independent researcher rating five of the included articles. This could be improved by rating all the papers included in the review, in order to increase the reliability further. As part of the exclusion criteria, unpublished research was not included within this review. This could have led to publication bias as it may not be an accurate representation of the research conducted on this topic area (Ferguson & Brannick, 2012). A further limitation of this review is that papers of partners and patients of prostate cancer were included due to the limited amount of papers available on partners alone. As there was not a big source of knowledge to compile, it was decided to add papers with both the partner and the patient and this may have therefore influenced the findings of this review.

1.5.3 Implications for Policy and Practice

It has been identified within this review that partners have a number of unmet needs which could be addressed within clinical services and policies. Partners of men with PCA need opportunities for their emotions to be listened to and their own needs to be met and consideration should be given for how partners are supported in adjusting to changes associated with diagnosis and treatment of PCA. There is a need for partners to be included in hospital and medical appointments, not only to support their partner, but to enable the opportunity to gain information and support

surrounding PCA and the different treatment options. Further to this, partners provide the majority of the practical care and therefore both verbal and written information would aid their understanding on how to fulfil the care-giving role. This is specifically identified in regard to the practical support needed after treatment, for example in relation to urinary incontinence. Group or individual interventions providing a space for partners' emotional needs, opportunities to gain advice and support on the caring role and to reduce caregiver burden would be of importance. Joint interventions with the partner with PCA may also be useful to aid difficulties in communication surrounding diagnosis or treatment of PCA, especially involving issues such as sexual intimacy. Previous interventions focusing on sexual intimacy have taken either psycho-educational or cognitive behavioural approaches (Wootten et al., 2014). Social support opportunities may also provide relief to partners as an opportunity to discuss their situation with other partners of men with PCA who are in a similar position. Health care professionals need to be aware of the needs of partners of men with PCA and where there are high levels of distress it may be necessary to meet with the partner alone, especially if the partner does not feel able to discuss their difficulties in front of the man with PCA. The potential implications of treatment need to be explicitly discussed with partners and men with PCA especially in relation to the potential changes to sexual function, in order to manage expectations within the relationship following treatment.

1.5.4 Future Research

A number of future research areas are identified in order to build on the current paper. Firstly, further research which focuses exclusively on the experiences of

partners. Partners may have wanted to protect their partner with PCA from their struggles with the caring role. Secondly, more research to further identify the experiences of same sex partners with PCA is suggested due to the limited amount of research papers focusing on this. Thirdly, it could aid the evidence base to have a specific understanding of how each part of the cancer journey may impact on the partner. Therefore, further research to focus on each individual area including diagnosis, decision making for treatment, treatment and survivorship. Further to this, specific research focusing on partners' experiences in relation to specific stage of cancer progression would be beneficial for identifying the different support and information needs accompanying different diagnoses.

1.6 Conclusion

This review aimed to synthesise the experiences of partners of men with PCA. The synthesised findings highlighted how partners made sense of the PCA diagnosis and provided support to the man with PCA before meeting their own needs. Changes to the intimate relationship were identified, specifically in relation to communication and sexual intimacy following treatment. Further support from professionals was identified in order to provide emotional support, inclusion in medical appointments and opportunities for partners to receive information for caring with someone with PCA. Further to this, interventions that promote communication within the relationship and support the unmet needs for partners of men with PCA are suggested.

1.7 References

* articles included in this review

Barnett-Page, E., and Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, Vol. 9(1), p59.

Beck, A. M., Robinson, J. W. & Carlson, L. E. (2009) Sexual intimacy in heterosexual couples after prostate cancer treatment: What we know and what we still need to learn. *Urologic Oncology: Seminars and Original Investigations*, Vol. 27, p137-143.

Bell, K. & Kazanjian, A. (2011) PSA testing: Molecular technologies and men's experience of prostate cancer survivorship. *Health, Risk & Society*, Vol. 13(2), p183-198.

Berterö, C. (2001) Altered sexual patterns after treatment for prostate cancer. *Cancer Practice*, Vol. 9, p245–51.

Boehmer, U. and Babayan, R. K. (2004) Facing erectile dysfunction due to prostate cancer treatment: perspectives of men and their partners. *Cancer Investigation*, Vol. 22, p840-848.

* Boehmer, U. and Clark, J. A. (2001) Communication about prostate cancer between men and their wives, *The Journal of Family Practice*, Vol. 50(3), p226-231.

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M. & Pill, R. (2002). Using meta-ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, Vol. 7(4), p209-215.

*Bruun, P., Pedersen, B. D., Osther, P. J. & Wagner, L. (2011) The Lonely Female Partner: A Central Aspect of Prostate Cancer. *Urologic Nursing*, Vol. 31(5), p294-299.

*Butler, L., Downe-Wamboldt, B. Marsh, S., Bell, D. & Jarvi, K. (2000) Behind the scenes: partners' perceptions of quality of life post radical prostatectomy. *Urologic Nursing*, Vol. 20(4), p254-258.

Caldwell, K., Henshaw, L. & Taylor G. (2005) Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues*, Vol. 6(1), p45-54.

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C., & Donovan, J. (2011). Evaluating meta- ethnography: Systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, Vol. 15(43), p1366-5278

Care Act (2014) Retrieved on 18th September 2016 from http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S. and O'Connell, D. L. (2011) A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education and Counseling*, Vol. 85, e75-e88.

Clark, J.A., Inui, T. S., Silliman, R. A., Bokhour, B.G., Krasnow, S.H., Robinson, R.A., Spaulding, M. & Talcott, J. A. (2003) Patients' perceptions of quality of life after treatment for early prostate cancer. *Journal of Clinical Oncology*, Vol. 21, p3777– 84.

Cleary, M., Horsfall, J. & Hayter, M (2014) Data collection and sampling in qualitative research: Does size matter? *Journal of Advanced Nursing*. Vol. 70(3), p473-475.

Couper, J., Bloch, S., Love, A., Macvean, M., Duchesne, G. M. & Kissane, D. (2006a) Psychosocial adjustment of female partners of men with prostate cancer: a review of the literature. *Psycho-Oncology*, Vol. 15(11), p937-953.

Couper, J., Bloch, S., Love, A., Duchesne, G., Macvean, M. & Kissane, D. W. (2006b) The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia*, Vol. 185(8), p428-432.

Dahn, J.R., Penedo, F. J., & Gonzales, J. S. (2004) The sexual functioning and quality of life after prostate cancer treatment: considering sexual desire. *Urology*. Vol. 63(2), p273-277.

*Docherty, A., Brothwell, C. P. D. & Symons, M. (2007) The Impact of Inadequate Knowledge on Patient and Spouse Experience of Prostate Cancer. *Cancer Nursing*, Vol. 30(1), p58-63.

Dunn, M. W. and Kazer, M. W (2011) Prostate Cancer Overview. *Seminars in Oncology Nursing*, Vol. 27(4), p241-250.

Ervik B., Nordoy T. & Asplund K. (2010) Hit by waves – living with local advanced or localised prostate cancer treated with endocrine therapy or under active surveillance. *Cancer Nursing*, Vol. 33, p382–389.

*Ervik, B., Norday, T. & Asplund, K. (2012) In the Middle & on the Sideline: The Experience of Spouses of Men with Prostate Cancer. *Cancer Nursing*, Vol.00, p1-7.

Eton, D.T, Lepore, S. J. & Helgeson, V. S. (2005) Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer*, Vol. 103, p2412-2418.

*Evertsen, J. M. and Wolkenstein, A. S. (2010) Female partners of patients after surgical prostate cancer treatment: interactions with physicians and support needs. *BMC Family Practice*, Vol. 11(19), p1-6.

Ezer, H., Chachamovich, J. R., Saad, F., Aprikian, A. & Souhami, L. (2012) Psychosocial Adjustment of men during the first year of prostate cancer. *Cancer Nursing*, Vol. 35(2), p141-147.

Ezer, H., Ricard, N., Bouchard, L., Souhami, L., Saad, F., Aprikian, A. & Taguchi, Y. (2006) Adaptation of wives to prostate cancer following diagnosis and 3 months after treatment: A test of family adaptation theory. *International Journal of Nursing Studies*, Vol. 43, p827-838.

Ferguson, C. J. and Brannick, M. T. (2012) Publication Bias in Psychological Science: Prevalence, Methods for Identifying, Controlling, and Implications for the Use of Meta-Analyses, *Psychological Methods*, Vol. 17(1), p120-128.

Filiault, S.M., Drumond, M. J. N. & Smith, J. A (2008) Gay men and prostate cancer: voicing the concerns of a hidden population. *Journal of Men's Health*, Vol. 5, p327-32.

Gailbraith, M. E., Fink, R. & Wilkins, G. G. (2011) Couples Surviving Prostate Cancer: Challenges in their Lives and Relationships. *Seminars in Oncology Nursing*, Vol. 27(4), p300-308.

Goonewardene, S. S., Persad, R., Young, A., Grover, L. and Makar, A. (2015) Prostate cancer survivorship and psychosexual care, *European Journal of Cancer Care*, Vol. 24, p281-282.

*Gray, R. E., Fitch, M. I., Phillips, C., Labrecque, M. & Klotz, L. (1999) Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice*, Vol. 7(3), p130-135.

Gray, R. E, Fitch, M., Phillips, C., Labrecque, M. & Fergus, K. (2000) To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, Vol. 9, p273-282.

*Gray, R. E., Fitch, M., Phillips, C, Labrecque, M. & Fergus, K. (2000) Managing the Impact of illness: The experiences of men with prostate cancer and their spouses. *Journal of Health Psychology*, Vol. 5(4), p531-548.

Gray, R. E., Fitch, M. I, & Fergus, M. (2002) Hegemonic masculinity and the experience of prostate cancer: a narrative approach. *Journal of Aging Identity*, Vol. 7(1), p43-60.

Hampton, A. J., Walker, L. M., Beck, A. & Robinson, J.W. (2013) A brief couples' workshop for improving sexual experiences after prostate cancer treatment: a feasibility study. *Support Care Cancer*, Vol. 21, p3403-3409.

*Harden, J., Schafenacker, A., Northouse, L, Mood, D., Smith, D., Pienta, K., Hussain, M. & Baranowski, K. (2002) Couple's experiences with prostate cancer: focus group research. *Oncology Nursing Forum*, Vol. 29(4), p701-709

Harden, J. (2005) Developmental Life Stage and Couples' Experiences with Prostate Cancer: A review of the literature. *Cancer Nursing*, Vol. 28(2), p85-93.

Harden, J., Sanda, M. G., Wei, J. T., Yarandi, H. N & Hembroff, L. (2013) Survivorship after prostate cancer treatment: Spouses' quality of life at 36 months. *Oncology Nursing Forum*, Vol. 40(6), p567-573.

Hartman, M.E., Irvine, J., Currie, K. L., Ritvo, P., Trachtenberg, L., Louis, A., & Matthew, A. G. (2014) Exploring gay couples' experience with sexual dysfunction after radical prostatectomy: A qualitative study. *Journal of Sex and Marital Therapy*, Vol. 40(3), p233–253.

Herr, H. (1997) Quality of life in prostate cancer patients. *CA: A cancer journal for clinicians*, Vol. 47(4), p207-217.

Heyman, E. and Rosner, R. (1996) Prostate Cancer: an intimate view from patients and wives. *Urology Nursing*, Vol. 16(2), p37-44.

Jones R, Taylor A, Bourguignon C, Steeves, R., Fraser, G., Lippert, M., Theodorescu, D., Mathews, H. & Kilbridge, K. L. (2008) Family interactions among African American prostate cancer survivors. *Family Community Health*, Vol. 31(3), p213-220.

*Ka'opua, L. S. I., Gotay, C. C., Hannum, M. & Bunghanoy, G. (2005) Adaptation to long-term prostate cancer survival: the perspective of elderly Asian/Pacific Islander wives. *Health & Social Work*, Vol. 30(2), p145-154.

*Ka'opua, L. S. I., Gotay, C. C. & Boehm, P.S. (2007) Spiritually based resources in adaptation to long-term prostate cancer survival: perspectives of elderly wives. *Health & Social Work*, Vol. 32(1), 29-39.

Katz, A. (2007) Quality of life for men with prostate cancer. *Cancer Nursing*, Vol. 30(4), p302-308.

