

# PSYCHOSOCIAL ADJUSTMENT OF FEMALE PARTNERS OF MEN WITH PROSTATE CANCER: A REVIEW OF THE LITERATURE

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## SUMMARY

Advances in prostate cancer treatments since the 1990s have led to a growing proportion of patients living with the effects of the cancer. Various challenges face the man and his partner from the point of learning of the diagnosis: deciding among numerous diverse treatment options, dealing with side-effects of treatment and possibly facing the terminal phase of the illness. This invariably has an impact on the patient's family and, in view of the older age group of men usually affected, the experience of a partner is particularly relevant. A thorough review of the research literature reporting directly from partners of prostate cancer patients has not been undertaken previously. For this review, five databases were searched for the decade 1994–2005, during which most of the work in this field has been done. Very few evaluations of psychosocial interventions involving the partner were found, but there was a preponderance of qualitative studies involving small numbers of participants and quantitative surveys with little consistency in the measures used. The literature suggests that partners report more distress than patients, yet believe that patients are the more distressed, and the focus of concern of patients on their sexual function is not shared to an equal degree by their partners. Copyright © 2006 John Wiley & Sons, Ltd.

**KEY WORDS:** prostate; cancer; oncology; partner; psychological; psychosocial; adjustment; quality of life

## INTRODUCTION

Although prostate cancer (PCA) is a major cause of death in men, advances in treatment since the 1990s have led to the clinical challenge of a growing cohort of patients living with PCA and the consequences of its treatment. These consequences—physical, psychological and social—also exert a variable impact on the family, but given the older age of this clinical group, the experience of partners is particularly relevant.

Psychosocial correlates of breast cancer and its treatment on women and their partners and families have been thoroughly researched (Baider and Kaplan De-Nour, 2000). Many studies have shed light on how breast cancer can affect key relationships, in particular spousal. Attention has turned recently to psychosocial aspects of PCA on men's partners and families and research findings are beginning to crystallise. However, unlike breast cancer, a thorough summary of the research literature on PCA has not been undertaken hitherto. Such an exercise can offer direction to future research and to the clinician, as well as point to appropriate psychosocial interventions.

The aim of this review, therefore, is to appraise published research on the psychosocial effects on women living with men diagnosed with PCA at

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whatever the point in their 'journey'. The role of psychological treatments in aiding adjustment is also examined.

## METHOD

Medline, PsycInfo, Biological Abstracts, Sociological Abstracts and Cumulative Index to Nursing and Allied Health (CINAHL) were searched for the period 1994–2005 to identify relevant material. Virtually all studies carried out on the subject have been reported during the past decade. Search terms used were prostate cancer (carcinoma), partner (wife, spouse, married or marital), psychiatric, psychological, psychosocial, morbidity, distress, depression, anxiety, coping, adjustment and quality of life. A second step was to 'hand search' references cited in pertinent articles. The review was confined to articles published in English.

Among the candidate studies identified was a broad range of research designs and methods—quantitative, qualitative, their combination, cross-sectional, prospective, retrospective, and a small number of experimental investigations.

Studies were included in the review only if they reached the following criteria. Firstly, the partner psychosocial data reported were, at least in part, gathered directly from female partners themselves, not solely by using patients, clinicians or other parties as proxies. Secondly, the study sample was not compromised by obvious sampling biases, such as participants being self-selected or clinician selected according to the very psychosocial criteria of interest. Thirdly, where samples comprised partners of PCA patients along with those of patients with other cancers (such as breast cancer), it was possible to identify and examine the data from the PCA group separately, unless the other cancer was deemed sufficiently similar in its likely psychosocial impact to be deemed equivalent for the purposes of the study in question (e.g. bladder cancer in males). Fourthly, where quantitative methodology was used, adequate descriptions of the instruments were given (or cited) and where qualitative methodology was used, evidence was provided that research participants' responses were reported verbatim or without inappropriate editorialising or re-interpreting by the researchers.

Using these criteria, 44 articles were identified as reaching the research criteria above. There was considerable diversity within the group of eligible studies, with some studies stipulating a defined

stage of PCA or mode of treatment, where in other studies these were handled indiscriminately. Recruitment of partners of patients from specified ethnic groups was only done in a couple of studies. Almost all partners recruited into the research under review were women, but note will be made, when necessary, where same-sex partners were also studied.

Having identified the eligible studies, the material was grouped into four coherent, mutually exclusive categories in order to evaluate it thoroughly: psychosocial distress in partners, coping patterns in partners, effect of PCA on the couples' relationship and psychosocial interventions. Each of the four categories will be addressed in turn, a critique of the overall corpus of research will follow and, finally, consideration will be given to future clinical and research implications.