Kornblith, A. B., Herr, H. W., Ofma, U.S., Scher, H. I. & Holland, J. C. (1994) Quality of life of patients with prostate cancer and their spouses: The value of a database in clinical care. *Cancer*, Vol. 73(11), p2791-2802.

*Lavery, J. F. and Clarke, V. A. (1999) Prostate cancer: patients' and spouses' coping and marital adjustment. *Psychology, Health & Medicine*, Vol.4(3), p289-302.

Macmillan (2012) More than a million: Understanding the UK's carers of people with cancer – a report by Ipsos Mori for Macmillan Cancer Support. Retrieved on 18th September 2016 from <https://www.ipsos-mori.com/Assets/Docs/Publications/sri-ipsos-mori-macmillan-more-than-a-million-2012.pdf>

Macmillan (2016) Identifying Cancer Carers and signposting them to support . Retrieved on 18th September 2016 from <http://www.macmillan.org.uk/documents/getinvolved/campaigns/carers/identifyingcancercarersandsignpostingthemtosupport.pdf>

*Maliski, S. L., Heilemann, M. V. & McCorkle, R. (2002) From 'death sentence' to 'good cancer': couples' transformation of a prostate cancer diagnosis. *Nursing Research*, Vol. 51(6), p391-397.

Manne, S., Babb, J., Pinover, W., Horwitz, E. & Ebbert, J. (2004) Psychoeducational group intervention for wives of men with prostate cancer. *Psychooncology*, Vol. 13, p37-46.

Mays, N. and Pope, C. (2000) Assessing quality in qualitative research. *British Medical Journal*, Vol. 320, p50-52.

*McCaughan, E., McKenna, S, McSorley, O. & Parahoo, K. (2015) The experience and perception of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration. *Journal of Advanced Nursing*, Vol. 71(8), p1871-1882.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine*, Vol. 151(4), p264-269.

NHS (2015) Prostate Cancer. Retrieved on 16th August 2016 from <http://www.nhs.uk/Conditions/Cancer-of-the-prostate/Pages/Introduction.aspx>

NICE (2014) Prostate Cancer: Diagnosis and Management. NICE guidelines CG175. Retrieved on 12th September 2016 from <https://www.nice.org.uk/guidance/cg175/resources/prostate-cancer-diagnosis-and-management-35109753913285>

NICE (2015) Suspected cancer: recognition and referral. NICE guideline NG12. Retrieved on 12th September 2016 from <https://www.nice.org.uk/guidance/ng12/resources/suspected-cancer-recognition-and-referral-1837268071621>

NICE (2004) Supportive and palliative care services for adults with cancer. Understanding NICE guidance – information for adults with cancer, their families and carers, and the public. N0476. Retrieved on 12th September 2016 from <https://www.nice.org.uk/guidance/csg4/resources/supportive-and-palliative-care-services-for-adults-with-cancer-2188778077>

NICE (2004) *Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer: The Manual*. London: NICE.

Noblit, G. W. and Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). Sage: Newbury Park.

Northouse, L. L., Mood, D. W., Schafenacker, A., Montie, J. E., Sandler, H. M. & Forman, J. D. (2007) Randomised clinical trial of a family intervention for prostate cancer patients and their spouses. *Cancer*, Vol. 110, p2809-2818.

*O'Callaghan, C., Dryden, T., Hyatt, A., Brooker, J., Burney, S., Wooten, A. C., White, A., Frydenberg, M., Murphy, D., Williams, S. & Schofield, P. (2014) 'What is this active surveillance thing?' Men's and partner's reactions to treatment decision making for prostate cancer when active surveillance is the recommended treatment option, *Psycho-Oncology*, Vol. 23, p1391-1398.

Office for National Statistics (2016) Cancer Registration Statistics: England 2014 retrieved on 16th August 2016 from <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2014>

*O'Shaughnessy, P. K., Ireland, C., Pelentsov, L., Thomas, L. A. & Esterman, A. J. (2013) Impaired sexual function and prostate cancer: a mixed method investigation into the experiences of men and their partners, *Journal of Clinical Nursing*, Vol. 22, p3492-3502.

Paterson, C., Robertson, A., Smith, A. & Nabi, G. (2015) Identifying the unmet supportive care needs of men living with and beyond prostate cancer: a systematic review. *European Journal of Oncology Nursing*, Vol. 19, p405-418.

*Petry, H., Berry, D. L., Spichiger, E., Kesselring, A., Gasser, T. C., Sulser, T. & Kiss, A (2004) Responses and experiences after radical prostatectomy: perceptions of married couples in Switzerland, *International Journal of Nursing Studies*, Vol. 41, p507-513.

Phillips, C, Gray, R. E, Fitch, M.I, Labrqcque, M., Fergus, K., & Klotz, L. (2000) Early post surgery experience of prostate cancer patients and spouses, *Cancer Practice*, Vol. 8(4), p165-171.

Pietromonaco, P. R., Uchino, B. & Schetter, C. D. (2013) Close Relationship Processes and Health: Implications of Attachment Theory for Health and Disease, *Health Psychology*, Vol. 32(5), p499-513.

Prostate Cancer UK (2014) *Prostate Cancer: A guide for men who have just been diagnosed*. London: Prostate Cancer UK

Resendes, L, A. and McCorkle, R. (2006) Spousal Responses to Prostate Cancer: An Integrative Review. *Cancer Investigation*, Vol. 24, p192-198.

*Rossen, S., Hansen-Nord, N. S., Kayser, L., Borre, M., Borre, M., Larsen, R. G., Trichopoulou, A., Boffetta, P., Tjonneland, A. & Hansen, R. D. (2016) The Impact of Husbands' Prostate Cancer Diagnosis and Participation in a Behavioral Lifestyle

Intervention on Spouses' Lives and Relationships With Their Partners. *Cancer Nursing*, Vol. 39(2), E1-E9.

Sanders, S., Pedro, L. W., Bantum, E. & Gailbraith, M. E. (2006) Couple's surviving Prostate Cancer: Long-term intimacy needs and concerns following treatment. *Clinical Journal of Oncology Nursing*, Vol. 10(4), p503-508.

Schumm, K., Skea, Z., McKee, L. & N'Dow, J. (2010) They're doing surgery on two people: a meta-ethnography of the influences on couples' treatment decision making for prostate cancer. *Health Expectation*, Vol. 13, p335-349.

Sharpe, L., Butow, P., Smith, C., McConnell, D. & Clarke, S. (2005) The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology*, Vol. 14, p102-114.

*Sinfield, P, Baker, R. Agarwal, S. & Tarrant, C. (2008) Patient-centred care: What are the experiences of prostate cancer patients and their partners, *Patient Education and Counseling*, Vol. 73, p91-96.

Sinfield, P., Baker, R., Camosso-Stefinovic, J., Colman, A. M., Tarrant, C, Mellon, J. K., Steward, W., Kockelbergh, R. & Agarwal, S. (2009) Men's and carers' experiences of care for prostate cancer: a narrative literature review. *Health Expectations*, Vol. 12, p301-312.

Steinke, E.E. (2005) Intimacy needs and chronic illness: Strategies for sexual counseling and self-management. *Journal of Gerontological Nursing*, Vol. 31, p40–50.

*Street, A. F., Couper, J. W., Love, A. W., Bloch, S., Kissane, D.W. & Street, B. C. (2010) Psychosocial adaption in female partners of men with prostate cancer. *European Journal of Cancer Care*, Vol. 19, p234-242.

*Tanner, T., Galbraith, M. & Hays, L. (2011) From a Woman's Perspective: Life as a Partner of a Prostate Cancer Survivor. *Journal of Midwifery & Women's Health*, Vol. 56(2), p154-160.

Ussher, J. M., Perz, J., Rose, D., Dowsett, G. W., Chambers, S., Williams, S., Davis, I., & Latini, D. (2016) Threat of Sexual Disqualification: The Consequences of Erectile Dysfunction and Other Sexual Changes for Gay and Bisexual Men with Prostate Cancer. *Archives of Sexual Behaviour*, pp 1–15.

Wall, D. and Kristjanson, L. (2005) Men, culture and hegemonic masculinity: understanding the experience of prostate cancer, *Nursing Inquiry*, Vol. 12(2), p87-97.

Wallace, M. (2003) Sexuality and aging in long-term care. *Annals of Long-Term Care*, Vol. 11, p53–59.

Weber, B. A. and Sherwill-Navarro, P. (2005) Psychosocial Consequences of Prostate Cancer: 30 Years of Research. *Geriatric Nursing*, Vol. 26, p166-75.

World Health Organisation (2015) Prostate Cancer Estimated Incidence, Mortality and Prevalence Worldwide, GLOBOCAN 2012. Retrieved on 16th August 2016 from http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx

*Wootten, A. C., Abbott, J. M., Osborne, D., Austin, D. W., Klein, B., Costello, A. J. & Murphy, D. G. (2014) The impact of prostate cancer on partners: a qualitative exploration. *Psycho-Oncology*, Vol. 23, p1252-1258.

Wootten, A. C., Abbott, J. M., Farrell, A., Austin, D., W. & Klein, B. (2014) Psychosocial interventions to support partners of men with prostate cancer: a systematic and critical review of the literature. *Journal of Cancer Survivors*, Vol. 8, p472-484.

CHAPTER 2: Empirical Paper

Men's experiences of living with a diagnosis of Bipolar Disorder

In preparation for submission to *Journal of Affective Disorders*
(See Appendix C for Author Guidelines)

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2.1 Abstract

Bipolar Disorder (BD) is considered to be a chronic and disabling condition in which significant distress and emotional suffering is reported. Treatment for BD has primarily included medication, however more recently a patient-centred, individualised approach has been introduced focusing on patient experience. Men have been shown to experience BD differently to woman and have been underrepresented within existing literature. This qualitative study explored the lived experience of 7 men with a diagnosis of BD. Interviews were conducted and analysed using Interpretative Phenomenological Analysis (IPA). One superordinate theme was identified: The Battle, which consisted of three sub-ordinate themes: *“Take it all on the chin and suffer in silence”*, *Struggling to find a fix: Trapped in a medical understanding* and *“It wasn’t just me then”*. Men struggled to acknowledge their difficulties due to the stigma surrounding help-seeking and receiving a mental health diagnosis. Further to this, there was a need to conform to masculine stereotypes to prevent being perceived as weak. Experiences of medication did not fit with men’s expectations of medical treatment holding a solution to their difficulties. Finding ways to re-connect with society and continue with a meaningful life after diagnosis were seen as important; these are in line with recovery models of mental health. Clinical implications include encouraging help-seeking in men with BD, offering patient choice and managing the expectations of treatment. Future research directions are identified.

2.2 Introduction

This section will introduce BD and the treatment options available within the UK. Following this, gender differences and models of care will be explored with particular reference to recovery and the importance of the lived experiences of service users within this.

2.2.1 Bipolar Disorder

Prevalence for BD is estimated at between 1-1.5% of the general population in the US and the UK (Weismann et al., 1996), highlighting a commonly applied mental health diagnosis (Jones, 2004). Bipolar and Related Disorders have their own chapter in the DSM-5 (American Psychiatric Association [APA], 2013) where the criteria for a diagnosis of BD include episodes of either mania or hypomania as well as clinical depression (Russell & Moss, 2013). More specifically, for a diagnosis of Bipolar I Disorder the criteria for a manic episode needs to be fulfilled at least once in a person's lifetime. A manic episode is defined as:

“a distinct period of abnormally and persistently elevated, expansive or irritable mood and abnormally and persistently increased goal-directed activity or energy lasting at least one week and present most of the day, nearly everyday (or any duration if hospitalisation is necessary)” (APA, 2013, p.124).

In addition to the above, a severe impairment to functioning is observed, as well as changes to usual behaviour which cannot be attributed to the physiological effects of a substance (APA, 2013). A diagnosis of Bipolar II Disorder is given where the period of abnormal mood lasts for at least four consecutive days (hypomanic episode) and a

major depressive episode has been experienced (APA, 2013). It is estimated that people with Bipolar Disorder are 15 times more likely than the general population to be at risk of suicide (APA, 2013) and that 15-19% of them will successfully commit suicide (Abreu et al. 2009). BP is considered a chronic and disabling condition due to the impact it has on an individual's everyday life functioning (Inder et al., 2011) and the significant distress and emotional suffering people with this diagnosis report (Russell & Moss, 2013).

2.2.2 NICE guidance and treatment

The psychiatric diagnostic system views emotional distress as the result of biological abnormalities, which in turn can therefore be treated by bio-medical interventions (Moncrieff, 2007). Treatment for BD has primarily included psychotropic medication to reduce symptoms, stabilise mood and prevent the occurrence of relapse (NICE, 2006). Even though there are many different pharmacological treatment options for BD (Fountoulakis, 2012), they do not necessarily guarantee an absence of relapses or recurrences that have been reported as 18% and 40% respectively for patients in a multinational study (Vieta et al., 2013). Treatment adherence to medication is a serious issue with only a quarter of patients being reported as adhering to treatment (Barraco et al., 2010). Non-adherence has been linked to alcohol consumption, negative attitudes towards medication, symptom severity and younger age at start of treatment (Barraco et al., 2010).

Rates of relapse are significantly reduced when there is adjunctive psychological treatment alongside standard psychiatric care (Scott et al., 2007), highlighting the importance of a person-centred approach (Division of Clinical Psychology [DCP],

2010). More recent updates to NICE guidelines for managing BD incorporate a larger focus on psychological therapies, the need for information and support, and physical health monitoring (NICE, 2014). Effective psychological treatments are shown to include cognitive behavioural therapy, psycho-education, interpersonal and social rhythm therapy, and family interventions, however these vary in efficacy depending on the characteristics of the individual and the course of their illness (Reinares, 2014). NICE (2015) recommends an individualised approach to care that is tailored to patients' needs, incorporating their views and preferences for treatment and management. In order to take a more person-centred approach to BD there is a need to understand service users' lived experiences rather than focusing on how a set of symptoms are treated and managed by medication (DCP, 2010). Through listening to service users' experiences of receiving a diagnosis (Proudfoot et al., 2009) and subsequent treatment experiences, information can be gathered to support the development of mental health services (DCP, 2010). Further to this, by recognising service users' expertise and knowledge of their own experience of illness, as well as their values and preferences (Kings Fund, 2014), clinicians can encourage patients to be experts of their own experience (DCP, 2010) and empower them to take more control and responsibility for their own health (Kings Fund, 2014). Enabling service users to take an active role in decision making surrounding their own mental health treatment, facilitates self-management approaches (DCP, 2010), and helps to readdress the balance of power to the individual (Kings Fund, 2014). In addition to this, recruiting service users to help other individuals with self management (DCP, 2010) encourages services to view people with bipolar experiences as equal partners in health care as opposed to inexperienced recipients of treatment (Lorig, 1993). This

can be likened to the model of the Expert Patient for chronic health conditions (Donaldson, 2003).

2.2.3 Recovery

The recovery model is considered to be more than just patient participation, patient-centeredness and shared-decision making within treatment decisions (Storm & Edwards, 2013). Recovery emphasises health, strengths and wellness as opposed to focusing solely on pathology, illness and symptoms which are predominant in the medical model (Davidson, 2005; Shepherd, Boardman & Slade, 2008). Within mental health, the recovery model emphasises control as being given to the individual rather than professionals, as well as collaborative care between providers and the involvement of families in the treatment and recovery (Duncan, Best & Hagen, 2010). Further to this, recovery has been viewed as a consumer movement where emphasis is placed on social inclusion and participation within the community for people suffering from mental health disorders (Storm & Edwards, 2013). Recovery therefore focuses on an individual working collaboratively to overcome the effects of being mentally ill, redefining the self and preserving an element of control over their own life, as opposed to the remission of symptoms, returning to normal function or finding a cure (Davidson et al., 2005; Wilken, 2007). Differences have been demonstrated in the way female and males make sense of their recovery which is important in order to provide appropriate care to facilitate this (Schon, 2010).

2.2.4 Men, Bipolar Disorder and help-seeking

Gender differences have been shown with regard to how BD presents itself for men and women. Specifically, women are more likely to experience mixed states, rapid cycling, comorbidity with eating disorders (APA, 2013) and a predominance of depression (Nivoli et al., 2011; Azorin et al., 2013). In contrast, for men mania is more likely to predominate, men are younger at onset and have comorbidities with substance misuse (Azorin et al., 2013) and alcohol (Nivoli et al., 2011). Men with BD have a lower rate of suicide attempts (Simon et al., 2007; Nivoli et al., 2011) but a higher rate of suicide deaths when compared to women with BD (Simon et al., 2007), highlighting that men are a vulnerable group. Men have shown to be less likely to seek help from services and professionals than women for a range of problems including mental health problems, stressful life events and depression (Galdas, Cheater & Marshall, 2005; Hernandez et al., 2014; Oliver et al., 2005). More specifically, men do not consider that it is socially acceptable to have mental health problems or that it is appropriate to seek help for these as specific support for men is lacking (Chuick et al., 2009). Further to this, men describe a reluctance to access services. They describe feeling vulnerable and embarrassed (Jeffries & Grogan, 2012), an awareness of social pressure to hide their emotions in order to retain masculinity (Chuick et al., 2009), and to suppress negative emotions as a way of coping, which results in other behaviours e.g. impulsive risk-taking, withdrawal and substance abuse (Brownhill, Wilhelm, Barclay & Schmied, 2005).

2.2.5 Qualitative studies on Bipolar Disorder

Qualitative studies focusing on people's experiences of BD have concentrated on diagnosis (Inder et al., 2010; Proudfoot et al., 2009), sense of self and identity (Chapman, 2002; Inder et al., 2008; Inder et al., 2011), the process of recovery (Mansell et al., 2010; Veseth et al., 2012), quality of life (Michalek et al., 2006), staying well (Russell & Browne, 2005), the impact of BD (Crowe et al., 2012), the meaning of living with BD (Jonsson, 2008; Rusner et al., 2009), perceptions of illness (Pollack & Aponte, 2001) and stigma (Michalak et al., 2011).

Russell and Moss (2013) conducted a meta-study which reviewed the current literature of qualitative studies focusing on the experiences of 'having a diagnosis' or 'symptoms' for people diagnosed with BD. This study reported 9 themes: 'struggles with identity', 'loss of control', 'disruption, uncertainty and instability', 'negative impact of symptoms across life and the experience of loss', 'negative view of self', 'positive or desirable aspects of mania', 'struggling with the meaning of diagnosis', 'stigma', and 'acceptance and hope', and identified the importance these themes could have in supporting clinical work with services users. However, Russell and Moss (2013) also highlighted that future research should focus on men's experiences of BD as the samples of the reviewed studies had a higher proportion of women.

This much lower representation of males in empirical studies is a concern due to the almost equal prevalence of BD (APA, 2013) and the reported gender differences in how BD is experienced (Azorin et al., 2013). Table 2.1 shows the sample size, age range and male representation (as a percentage in comparison to women) within the studies included in the Russell and Moss' (2013) review.

Table 2.1: Studies included in Russell and Moss' (2013) review

Study	Sample size	Men %	Age range (years)	Mean age (years)
Chapman (2002)	12	25%	22-62	41 (median)
Crowe et al. (2012)	21	24%	22-71	40.7
Inder et al. (2008)	15	20%	15-35	26.4
Inder et al. (2011)	2	0%	15-31	23
Michalak et al. (2006)	35	36%	21-68	43
Michalak et al. (2011)	32	37.5%	unknown	41.1
Mansell et al. (2010)	13	31%	32-61	50.5
Pollack & Aponte (2001)	15	46%	21-52	35.3
Proudfoot et al. (2009)	26	46%	18-59	unknown
Rusner et al. (2009)	10	40%	30-61	unknown
Russell & Browne (2005)	100	37%	18-83	(86% over 30)
Veseth et al. (2012)	13	46%	27-65	47

It is clear that while men are represented by up to 46% in some studies, overall their representation is quite low in comparison to women.

2.2.6 Rationale

Considering there is an almost equal prevalence of BD in men and women (APA, 2013), the gender differences in the way in which BD is experienced (Azorin et al., 2013), the higher rate of suicide deaths in men with BD (Simon et al., 2007) and that men have shown to be less likely to seek help from services and professionals than women, learning more about men's experiences of BD would be highly valuable. This would consider individual variation, the person as an expert of their own experience and potentially highlight ways in which services could be improved in order to engage male service users (DCP, 2010).

The focus of this study will therefore be to explore the lived experiences of men who have received a diagnosis of BD. Focusing on lived experiences enables the personal meaning and sense-making of receiving a diagnosis of BD for men to be further understood and examined (Smith, Flowers and Larkin, 2009). Further to this, by focusing on the detailed examination of an individual's life-world, personal perceptions and meanings of an event can be explored (Smith, 2003). More specifically, this study will explore how individuals made sense of their personal experiences before and after receiving a diagnosis of BD, including any support and/or treatment that was received, and how men make sense of living with BD in everyday life.

2.2.7 Aims and Research Questions

The proposed study aims to explore how men experience living with a diagnosis of BD.

More specifically this study will attempt to answer the following research questions:

- What are men's experiences of receiving a diagnosis of BD?
- What are men's experiences of any treatment or support?
- What are their experiences of managing everyday life living with BD?

2.3 Methodology

2.3.1 Design

A qualitative approach using IPA was taken to enable a rich understanding of men's experiences within an area of limited research. IPA has been utilised within research in healthcare settings (Biggerstaff & Thompson, 2008) and was chosen as it focuses on an individual's comprehensive account of their lived experience and the meaning they take from this (Smith, et al., 2009). IPA is informed by three key areas of theoretical underpinning: phenomenology, hermeneutics and ideography. A phenomenological approach is incorporated into IPA by focusing on the sense an individual makes of their experience, while hermeneutics involves the focus of the interpretation of this experience. Aspects of ideography are adopted through gaining an in depth understanding of an experience through a particular group of individuals using systematic analysis (Smith et al., 2009).

2.3.2 Subjective position of researcher

The researcher approached this study from the epistemological position of social constructionism, in which it is assumed that knowledge, understanding and reality of the world is constructed between people (Gergen, 1999). Further to this, experiences are based in time and context, and considered unique to an individual (Berger & Luckmann, 1966). Due to the phenomenological elements of IPA, the researcher is involved in making sense of how a participant makes sense of an experience and therefore the researcher is required to make interpretations (Smith et al., 2009). It is important for the researcher to recognise their own assumptions, judgements and

emotions while engaging with participants and the data (Biggerstaff & Thompson, 2008). This can be aided through the use of bracketing interview which incorporates reflexivity and reflection (Ahern, 1999). The use of a reflexive journal and discussions with the research supervision team allowed the researcher opportunities to consider their own role, emotions and interactions in relation to the research.

The researcher was employed as a Trainee Clinical Psychologist at the time of the interviews working within a physical health and palliative care setting predominantly using an Acceptance and Commitment Therapy (ACT) approach (Harris, 2009). The researcher reflected on interactions within the interviews conducted, especially where ACT was mentioned. The researcher also had previous experience of working within a service for people with BD and of running an Information and Support Group which again could have had an influence on the interactions with participants and the data.

2.3.3 Materials

A semi-structured interview schedule was devised to guide data collection following a review of the current qualitative literature focusing on experiences of BD and by considering the research questions (Smith et al., 2009; Appendix D). This was used as a basis for conversation, taking into account the need for the participant to lead the interview (Biggerstaff & Thompson, 2008). Demographic details of participants were also collected (Appendix E).

2.3.4 Procedure

2.3.4.1 Ethical Approval

Guidance from the British Psychological Society Code for Human Research Ethics (2010) was adhered to when designing and conducting this research. Ethical approval was sought from Coventry University Ethics Committee (Appendix F) the West Midlands National Research Ethics Committee (Appendix G) and 3 local NHS Research and Development Departments (Appendix H).

2.3.4.2 Recruitment

Due to the nature of an IPA study, participants were purposively selected due to their particular lived experience in order to create a small sample of detailed accounts from a homogenous group (Smith et al., 2009). Participant inclusion and exclusion criteria are presented in Table 2.2.

Table 2.2: Participant inclusion and exclusion criteria

Inclusion criteria	Men with a diagnosis of Bipolar I or II Disorder who are currently receiving or have previously received support from a National Health Service (NHS) mental health service Aged 18 or over
Exclusion criteria	Acutely unwell at the time of interview Under the influence of alcohol or substances at the time of interview Under the age of 18

Recruitment sites were NHS secondary care mental health services across the West Midlands. This included Psychology Services, Early Intervention in Psychosis Services,

Specialist Bipolar Disorder Services, Community Mental Health Teams and Recovery Services. Clinicians within these teams were approached by the researcher (via email and in person) and asked to identify individuals who met the inclusion criteria for the study. An information pack was provided for clinicians to distribute to potential participants which included an information sheet, consent form, reply slip and pre-paid addressed envelope (See appendices I, J, K). After acknowledging interest in the study, participants were contacted via email or phone to arrange an interview.

2.3.4.3 Interview Procedure

All interviews took place in clinical rooms on NHS sites. For most participants it was a place they were familiar with. Interviews took place over May and June 2016, involving the researcher and the participant. Prior to the interview the participant was reminded and shown a copy of the information sheet and either signed or reviewed a consent form. Demographic information was collected before the interview started and an opportunity was given for any further questions. The participant was reminded that the interview could be stopped at any time. Interviews were audio recorded and lasted between 45-70 minutes. Once the interview was completed, participants were given a verbal debrief and received a debrief form which included details for further support (appendix L). Participants were given the option to withdraw from the study until the 30th June 2016. Recruitment ended after 7 interviews as there appeared to be a sufficient amount of rich data collated.

2.3.5 Participants

The demographics of the 7 participants are shown in Table 2.3.

Table 2.3: Demographics of participants

Participant	Age	Marital status	Employment status	Age at Diagnosis	BD Diagnosis	Time since Diagnosis
1	25	Single	Unemployed	24	Type I	1 year
2	41	Married	Employed	21	Type II	20 years
3	42	Single	Self employed	40	Type II	2 years
4	36	Single	Employed	32	Type II	4 years
5	38	Single	Employed	19	Type I	19 years
6	21	Single	Unemployed	19	Type I Rapid Cycling	2 years
7	30	Single	Employed	25	Type II	5 years

2.3.6 Data Analysis

The audio recorded interviews were transcribed verbatim and any identifiable information was anonymised. Transcripts were analysed using IPA according to the steps in Smith et al. (2009) (as shown in Appendix M). Initial comments were made on the transcript as they were read line by line. These were reviewed and grouped together to create emergent themes for that transcript. The emergent themes for each transcript were collated to identify connections between emergent themes across transcripts (Appendix N). These were then used to create superordinate and subordinate themes.

2.3.6.1 Credibility of the analysis

The validity and quality of qualitative research is important (Yardley, 2000) and this has been considered by incorporating a number of techniques suggested by Mays and Pope (2000) during the analysis process. A clear account of the data collection and analysis has been documented and supported by excerpts of data where possible. The research supervision team has been utilised in order to reflect on any experiences throughout data collection, to review the development of themes and aid reflective

practice. A sample of transcript was analysed by an additional researcher who was familiar with IPA in order to verify coding.

2.4 Results

One superordinate theme was identified from the analysis: **The Battle**. It included three subordinate themes as shown below:

The Battle

- *“Take it all on the chin and suffer in silence”*
- *Struggling to find a fix: Trapped in a medical understanding*
- *“It wasn’t just me then”*

The superordinate theme and subordinate themes will be explored in more detail including anonymised quotes from the transcripts to highlight men’s lived experiences.

2.4.1 The Battle

This superordinate theme identifies how men experienced ongoing battles of vulnerability both internally and externally on their journey of receiving a diagnosis of BD. Internally men battled with the loss of their masculine identity, and externally men battled through society due to the stigma surrounding mental illness. It includes three subordinate themes: *“Take it all on the chin and suffer in silence”*, *Struggling to find a fix: Trapped in a medical understanding* and *“It wasn’t just me then”*. These are presented below.

2.4.1.1 “Take it all on the chin and suffer in silence”

This subordinate theme explores the battle men experienced between recognising changes within themselves and an overwhelming urge to keep this hidden from the

external world. Admitting problems was perceived as too risky in a society where men are expected to be strong and stable.

Most men denied their emotions and behaviours were problematic at first as these were long-standing. They protected themselves by building barriers in order to hide their feelings. Although this was an attempt to ensure their own safety, participants became increasingly isolated and lonely.

“I became kind of quite erm, yeah sort of withdrawn from the world and I suppose a little bit sort of you know er paranoid, a bit of a funny take on everything, [...] I felt completely you know surrounded by a wall that I’d sort of created for myself and this then just got worse and continued for sort of many many years to come after that”

Luke, lines 49-56

Handling difficulties alone maintained the masculine identity of being in control, independent and powerful, however suffering was not averted by adopting strategies of avoidance and pretence. Men were torn by the conflict between voicing their own needs and upholding the expectations of what it means to be male.

“you just think you’re a bit pathetic, not what you should be, you should be able to take it all on the chin, should be like my Grandad, they probably went through all the same thing, but they didn’t go crying to the doctor did they, they just got on with it, so yeah your sense of self, you feel weaker than you should be”

Lee, lines 366-370

Some men conformed by hiding vulnerability and this became psychologically and emotionally overwhelming. The message men perceived as given to them was to continue with their life despite any difficulties or problems and that it is not appropriate for men to open up about their feelings. This left them trapped with a myriad of feelings associated with fear, shame and weakness.

"I tried to keep it hidden, like I was a million miles away, like it was a delusion that I need to still hold up good face and never look like I was failing, even if I was, like I'd never emotionally open up to people, which is still a barrier I'm trying to break down"

Michael, lines 64-66

"Probably a bit of the macho, you know, don't want to admit that I'm not being successful, because I find it hard to talk to people now that I knew when I was really successful [...] some people might think oh I'm still ultra successful [...] on Facebook I don't post stuff that's negative, it's always upbeat, it's funny, it's chirpy, it's, you know I don't post negative stuff or I don't post when I'm feeling crap, so people think that I'm doing really well er so I don't really want to say to them 'well to be honest, I'm not doing that great, er so it's a bit of a deception really, but I don't want to bring other people down by talking about it"

Gareth, lines 547-555

Men showed great value in preserving employment, learning new skills, completing educational courses or providing for others as these were shown to be important to the masculine identity. Success, achievement and knowledge promoted a man's strength. Admitting to changes in functioning such as being unsuccessful at work, or unable to achieve everyday tasks may result in men adopting a position of failure. When the strategy of hiding their internal struggle was no longer successful, men were left destroyed, lost or broken.

2.4.1.2 Struggling to find a fix: Trapped in a medical understanding

This subordinate theme illustrates how these men entered a medical approach in order to gain help, with the hope of being 'fixed'. Internal difficulties were medicalised and given the medical label of BD. Their battle continued as the solutions offered did not allow them to return to their previous self.

Men may go to extreme lengths to deny their struggle, avoid verbally opening up and seeking support. Self-harm or attempted suicide was a way of communicating the

need for help when men felt completely crushed and felt they had no other options left.

"I'd attempted, er attempted suicide sounds quite, sounds overly dramatic in a sense coz I have friends who have attempted and succeeded in suicide and that seems much more of a commitment if you like, the way that they did it, than I did which was just by taking too many paracetamols type thing so I suppose mine was probably more a cry for help in a sense but erm so yeah, [...] because I just didn't know what to do and was at my wits end"

Luke, lines 81-86

When men did find the courage to be open about their problems with professionals, friends or family, the potential losses associated with help-seeking were overwhelming both internally and externally. The stigma surrounding mental health problems meant that men reluctantly entered into a medical understanding, not out of choice but as there was no other option left.

"I was like 'this isn't me, I know this isn't me' so I decided to go and see a doctor, I knew I was quite depressed but you know until that point, I mean five years ago it was a lot of stigma around and I was really cautious coz I'd got a job for a great company you know and I was worried about losing my job, losing my friends, you know, everything and so there was a lot riding on it"

David, lines 113-117

"he [psychiatrist] actually said do you want me to diagnose you, coz that's it, you've got that for life then, and I just said to him, if that's what I've got, if that's what I need to get the help I need, then yes, but I can see what he meant, you know it is quite a big thing"

Lee, lines 83-86

For some men it was more acceptable to discuss their diagnosis with female friends, family or professionals than other men. Talking about their internal processes and emotions with women made these men feel less vulnerable.

“it’s me being a bloke it’s, coz it’s about men isn’t it, it’s not easy to talk about it or admit it or admit that you know, you’ve got this [BD] because, most of my friends are female, I’ve a few male friends and we even talk about this even less, there’s only one male friend that I’ll talk about this sort of thing to, it’s very hard to, for blokes to talk at that sort of level, whereas I find it easier to talk to my female friends about this sort of thing, so I’d imagine if a man’s got a lot of close male friends, it, it would be a, a lot harder to talk about this”

Gareth, lines 533-538

Having entered into the medical model of understanding illness, men were advised that BD was treated with prescribed medication. Men varied in their openness to trying and taking medication, however most were either encouraged with or administered medication at points throughout their lives. Doubt ensued for most men who tried various medications and their combinations with little impact on feeling better. Even when a medication appeared to work for a number of years, this would become less helpful over time. Men’s deteriorating ability to manage everyday functioning pushed them further away from the person they were trying so hard not to lose.

“my psychiatrists always say, psychology won’t can’t do anything, it’s medication based, you’ve got a biological problem, so no amount of psychology is going to make it any better”

Luke, lines 345-346

“I didn’t really want to go on medication (laughs) erm because they’re powerful drugs and I didn’t want to really change myself too much but er but a lovely doctor, the lady, she kind of talked to me about the benefits of what it was and so I decided to trust her and she obviously knows more about it than I do, so we decided to start taking the medication which was awful to be honest, I went on to quetiapine and sodium valproate, I Seroquel it was called and that just sent me completely and utterly depressed, I took it for six months and I ended up in hospital after I’d taken too many, erm after a suicide attempt”

David, lines 144-151

"I'm pretty sure they put me on, [...] quite a few different anti-depressants and a lot of them didn't work and a lot of them made me a lot worse [...] in some ways that was the worst period of my life, [...] my brain was so cloudy that I went to make a cup of tea and I thought okay a cup of tea, there's my mug, mug, what do I need, oh I need tea bag, tea bag, tea bag needs to go into the mug, okay now what, oh, hot water, it was a real struggle to make a cup of tea, a simple process, step by step process and that really upset me because I went from You know speaking in front of hundreds of people, being really successful to struggling to make a cup of tea and that really sent me downhill because I just thought 'what's the point now' you know my life's pretty much, I can't make a bloody cup of tea now, erm and I did thinkI did get worse and just feel like ending it then"

Gareth, lines 234-244

A sense of powerlessness and helplessness approached as most men were trapped in a medical world without a solution. Some men questioned the validity of their diagnosis due to the medication not working. Other men questioned whether life was worth continuing. The hope of returning to their previous sense of self was unfounded and some men were left feeling damaged, weak and unfixable.

2.4.1.3 "It wasn't just me then"

This subordinate theme captures how men re-connected with other people in society in order to establish hope, meaning and purpose in life. Some men overcame their battle and despite the stigma, became role-models for promoting the message that men can have BD and still be themselves. Their battle continued with re-educating the external world that it is ok for men to have a mental illness.

Normalising men's experiences by meeting other people with BD was shown to be of particular importance as there were opportunities for shared understanding and reduced feelings of isolation and loneliness. Men felt a sense of belonging and connection with others who had not only experienced the battles with professionals and rollercoaster of emotions, but also had similar, creative interests too.

“all on the same wavelength, so you didn’t have to explain anything, if you sort of, if you tried to describe something that erm immediately might sound you know to somebody else would sound ‘that’s a bit weird or that’s a bit paranoid’ or something like that then, they’d be going ‘yeah, god yeah I know exactly what you mean’ and it you immediately, you just, you knew, you’d just feel comfortable because yeah they, you could tell that they’d been going through exactly the same thing and also I think the fact that by, by you saying something other people say it agreeing, so you think, oh right, so it wasn’t just me then, there really was all this, you know, you’re not the only person who’s experienced this, you’re not the only, you’re not on your own”

Luke, lines 354-362

Further to this, most men developed more self-awareness and insight to appreciate their difficulties, through their own research, psychological interventions or a holistic approach to BD. Some men identified ways to regain a sense of power, strength and control which enabled them to re-build their identity. For many men a sense of purpose was achieved through employment, education or learning something new.

“when I was first diagnosed I didn’t know who I was or what I was doing or anything like that and I think building my own life up again has been a lot of fun [...], my identity is very strong now you know, I’ve found a place, having a mental health condition has kind of given me the ability to and want and need to find my place in the world”

David, lines 412-418

Some participants took on the role of an ambassador and actively promoted that it is acceptable to be open with other people about having BD. These men became mentors within their work places showing empathy and compassion to other people who were experiencing their own struggles with mental health. These participants were actively promoting the need for other people in society to understand and accept the person behind the diagnostic label, as opposed to responding to cultural stereotypes.

“at work I just er, obviously they knew, I had to tell them, well I didn’t have to I suppose but I told them erm and I decided to be quite open about it, rather than, and my boss boss said well you don’t have to do that you can just keep, and I said no I think it’s probably best I do, so not so much for me, it might actually hurt me in a way but you know, five years down the line and someone else is diagnosed or you know, it’s not gonna be such a problem for them, I think it’s kind of my duty to push it if you like, just to say right this has happened and the more that happens the better, I think there’s probably a few people at work who’ve gone, that don’t like it and like yeah I did notice a few people dropping off and not speaking to me anymore but sod ‘em they’re ignorant”

Lee, lines 337-344

“where I work they have never seen it as a stigma, I don’t think it’s ever sort of held me back, [...] in positions of authority in management and I was one of the chairs of one of the corporation groups [...] which is obviously a very big important deal that affected thousands of people [...] I don’t think they would have trusted me to do, to be in these positions if you know if I, if I couldn’t sort of be trusted if you like because at least you know, I’ve got mental health problems [...] so I quite liked being a bit of an ambassador in a sense for you know ‘it can be ok’ you’ve just got to kind of stick with it”

Luke, lines 438-445

Other men described the need for further education and awareness of BD within wider society in order to tackle the stigma that is associated with it. This included friends, family and professionals as well as the media. Most participants explored how generalisations and labels can be attributed to people with mental health problems without considering the individual nature of the person or the impact this may have on how men with BD are viewed or treated.

“it would just make life a bit better if there was more, I mean they spend all [...] this money on talking about cancer and all other things that are wrong with you, diabetes and you know all this other stuff, where’s the adverts on the telly, [...] where’s the posters saying that ‘Bob’s got this problem but you can’t see it’ and there’s Bob here and he looks fine but then have a picture of actually what’s going on inside his head and it’s just a tangled mess, more awareness, more effort from the NHS to push it, coz then I think more people would go actually ‘I’m not too good”

Lee, lines 484-491

Some men shifted from trying to fix themselves to promoting the need to fix the medical understanding. The diagnosis was shown to actively prevent people from fulfilling their hopes and dreams due to the expectations themselves and others placed on them. There was a need to challenge this generic view of treatment and to empower individuals with information that promoted that they could still continue to be someone despite a diagnosis.

"I think half the problem with having a mental health issue is that people are afraid then to try, they've already got something that you know is a stigma and people laugh at them for, you know if they go out and do, they play a game of football and let in 20 goals you know, how self-conscious are they going to feel then? And it's about sort of giving them that opportunity to fail and go 'what's it matter?' it doesn't matter what you know, it just matters what you feel, you're never going to see those people again"

David, lines 433-438

2.5 Discussion

2.5.1 Summary of findings

This study focused on exploring men's experiences of living with a diagnosis of BD. More specifically, it aimed to consider men's experiences of receiving a diagnosis, their experiences of any treatment or support and how men manage everyday life living with BD. One superordinate theme, *The Battle*, explored the ongoing conflicts men experienced internally and externally in relation to their journey of receiving a diagnosis and living with BD. Within this superordinate theme, three subordinate themes were identified: *"Take it all on the chin and suffer in silence"*, *Struggling to find a fix: Trapped in a medical understanding* and *"It wasn't just me then"*.

"Take it all on the chin and suffer in silence" captures men's experiences of withholding their internal emotions from other people in order to preserve male societal expectations. *"Struggling to find a fix: Trapped in a medical understanding"* explores men's experiences of either seeking help or having help imposed, their experiences of being given a diagnosis and subsequent medical treatment, specifically medication. *"It wasn't just me then"* highlights men's experiences of finding ways in which they re-connected with themselves and other people following their diagnosis, in order to continue with their life and combat societal stigma.

All three research questions (i.e. What are men's experiences of receiving a diagnosis of BD?; What are men's experiences of any treatment or support?; What are their experiences of managing everyday life living with BD?) are reflected within the above themes and will be explored further in relation to existing literature. *"Take it all on the chin and suffer in silence"* however, identifies the barriers men experienced in relation

to being able to admit or show that they were having difficulties and the way in which they avoided seeking help before ever receiving a diagnosis of BD.

2.5.2 Discussion of results in relation to the literature

Men within this study struggled to acknowledge their difficulties due to the stigma surrounding help-seeking and receiving a mental health diagnosis. Further to this, there was a need to conform to masculine stereotypes to prevent being perceived as weak. This is consistent with existing health literature where men are shown to delay help-seeking when they become ill (Galdas, Cheater & Marshall, 2005) and to avoid seeking help from health services (Sharp & Arnold, 1998). It has been identified that help-seeking is dictated by social norms, where only severe problems are sufficient to justify help (Richardson & Raibee, 2001). In line with the experiences of men in this study, barriers to help-seeking involve restricting the expression of negative emotion (Chan & Hayashi, 2010; Johnson, Oliffe, Kelly Galdas & Ogrodniczuk, 2012; Rochlen et al., 2010) and striving for independence and control (Coles et al., 2010; Johnson et al., 2012), as this is imperative to the masculine self-concept (Noone & Stephens, 2008; Yousaf, Grunfield & Hunter, 2015). The more strongly men endorse traditional masculinity norms, the less likely they are to have strong intentions to seek help as their attitudes towards help-seeking are increasingly negative (Smith, Tran & Thompson, 2008). Emotions of embarrassment, fear, anxiety and distress have been related to using health care services, where men have expressed feelings of weakness surrounding the vulnerable position of asking for help with their health (Yousaf, Grunfield & Hunter, 2015). Confiding in a General Practitioner (GP) has been avoided by men due to heightened feelings of vulnerability as well as issues with

communication (Richardson & Raibee, 2001). Tasks associated with help-seeking, such as opening up and relying on other people, are in conflict with the ideals of being masculine, which involve self-reliance and being physically tough (Addis & Mahalik, 2003). In contrast to this, however, a qualitative study of men's experiences with depression identified how actively seeking help for an illness that made men vulnerable in the eyes of masculine norms, enabled men to retain control, be strong and regain independence (Hernandez, Han, Oliffe & Ogrodniczuk, 2014). Therefore, help-seeking was re-defined as being part of the masculine identity enabling empowerment, as opposed to being viewed as a weakness.

The fear of receiving a diagnosis of BD for men within this study was due to the perceived and actual losses it would evoke in relation to their sense of self and their expectations for life. This is highlighted in other studies focusing on BD where struggles with identity, loss or absence of self, loss of control and loss within an individual's social world have been identified (Russell & Moss, 2013). Further to this, grief can be experienced surrounding the expectations or aspirations for how an individual's life could have been, and the new, limited expectations for a future life with a severe mental health diagnosis (Inder et al., 2011). As with the men in this study, stigma has been reported in previous literature involving family members, close friends, the general community and some health professionals (Proudfoot et al., 2009). Stigma may be portrayed in different ways, often involving: negative stereotyping, labelling, distinguishing between 'us' and 'them', loss of status, discrimination and inequalities (Link & Phelan, 2001). More specifically, stigma-related treatment barriers include the impact on applying for jobs, being perceived as 'weak' or 'crazy', the impact on employment and feeling embarrassed or ashamed

(Dockery et al., 2015). Some individuals accept the stigmatising views others hold of mental illness as a form of self-stigma, which impacts on their hope for the future and self-esteem (Lysaker et al., 2007), and may further prevent accessing services for support with social inclusion and recovery (Corrigan et al., 2009).

Men within this study were under the impression that once they had overcome the stigma of requiring medical support, a solution would be provided for their difficulties.

This highlights the traditional biomedical model of illness where patients are predominantly given medicinal treatment in order to recover from a biologically determined illness (Pilgrim, 2008). Within this paradigm, patients may either recover from their symptoms, become treatment resistant or be non-adherent to the treatment regime. However, not all men within this study found that medical treatment enabled them to continue with their lives. With varying views on what recovery from a mental health illness entails (Storm & Edwards, 2013), recovery models emphasise health, strengths and wellness, as opposed to focusing solely on pathology, illness and symptoms, which are predominant in the medical model (Davidson, 2005; Shepherd, Boardman & Slade, 2008). Davidson and Roe (2007) distinguish between 'recovery from' a mental illness and 'recovery in' mental illness. Recovery from an illness alludes to the amelioration of symptoms to a satisfactory level in order to allow daily functioning within personal, social and vocational activities. Recovery in an illness involves pursuing personal hopes and aspirations with dignity and independence, in spite of ongoing illness and the possibility of relapse. Further to this however is a third position in which recovery has been viewed as a consumer movement where emphasis is placed on social inclusion and participation within the community (Storm & Edwards, 2013). In this position, patients are 'experts

by experience', survivors of the psychiatric system and may reject professional views of recovery or potentially view professionals as part of the problem (Pilgrim, 2008). For men within this study, recovery was viewed as a very individual process. The concept of personal recovery has been explored in BD where factors such as hope, respect, self-directed empowerment and having a meaningful role were seen as being part of the later stages of the process of recovery (Tse et al., 2014). Recovery does not mean being symptom free, but requires an element of taking responsibility for being well, involves self-management techniques and overcoming negativity, taboo and stigma (Todd et al., 2012). A valid understanding of recovery must be based on lived experience (Slade et al., 2012), from which a number of recovery processes have been identified as being important: connectedness, hope and optimism about the future, identity and meaning in life (CHIME) (Leamy et al., 2011). Recovery is considered an active, individual and unique process. Self-acceptance and adjustment of expectations (Inder et al., 2011), staying well strategies involving education, recognising triggers and early warning signs (Russell & Browne, 2005), and self-care strategies including relaxation and setting limits (Veseth et al., 2014) have been highlighted as useful strategies for recovery for people with BD. The self-management of chronic health conditions involves increasing knowledge, understanding of and further information about an illness (Gray, 2004) in order to promote choices, agency and autonomy (Borg and Davidson, 2008; Davidson, 2003). Traditional medical approaches in which a patient is prescribed medication from a doctor and expected to attend clinic appointments, does not always allow space for processing and understanding the difficulties surrounding receiving a diagnosis (Pollack & Aponte, 2001). Further to this, men's experiences of medication within this study were mainly negative. The common

disadvantage of taking mood stabilisers, antidepressants or antipsychotic medication is the unwanted side effects experienced, and the associated negative implications on physical health (DCP, 2010). There is debate over the use of medication for mental illness. The disease-centred model of modern drugs for specific disorders relies on a biological cause which has never been firmly established (Moncrieff, 2007). In addition to this, mood stabilisers such as Lithium have been considered toxic substances that cause effect through sedation rather than being specific to the particular disease of Bipolar Disorder (Moncrieff, 1997). The historical influence of the pharmaceutical industry in promoting a bio-medical approach to mental distress, has fuelled the way in which medical treatment has been compromised (Moncrieff, 2007; Mosher, Gosden & Beder, 2004), resulting in a limited focus on psychological and social factors or an individualised approach to care.

2.5.3 Clinical Implications

There are a number of implications for health care services and individual professionals to consider. Firstly, it is important to consider the engagement of males with BD in help-seeking behaviours, as delays in treatment are associated with an increased risk of substance misuse (Lagerberg et al., 2010) and suicide attempts (Nery-Fernandes et al., 2012). This includes the need to educate and promote awareness of the stigma associated with male help-seeking and mental health, not only for primary and secondary care services, but also wider society, particularly within the workplace. Secondly, clinicians need to manage the expectations of treatment, where within the medical model there is a tendency to focus on alleviating or fixing symptoms using medication. Interventions alongside medication need to be considered in order for a

deeper understanding of what a diagnosis of BD actually means to a patient. Utilising models of recovery which not only incorporate patient participation, patient-centeredness and shared-decision making within treatment decisions, but also attend to a person's needs, strengths, hopes, relationships and social integration within the community, as suggested by Storm and Edwards (2013), are needed. Psychiatric treatments, medication side effects and other interventions should be considered within the context of an individual's life goals and used as tools towards personal recovery. Individualising care for chronic illness involves increasing control within the patient by informing them of the evidence of their condition, allowing them to reflect on options in relation to the values they attribute to potential benefit or harm, and individualising the consultation according to the specific patient (Gray, 2004). It would be useful for services and professionals to be aware of the difficulties some men had with communicating to a male GP, therefore it would be important for services to advocate a choice of clinician to patients where possible.

2.5.4 Limitations and Further Research

A number of limitations have been identified within the current study. Participants were included if they were male with a diagnosis of either Bipolar I Disorder or Bipolar II Disorder to ensure an adequate sample size, however this has meant that the sample was not as homogenous as it could have been. Further research could allow for a more homogenous sample by focusing on either Bipolar I Disorder or Bipolar II Disorder. Participants also varied in the time since their diagnosis. Some men had been diagnosed over ten years ago, whereas others had been diagnosed within the last two years; this could have influenced the themes that emerged. Further research

should focus more specifically on certain stages since diagnosis, for example, recently diagnosed (within the last year) or diagnosed over five to ten years ago, to highlight whether there are differences in experiences of living with BD. Due to the nature of IPA focussing on lived experience, there is a need to keep in mind the contribution that is made in how this is perceived and interpreted by the researcher. Although measures have been taken in order to ensure this has been considered, the influence of the researcher on qualitative research cannot be taken for granted.

2.6 Conclusion

The aim of this qualitative study was to explore the lived experiences of men with a diagnosis of BD, including their experiences of treatment and managing everyday life. The struggles men encountered internally and externally in relation to the stigma surrounding help-seeking, receiving a mental health diagnosis, conforming to masculine stereotypes and expectations of medical treatment were identified. This study highlights how re-connecting with society and continuing with a meaningful life after diagnosis were seen as important parts of living with BD. Further to this, there is a need to listen and validate men's everyday experiences of BD in order to offer an individualised, collaborative approach to any treatment and support.

2.7 References

Abreu, L.N., Lafer, B., Baca-Garcia, E, & Oquendo, M.A. (2009) Suicidal Ideation and suicide attempts in Bipolar Disorder type I: an update for the clinician. *Revista Brasileira de Psiquiatria*, Vol. 31(3) p271-80.

Addis, M. E. and Mahalik, J. R. (2003) Men, masculinity, and the contexts of help seeking. *American Psychologist*, Vol. 58, p5-14.

Ahern, K. J. (1999) Ten tips for Reflexive Bracketing. *Qualitative Health Research*, Vol. 9(3), p407-411.

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*. American Psychiatric Publishing.

Azorin, J., Belzeaux, R., Kaladjian, A., Adida, M., Hantouche, E., Lancrenon, S & Fakra, E. (2013) Risks associated with gender differences in bipolar I disorder. *Journal of Affective Disorders*, Vol. 151, p1033-1040.

Barlow, J., Wright, C., Sheasby, J., Turner, A. & Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, Vol. 48, p177-187.

Barraco, A., Rosso, A. & Nicolo, G. (2010) Description of Study Population and Analysis of Factors Influencing Adherence in the Observational Italian Study "Evaluation of Pharmacotherapy Adherence in Bipolar Disorder" (EPHAR). *CNS Neuroscience & Therapeutics*, Vol. 18, p110-118.

Berger, P. and Luckmann, T. (1966) *The Social Construction of Reality: A treatise in the sociology of knowledge*. New York: Doubleday.

Biggerstaff, D. and Thompson, A. R. (2008) Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, Vol. 5(3), p214-224.

Borg, M. and Davidson, L. (2008) The nature of recovery as lived in everyday experience. *Journal of Mental Health*, Vol. 17, p129-140.

British Psychological Society. (2010). *Code of Human Research Ethics*. Leicester: British Psychological Society.

Brownhill, S., Wilhelm, K., Barclay, L., & Schmied, V. (2005) "Big build": Hidden depression in men. *Australian and New Zealand Journal of Psychiatry*, Vol. 39(10), p921–931.

Chan, R. K. H., and Hayashi, K. (2010) Gender roles and help-seeking behaviour: Promoting professional help among Japanese men. *Journal of Social Work*, Vol. 10(3), p243-262.

Chapman, J. R. (2002) *Bipolar Disorder: Responding to challenges with Identity*. Unpublished PhD dissertation, University of Texas, USA.

Chuck, C. D., Greenfeld, J. M., Greenberg, S. T., Shepard, S., Cochran, S. V. & Haley, J. T. (2009) A Qualitative Investigation of Depression in Men. *Psychology of Men and Masculinity*, Vol. 10(4), p302-313.

Coles, R., Watkins, F., Swami, V., Jones, S., Woolf, S. & Stanistreet, D. (2010) What men really want: A qualitative investigation of men's health needs from the Halton and St Helens Primary Care Trust men's health promotion project. *British Journal of Health Psychology*, Vol. 15(4), p921-939.

Corrigan, P., Larson, J. & Rusch, N. (2009) Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry*, Vol. 8(2), p75–81.

Crowe, M., Inder, M., Carlyle, D., Wilson, L., Whitehead, L., Panckhurst, A., O'Brien, A. & Joyce, P. (2012) Feeling out of Control: A Qualitative Analysis of the Impact of Bipolar Disorder. *Journal of Psychiatric and Mental Health Nursing*, Vol. 19, p294-302.

Davidson, L. (2003) *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York University Press.

Davidson, L. (2005) Recovery, self management and the expert patient: Changing the culture of mental health from a UK perspective. *Journal of Mental Health*, Vol. 14(1), p25–35.

Davidson, L. and Roe, D. (2007) Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *Journal of Mental Health*, Vol. 16(4), 459-470.

Davidson, L., O'Connell, M. J., Tondora, J., Lawless, M. & Evans, A. C. (2005) Recovery in serious mental illness: A new wine or just a new bottle? *Professional Psychology-Research and Practice* Vol. 36(5), p480–487.

Division of Clinical Psychology (2010) *Understanding Bipolar Disorder: Why some people experience extreme mood states and what can help*. Leicester: The British Psychological Society

Dockery, L., Jeffery, D., Schauman, O., Williams, P., Farrelly, S., Bonnington, O., Gabbidon, J., Lassman, F., Szmukler, G., Thornicroft, G. & Clement, S. (2015) Stigma and non-stigma-related treatment barriers to mental healthcare reported by service users and caregivers. *Psychiatry Research*, Vol. 228, p612-619.

Donaldson L. (2003) Expert patients usher in a new era of opportunity for the NHS. *British Medical Journal*, Vol. 326, p1279-80.

Duncan, E., Best, C. & Hagen, S. (2010) Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews*,

Issue 1.

Fountoulakis, K.N., Kasper, S., Andreassen, O., Blier, P., Okasha, A., Severus, E., Versiani, M., Tandon, R., Moller, H.J. & Vieta, E., (2012) Efficacy of pharmacotherapy in bipolar disorder: a report by the WPA section on pharmacopsychiatry. *European Archives of Psychiatry and Clinical Neuroscience*, Vol. 262(1), p1-48.

Galdas, P. M., Cheater, F. & Marshall, P. (2005) Men and health help-seeking behaviour: literature review. *Journal of Advanced Nursing*, Vol. 49(6), p616-623.

Gergen, K. (1999) *An invitation to social construction*. London: Sage

Gray, J. A. (2004) Self Management in chronic illness. *The Lancet*, Vol. 364, p1467-1468.

Harris, R. (2009) *ACT made simple*. Oakland: New Harbinger Publications.

Hernandez, C.A, Han, C., Oliffe, J. L. & Ogrodniczuk, J.S. (2014) Understanding help-seeking among depressed men. *Psychology of Men & Masculinity*, Vol. 15(3), p346-354.

Inder, M. L., Crowe, M. T., Moor, S., Luty, S. E., Carter, J. D. & Joyce, P. R. (2008) "I Actually Don't Know Who I Am": The Impact of Bipolar Disorder on the Development of Self. *Psychiatry*, Vol. 71(2), p123-133.

Inder, M. L., Crowe, M. T., Joyce, P. R., Moor, S., Carter, J. D. & Luty, S. E. (2010) "I Really Don't Know Whether it is Still There": Ambivalent Acceptance of a Diagnosis of Bipolar Disorder. *Psychiatric Quarterly*, Vol. 81(2), p157-165.

Inder, M. L., Crowe, M. T., Moor, S., Carter, J. D., Luty, S. E. & Joyce, P.R. (2011) 'It wouldn't be me if I didn't have bipolar disorder': managing the shift in self-identity with bipolar disorder. *Journal of Nursing and Healthcare of Chronic Illness*, Vol. 3(4), p427-435.

Jeffries, M. and Grogan, S. (2012) 'Oh, I'm just, you know a little bit weak because I'm going to the doctor's': young men's talk of self-referral to primary healthcare services. *Psychology & Health*, Vol. 27(8), p898-915.

Johnson, J. L., Oliffe, J. L., Kelly, M. T., Galdas, P., & Ogrodniczuk, J. S. (2012) Men's discourses of help-seeking in the context of men's depression. *Sociology of Health & Illness*, Vol. 34(3), p345-361.

Jones, S. (2004) Psychotherapy of Bipolar Disorder: A review. *Journal of Affective Disorders*, Vol. 80, p101-114.

Jonsson, P. D., Wijk, H., Skarsater, I & Danielson, E. (2008) Persons living with Bipolar Disorder – their view of the illness and the future. *Issues in Mental Health Nursing*, Vol. 29, p1217–1236.

Kings Fund (2014) *People in control of their own health and care. The state of involvement*. London: The Kings Fund.

Lagerberg, T.V., Larsson, S., Sundet, K., Hansen, C.B., Hellvin, T., Andreassen, O.A. & Melle, I., (2010) Treatment delay and excessive substance use in bipolar disorder. *Journal of Nervous and Mental Disease*, Vol. 198(9), p628–633.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011) Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, Vol. 99, p445-452.

Link, B. G. and Phelan, J. C. (2001) Conceptualising Stigma. *Annual Review of Sociology*, Vol. 27, p363-85.

Lorig, K. (1993) Self management of chronic illness: A model for the future. *Generations*. Vol. 17(3), p11-14.

Lysaker, P.H., Roe, D. & Yanos, P.T., (2007) Toward understanding the insight paradox: internalized stigma moderates the association between insight and social functioning, hope, and self-esteem among people with schizophrenia spectrum

disorders. *Schizophrenia Bulletin*, Vol. 33(1), p192–199.

Mansell, W., Powell, S., Pedley, R., Thomas, N. & Jones, S.A. (2010) The Process of Recovery from Bipolar 1 disorder: A qualitative analysis of personal accounts in relation to an integrative cognitive model. *British Journal of Clinical Psychology*. Vol. 49, p193-215.

Mays, N. and Pope, C. (2000) Assessing quality in qualitative research. *British Medical Journal*, Vol. 320, p 50-52.

Michalak, E.E., Yatham, L. N., Kolesar, S. & Lam, R. W. (2006) Bipolar Disorder & Quality of Life: A patient centred perspective. *Quality of Life Research*, Vol. 15, p 25-37.

Michalak, E., Livingstone, J. D., Hole, R., Suto, M., Hale, S. & Haddock, C. (2011) It's something that I manage but it's not who I am. *Chronic Illness*, Vol. 7(3), p209-224.

Moncrieff, J. (1997) Lithium reconsidered. *British Journal of Psychiatry*, Vol. 171, p113–119.

Moncrieff, J. (2007) Diagnosis and drug treatment. *The Psychologist*, Vol. 20(5), p296-297.

Mosher, L. R., Gosden, R. & Beder, S. (2004) 'Drug companies and schizophrenia' in J. Read, L. R. Mosher & R. P. Bentall. (Ed.) *Models of Madness* (pp.115-130). East Sussex: Routledge.

Nery-Fernandes, F., Quarantini, L.C., Guimaraes, J.L., de Oliveira, I.R., Koenen, K.C., Kapczinski, F. & Miranda-Scippa, A. (2012) Is there an association between suicide attempt and delay of initiation of mood stabilizers in bipolar I disorder? *Journal of Affective Disorders*, Vol. 136(3), p1082–1087.

NICE (2006) *Bipolar disorder. The management of bipolar disorder in adults, children and adolescents, in primary and secondary care. clinical guideline 38*. London: NICE.

NICE (2014) *Bipolar disorder: Assessment and Management. clinical guideline 185*. London: NICE.

NICE (2015) *Patient experience in adult NHS services overview. NICE Pathway*. London: NICE.

Nivoli, A. M. A., Pacchiarotti, I., Rosa, A. R., Popovic, D., Murru, A., Valenti, M., Bonnin, C. M., Grande, I., Sanchez-Moreno, J., Vieta, E. & Colom, F. (2011) Gender Differences in a cohort of 604 bipolar patients: The role of predominant polarity. *Journal of Affective Disorders*, Vol. 133, p443-449.

Noone, J. H. and Stephens, C. (2008) Men, masculine identities and health care utilisation. *Sociology of Health & Illness*, Vol. 30(5), p711-725.

Oliver, M.I., Pearson, N., Coe, N., & Gunnell, D. (2005) Help-seeking behaviour in men and women with common mental health problems: Cross sectional study. *British Journal of Psychiatry*, Vol. 186(4), p297-301.

Pilgrim, D. (2008) 'Recovery' and current mental health policy. *Chronic illness*, Vol. 4, p295-304.

Pollack, L. E, and Aponte, M. (2001) Patients' perceptions of their bipolar illness in a public hospital setting. *Psychiatric Quarterly*, Vol. 72, p167-179.

Proudfoot, J., Parker, G. B., Benoit, M., Manicavasagar, V., Smith, M. & Gayed, A. (2009) What happens after diagnosis? Understanding the experiences of patients with newly-diagnosed bipolar disorder. *Health Expectations*. Vol. 12, p120-129.

Read, J., Mosher, L. R. & Bentall, R. P. (2004) *Models of Madness*. East Sussex: Routledge.

Reinares, M., Sanchez-Moreno, J. & Fountoulakis, K. N. (2013) Psychosocial interventions in bipolar disorder: what, for whom and when. *Journal of Affective Disorders*, Vol. 156, p46-55.

Richardson, C. A. and Rabiee, F. (2001) A question of access: an exploration of the factors that influence the health of young males aged 15 to 19 living in Corby and their use of health care services. *Health Education Journal*, Vol. 60(1), p3-16.

Rochlen, A. B., Paterniti, D. A., Epstein, R. M., Duberstein, P., Willeford, L. & Kravitz, R. L. (2010) Barriers in diagnosing and treating men with depression: A focus group report. *American Journal of Men's Health*, Vol. 4(2), p167-175.

Rusner, M., Carlsson, G., Brunt, D. & Nystrom, M. (2009) Extra dimensions in all aspects of life meaning of life with bipolar. *International Journal of Qualitative Studies on Health and Well-being*, Vol. 4, p159-169.

Russell, S. J. and Browne, J. L. (2005) Staying well with bipolar disorder. *Australian and New Zealand Journal of Psychiatry*, Vol. 39, p187-193.

Russell, L. and Moss, D. (2013) A meta-study of qualitative research into the experiences of 'symptoms' and 'having a diagnosis' for people who have been given a diagnosis of bipolar disorder. *Europe's Journal of Psychology*, Vol. 9(3), p643-663.

Schon, U. (2010) Recovery from severe mental illness, a gender perspective. *Scandinavian Journal of Caring Studies*, Vol. 24, p557-564.

Scott, J., Colom, F & Vieta, E. (2007) A meta-analysis of relapse rates with adjunctive psychological therapies compared to usual psychiatric treatment for bipolar disorders. *International Journal of Neuropsychopharmacology*, Vol. 10(1), p123-129.

Sharpe, S. and Arnold, S. (1998) *Men, Lifestyle and Health: A Study of Health Beliefs and Practices*. Unpublished Research Report no. R000221950, ESRC, Swindon, UK.

Shepherd, G., Boardman, J. & Slade, M. (2008) *Making Recovery a Reality*. London, Sainsbury Centre for Mental Health.

Simon, G.E., Hunkeler, E., Fireman, B., Lee, J. Y. & Savarino, J. (2007) Risk of suicide attempt and suicide death in patients treated for bipolar disorder. *Bipolar Disorders*, Vol. 9, p526–530.

Slade, M., Williams, J., Bird, V., Leamy, M & Le Boutillier, C. (2012) Recovery grows up, *Journal of Mental Health*, Vol. 21(2), p99-104.

Smith, J. A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory Method and Research*. London: SAGE Publications Ltd.

Smith, J. A. (2003) *Qualitative Psychology: A practical guide to research methods*. London: SAGE Publications Ltd.

Smith, J. P., Tran, G. Q. & Thompson, R. D. (2008) Can the theory of planned behaviour help explain men's psychological help-seeking? Evidence for a mediation effect and clinical implications. *Psychology of Men and Masculinity*, Vol. 9(3), p179-192.

Storm, M. and Edwards, A. (2013) Models of User Involvement in the Mental Health Context: Intentions and Implementation Challenges. *Psychiatric Quarterly*, Vol. 84, p313-327.

Todd, N. J., Jones, S. H. & Lobban, F. A. (2012) "Recovery" in bipolar disorder: How can service users be supported through a self-management intervention? A qualitative focus group study. *Journal of Mental Health*, Vol. 21(2), p114-126.

Tse, S., Murray, G., Chung, K. F, Davidson, L., Ng, K.L & Yu CH. (2014) Exploring the recovery concept in bipolar disorder: a decision tree analysis of psychosocial correlates of recovery stages. *Bipolar Disorder*, Vol. 16(4), p366–377.

Veseth, M., Binder, P., Borg, M. & Davidson, L. (2012) Toward Caring for Oneself in a Life of Intense Ups and Downs: A Reflexive-Collaborative Exploration of Recovery in Bipolar Disorder. *Qualitative Health Research*. Vol. 22(1) p119-133.

Vieta, E., Langosch, J. N., Figueira, M. L., Souery, D., Blasco-Colmenares, E., Medina, E., Moreno-Manzanaro, M., Gonzalez M. A., & Bellivier, F. (2013) Clinical management and burden of bipolar disorder: results from a multinational longitudinal study (WAVE-Bipolar Disorder). *International Journal of Neuropsychopharmacology*. Vol. 16(8), p1719-1732.

Weismann, M. W., Bland, R. C., Canino, G. J., Faravelli, C., Greenwald, S., Hwu, H., Joyce, P.R., Karam, E.G., Lee, C., Lellouch, J., Lepine, J., Newman, S.C., Rubio-Stipec, M., Wells, J.E., Wickramaratne, P.J., Wittchen, H. & Yeh, E. (1996) Cross-national epidemiology of major depression and bipolar disorder. *Journal of the American Medical Association*, Vol. 276(4), p293-9.

Wilken, J. P. (2007) Understanding recovery from psychosis. A growing body of knowledge. *Tidsskrift for Norsk Psykologforening*, Vol. 44(5), p658–666.

Yardley, L. (2000) Dilemmas in qualitative health research. *Psychology & Health*, Vol. 15, p215-228.

Yousaf, O., Grunfield, E. A. & Hunter, M. S. (2015) A systematic review of the factors associated with delays in medical and psychological help-seeking among men. *Health Psychology Review*, Vol. 9(2), p264-276.

CHAPTER 3: Reflective Paper

The experience of the research process

Word count: 3563 (Exclusive of references)

3.1 Introduction

This chapter will focus on my own personal reflections of the research process. As both of the previous papers have focused on experiences of a diagnosis, this paper will continue with an emphasis of my own experiences of conducting research. Firstly, the relevant core competencies of being a Clinical Psychologist will be provided as well as a definition of reflection. Secondly, two theoretical models will be introduced in order to provide a framework from which to formulate the journey through this research project. Specific experiences will be identified and reflected upon which have been personally significant to me within the development of this research.

3.1.1 Core Competencies and Reflective Practice

As a part of training to become a Clinical Psychologist, a number of core competencies are expected to be developed in order to fulfil the Clinical Psychologist role and complete training (BPS, 2010). Both therapeutic and research skills are of high value to the role, enabling Clinical Psychologists to work as reflective scientist practitioners. Therefore, reflection is considered to be of particular importance in order to improve practice and develop both personally and professionally. While there is no definitive way for Clinical Psychologists to incorporate reflective practice into their role (Fisher, Chew & Leow, 2015), the model of reflection proposed by Schon (1983) may be utilised in order to incorporate reflection in the moment as well as reflection retrospectively. Within this model, reflection involves identifying emotions and cognitions in the moment, in order to identify what to do next and also involves reflection after an event has taken place (Youngson, 2009). In addition to this,

reflective practice may enable Clinical Psychologists to reflect upon their impact on others and the relationship between the self and the work being conducted (Lavender, 2003). An awareness of these aspects of reflective practice have been utilised when conducting this research project.

3.1.2 Attachment Theory and Acceptance & Commitment Therapy (ACT)

In order to add depth and psychological understanding to my reflections, Attachment Theory (Bowlby, 1973) and ACT (Harris, 2009) will be utilised at points throughout this reflective paper. These approaches were chosen as they were the therapy models used to formulate my psychological work on placement at the time of conducting and writing up this thesis. It therefore seemed relevant to use these approaches as they influenced the way in which I reflected on and made sense of different parts of the research process. A brief overview of these approaches are provided below.

Attachment theory was originally proposed as an evolutionary theory in which infants are biologically predisposed to develop relationships in order for survival (Bowlby, 1973). This has been applied more widely to relationships between adults (Hazan & Shaver, 1990) and applied by professionals in health care settings in response to illness (Pietromonaco, Schetter & Uchino, 2013). When a threat or danger is encountered, a feeling of vulnerability is evoked and people seek out someone who is strong and protective in order to survive (Howe, 2011). Attachment or care seeking behaviours are exhibited in order to elicit a care giving response from another person. This emotional bond and protection between people allows safety and security from which exploratory learning and social interaction can take place. In this way, when adults are

presented with a threat of illness, they may display care seeking behaviours in order to get their needs of care, support, and protection met.

The foundations of ACT are based on relational frame theory and functional contextualism, where events are understood in a particular context due to the meanings that are ascribed to them (Harris, 2009). ACT focuses on how people can move towards living a rich and meaningful life whilst accepting the pain that may inevitably accompany this (Harris, 2009). ACT involves a focus on underlying values in order to promote action. By increasing awareness of their behaviour, people are able to notice the function of their behaviour in context and the impact on their quality of life. There are six core therapeutic processes within ACT: values, committed action, observing self, cognitive defusion, experiential acceptance and contact with the present moment. These are linked together through the concept of psychological flexibility. This involves the ability to live in the present moment, be open to experiences and do what matters by basing actions on values. It is assumed within ACT that people can still find meaning and purpose in life despite their pain and suffering. Individuals may experience suffering when they are fused with their thoughts, are experientially avoidant, lack clarity or contact with their values, stuck in unworkable action and attached to the conceptualised self. Metaphors are often used to help give understanding to an individual's difficulties (Hayes et al., 1999). For example, values may be compared to a compass which offers you direction and keeps you on track when traveling (Harris, 2009).

3.2 The Beginning – Finding a safe base

Deciding on a topic for my research proposal was a difficult task as there were a number of areas I was interested in. Prior to Clinical Psychology training I had worked as an Assistant Psychologist and within this role, co-facilitated an information and support group for people with Bipolar Disorder (BD). This experience fuelled my interest in considering the role and impact of a diagnosis, the influence of life events and where I learnt about the importance of the service user voice within patient-centred care (DCP, 2010). I had been emotionally touched by some of the stories I had heard from individuals within the group about their experiences of receiving a diagnosis and their subsequent difficulties with treatment and support. With a growing sense of pressure to decide on a topic for my research project due to University deadlines, I returned to a service in which I had previously worked, in order to discuss my ideas with previous supervisors and colleagues. I started my research journey by connecting with a service and team in which I felt comfortable and safe. Supporting people with BD and Psychosis was something I was familiar with and I had witnessed the struggles individuals had been exposed to in their search to understand and manage their lives with a mental health diagnosis. I wanted to understand more about the lives of people who were receiving a diagnosis of BD and the ways in which this could be improved. I wanted to give people the opportunity to share their stories and experiences. This therefore led me to a qualitative research project focusing on the lived experiences of service users. Through further discussion and clarification with research tutors at University, the methodological approach of interpretative phenomenological analysis (IPA) was decided upon. On reflection, I can see how my previous experiences of working within the Information and Support group for people

with BD led me to draw on my own values of compassion and determination to help those in need of care. Further to this, I knew I wanted to recruit my participants from the National Health Service (NHS) to gain the lived experiences of those people who had used mental health services, despite the barriers of a lengthy ethical approval process and the narrow pool of available participants. The relief and excitement on receiving a confirmation email which allowed me to start recruiting and interviewing participants is a memory that I hold very clearly.

3.3 The Middle – A stormy sea

Conducting the research interviews, transcribing the audio-recordings and analysing the transcripts was incredibly emotive for me. I was moved by how open men were about their experiences within their interviews and how they had overcome such struggles and difficulties. I was aware of the emotions accompanying men's experiences and how at times this pulled me into my role of practitioner. I wanted to offer care, support and protection, especially when some men appeared so hopeless and stuck. At these times, I tried to become aware of what I was noticing and reminded myself of my role as a researcher, rather than intervening with empathy and advice. With discussions involving current self-harm and suicidal ideation, I found that the researcher and practitioner roles overlapped. I was open with participants about the course of action I would pursue in order to ensure their safety. It felt surprisingly difficult for me to discuss self-harm and suicide with participants without being aware of the care team that would be available to support them. In my own clinical practice, I would be able to rely on a team approach, when needed, to support someone in distress. On reflection, I felt that someone had opened up about something extremely

distressing and that I was potentially abandoning someone in need. I was also fused with thoughts around whether I had said and done enough for this person. With more distance from this experience, it has allowed me to understand the differences between my role as a researcher and my role as a practitioner. In my role as researcher, men were not expecting a therapy session and had made an informed choice about participating in a research interview of which they were fully aware of the topic.

When transcribing interviews and coding the data, I was struck by the way in which receiving a diagnosis had changed men's lives. Men described experiences of happiness, success, loss, grief and for some acceptance. While reading transcripts, there were times when I cried with empathy for what men had experienced. I was aware of common links with my own experiences of help-seeking, health difficulties and experiences of loss. Due to similarities in age with some of my participants, this made their experiences more personally relevant as I could relate to being at a similar stage of life. At these times I used written reflections to think about how my own experiences, assumptions and values may have impacted on the way I was interpreting the data. Further to this, discussion with my supervision team allowed us to explore this further and highlight the ways in which themes were emerging from the data.

Three areas that were particularly prominent from the themes that emerged were stigma, treatment expectations and the power dynamics that men experienced in relation to healthcare professionals. I was struck by the vulnerability, shame and

weakness men felt when opening up and admitting that they were struggling. My curiosity ensued as I considered whether men were able to open up more in my interviews as they felt less threatened by my position of researcher rather than clinician. I wondered whether the interaction in the interviews could have been influenced by my gender, age and status of being 'in training' rather than a qualified member of staff. This could have either made men feel less vulnerable or more vulnerable depending on whether it was considered a safe space. Further to this, I was genuinely interested in men's stories and providing them with the space and time to talk about their struggles, which may not have been available to them previously. Men were not expecting me to 'fix them' which may have also impacted on the quality of the interaction, as they were not having to rely on me for care, treatment and support.

The notion of not being able to 'fix' people made me reflect on the service I was based in at the time of conducting and transcribing my interviews. I was working within a physical health service in the speciality of oncology and palliative care, therefore working with people adjusting to terminal diagnoses. For most of my patients there was no curative treatment options left. Even though the men within my research study had treatment options available, it appeared that medication did not fix their difficulties and their expectations were left shattered. There were stark similarities between the way in which men within my research study were experiencing their diagnosis and the way in which patients in a physical health setting were experiencing their difficulties. This led me to think about the ways in which adjusting to physical health difficulties overlapped with mental health difficulties. It was on this placement that I re-considered the topic of my literature review paper and decided to focus on

cancer. As previously noted, when deciding on the topic of my empirical paper I chose a topic which I had experience of working with in practice. As I had recent experiences of working with patients with cancer and their families, I was interested in utilising this passion and interest to identify a topic for my literature review. On reflection, I moved from an area of safety and familiarity by focusing on mental health difficulties and into a more unfamiliar area by focusing on physical health research.

The experience of developing themes for my literature review paper appeared much more straight forward than my empirical paper. I was able to obtain a position of observer and objectively synthesise the results from the research papers into themes, without getting too drawn into the emotion. I was less connected to the individuals within the research studies as I had not met them and had only received a small section of their journey through their partner's cancer diagnosis and/ or subsequent treatment. I did connect with the limited opportunities in which partners had to get their needs met and again found myself wanting to help not only patients but also family members who were in need. I could relate these experiences to my role within a hospice setting where families were often heavily involved in the support provided by a Clinical Psychologist.

3.4 The End – The last hurdle

Personally, the hardest part of this research process was attempting to write the research papers. I could fully empathise with men's experiences of being stuck. Like the men in my study, I experienced my own battles in which I had days where my project was coming together and other days where it was not moving forward at all. I

found it difficult to balance the demands of writing up my thesis with the demands of placement as well as ensuring space for self-care. At these times I tried to identify my own unworkable action and the thoughts I was fusing with, in order to find a way to continue. These often involved thoughts surrounding not being good enough and not having enough time. At these times I considered the values which had drawn me to the research project in the first place and I connected with people I could rely on for encouragement and support, in order to keep moving forward.

The importance of connection with other people was highlighted in both of my papers. Some men became ambassadors for living with mental illness and went on to support other people with their difficulties highlighting a sense of caring and compassion. They created meaningful roles within their lives despite the pain they had endured, showing courage and bravery in finding a way to give something back and help others. Partners of men with prostate cancer found other people to share their difficulties with in order to gain support within peer relationships where professionals were not available. The importance of peer support has been vital for me within the research process, especially at times when feeling stuck or unable to move forward. The ethical process was lengthy and it was useful to know that other people were in a similar position. Similarly, when recruiting participants, it was helpful to hear other people's struggles with recruitment to normalise and validate the situation. In addition to this it was also beneficial to discuss the nature of IPA and the way in which themes emerged and developed.

Throughout writing up my research project, I have found it valuable to link the positions of researcher and practitioner together, in order to explicitly formulate the experiences of the men within my empirical study. From an attachment perspective, men were faced with a threat of illness which was unpredictable and caused them vulnerability. For most men, avoidance of displaying their needs for comfort and support was seen as the preferable option. Once men could no longer manage alone, they relied on medical professionals in order for treatment and support, however men felt let down by the care they had received which left them striving to find their own independent ways to manage their difficulties again. From an ACT perspective it could be formulated that, participants were fused with thoughts of being weak, pathetic and failing to be a man if they asked for help. Participants were consumed by their illness, unable to take a step back and consider alternative ways to reconnect with their values in order to move forward with their lives. When they were able to open up and experience the pain of their diagnosis then this led them to find ways to connect with their values. Further to this, participants created meaningful lives based on their values which enabled them to move forward.

Professionally, there are a number of key learning points which I have discovered through the course of my research journey which will help me to develop further as a researcher and a practitioner. Initiated by my empirical study, I have considered the impact of stigma and how mental health problems are viewed in society. The way in which men were fighting to change the view of mental health in society prompted me to consider my own values and opinions on how I have a passion to try and make services more accessible for the individuals engaging in them. The importance of

patient feedback and service evaluation from service users in order to improve services is a part of my role I could utilise further in the future.

Another area in which I have increased my awareness is the way in which expectations of a diagnosis and/ or treatment need to be explicitly addressed through communication with both patients and partners. As a practitioner I have often provided psychological tools to aid patients with their recovery. In this way, I could have inadvertently prepared patients to find ways to 'fix' their problems and therefore may need to consider the way in which therapy approaches are explained to patients. When I have worked with terminal diagnoses however, the emphasis has been on acceptance and empathy, therefore I could expand this out to other diagnoses too. Further to this, I will carefully consider the way in which a diagnosis may be experienced by individuals who I am working with in order to take into consideration the impact on their quality of life. This would also be relevant when considering formulations involving partners or family members too. My literature review paper has highlighted the importance of considering the distress in partners or family members due to having to consider their adjustment to a caregiving role as well as the shock of a loved one receiving a diagnosis.

Through men's experiences of help-seeking, it has highlighted the importance of patient choice. I had not considered the severity of how problematic it could be for men to open up and seek support or how this may be considerably more difficult when it is a male professional. Although personal preference may be relevant in whether men would prefer a female or male practitioner, being able to have a choice of

therapist or at least acknowledging the difficulties men may experience in seeking help, could make their experiences more manageable. Further to this, I will also consider the power dynamics within the therapeutic relationship and consider ways to understand this further within the therapeutic situation.

This research process has enabled me to consider the way in which my values not only influence the way I work as a practitioner but have also influenced the way in which I decided upon my research areas and conducted my research. I find connecting to other people important and have provided a safe space in which to allow people to share their experiences of suffering or illness. My values of being caring, open, calm and compassionate as a practitioner are transferable to my role of researcher too. If I were to do further research in the future, I would consider the project as a whole rather than individual papers. I think this would help with the continuity between papers. If I were to conduct interviews again then I would try to keep more of an observing position, although I would be aware that the interaction is taken into consideration when conducting analysis.

Through developing both personally and professionally over the course of my research project it has left me with a better understanding of where I would prefer to work in the future and the kind of research I am interested in. I am aware that these are likely to change as I continue to develop and learn in my role once I have qualified as a Clinical Psychologist.

3.5 Conclusion

This paper has considered my reflections over the research process, involving both the literature review and empirical papers. Areas for future consideration have been identified in order to develop further both personally and professionally in the role of a Clinical Psychologist, taking on board aspects of both researcher and practitioner. Further to this, reflection has helped to identify and clarify my values for being a Clinical Psychologist and helped me to consider how to utilise these in order to work in an area in which I am interested and I feel passionate about.

3.6 References

- BPS (2010) *The core purpose and philosophy of the profession*. Leicester: British Psychological Society
- Bowlby, J. (1973) *Attachment and Loss, Vol. II Separation: Anxiety and Anger*. New York: Basic Books.
- Fisher, P., Chew, K. and Leow, Y. J. (2015) Clinical psychologists' use of reflection and reflective practice within clinical work. *Reflective Practice*, Vol. 16(6), p731-743.
- Harris, R. (2009) *ACT made simple*. Oakland: New Harbinger Publications.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999) *Acceptance and Commitment Therapy: An experiential approach to behaviour change*. New York: Guildford Press.
- Hazen, C. & Shaver, P. R. (1990) Love and work: An attachment-theoretical perspective. *Journal of Personality and Social Psychology*, vol. 59(2), p270
- Howe, D. (2011) *Attachment across the Lifecourse: A Brief Introduction*. London: Palgrave.
- Hughes, J. and Youngson, S. (2009) *Personal development and clinical psychology*. West Sussex: British Psychological Society and Blackwell Publishing Ltd.
- Lavender, T. (2003) Redressing the balance: The place, history and future of reflective practice in clinical training. *Clinical Psychology*, vol. 27, p11–15.
- Pietromonaco, P. R., Uchino, B. and Schetter, C. D. (2013) Close Relationship Processes and Health: Implications of Attachment Theory for Health and Disease. *Health Psychology*, Vol. 32(5), p499-513.
- Schon, D. A. (1983) *The Reflective Practitioner*. New York: Basic Books
- Youngson, S. (2009) Personal Development in Clinical Psychology: The Context. In J. Hughes and S. Youngson (Ed.) *Personal development and clinical psychology* (pp. 8-23). West Sussex: British Psychological Society and Blackwell Publishing Ltd.