## RESULTS

### *(A) Psychosocial distress in partners of PCA patients*

From reviewing the work in this area, it becomes clear that studies of sound quality are uncommon (see Table 1 for a summary of the quantitative studies discussed below). Fortunately, the better studies show what can be done. Samples drawn from consecutive attendees at clinics or, better still, from cancer registers, reduce selection bias, a perennial problem where recruitment occurs in tertiary settings and convenience samples predominate. In terms of measurement, cancer-specific measures of distress for partners who are not themselves suffering from cancer need to be devised and validated. Meanwhile, general measures of partner distress, such as the Caregiver Burden Interview employed by Kornblith *et al.* (2001), and the Caregiver Strain Index employed by Campbell *et al.* (2004) (see next section) give some useful information in this regard. Several studies used established psychosocial measures for both patient and partner, such as Dyadic Adjustment Scale, Mental Health Inventory or Profile of Moods States, to examine comparative psychological effects on both patient and partner. Stage of cancer and mode of treatment need be considered in the design since the experience of patient and partner upon first learning of the diagnosis are likely to differ substantially compared to grappling

Table 1. Psychosocial distress in partners of patients with prostate cancer

Study	Design	Characteristics of the sample	Major findings
Kornblith <i>et al.</i> (2001)	<ul style="list-style-type: none"> <li>● Prospective with 4 observation points over 6 months</li> <li>● Mental Health Inventory-17, Caregiver Burden Interview</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 33</math> partners of men with hormone-refractory progressive systemic PCA receiving chemotherapy as part of a phase II chemotherapy trial</li> <li>● Convenience sample from specialised PCA clinic</li> </ul>	<ul style="list-style-type: none"> <li>● Significant decrease in partners' anxiety from baseline to 4 and 6 months</li> <li>● At baseline, 2 and 4 months partners of patients with better physical, social and emotional functioning reported less distress and caregiver burden</li> </ul>
Cliff and Macdonagh (2000)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Hospital Anxiety and Depression Scale, unvalidated instrument measuring psychosocial morbidity in PCA (validated in pilot)</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 135</math> partners of sequential attendees at a general urology outpatient clinic with any stage of PCA</li> <li>● Patients categorised into 4 categories: early localised, locally advanced, metastatic and hormone-relapsed</li> </ul>	<ul style="list-style-type: none"> <li>● Half the partners reported psychological morbidity compared to 21% of patients</li> <li>● Partners worry more than patients about pain and physical limitations, patients worry more about sexual dysfunction</li> </ul>
Banthia <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Profile of Mood States, Dyadic Adjustment Scale, Impact of Events Scale-Revised</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 154</math> partners of men diagnosed with PCA within previous 5 years</li> <li>● Convenience sample from medical centres, PCA support groups and responders to media reports</li> </ul>	<ul style="list-style-type: none"> <li>● Couples' relationship worsens when partner reports distress, avoidance, intrusiveness and hyper-arousal</li> <li>● Avoidance, intrusiveness and hyper-arousal predict psychological distress in partners</li> </ul>
Kornblith <i>et al.</i> (1994)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● European Organization for Research and Treatment of Cancer, Prostate Cancer Quality of Life Questionnaire, Intrusion subscale of Impact of Events Scale-Revised, Seiby's QL Uniscale</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 83</math> partners of PCA patients of all stages and treatment modalities (77 matched couples)</li> <li>● Convenience sample of attendees at a PCA health education lecture series</li> </ul>	<ul style="list-style-type: none"> <li>● Partners more distressed than patients</li> <li>● As quality of life in patients worsened, quality of life and level of psychological distress in partners worsened</li> <li>● Urinary difficulties in patients highly related to partners' distress</li> </ul>
Baider <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Brief Symptom Inventory, Perceived Family Support</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 118</math> partners of PCA patients in remission (no metastatic disease, no hormone therapy)</li> <li>● Consecutive hospital patients interviewed 6 months or more after end of treatment (mostly local radiation therapy)</li> </ul>	<ul style="list-style-type: none"> <li>● Overall psychological distress lower for partners than for patients</li> <li>● Couples with high distress reported lower levels of family support than couples in which both members report normal levels of distress</li> </ul>
Perez <i>et al.</i> (2002)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Dyadic Adjustment Scale, Sexual Satisfaction Scale, Unvalidated Quality of Life Instrument</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 134</math> partners of radical prostatectomy patients (1 same-sex)</li> <li>● Convenience sample of patients attending a major cancer centre</li> </ul>	<ul style="list-style-type: none"> <li>● partner ratings of sexual satisfaction predicted their quality of life</li> <li>● patient medical or sexual variables did not predict partners' quality of life</li> </ul>

Table 1. (*continued*)

Study	Design	Characteristics of the sample	Major findings
Valdismarsdottir <i>et al.</i> (2002)	<ul style="list-style-type: none"> <li>● Retrospective</li> <li>● Centre for Epidemiological Studies-Depression, State-Trait Anxiety inventory</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 506</math> widows of men who had died of PCA or bladder cancer 2–4 years earlier</li> <li>● Women identified from Swedish National Register of Causes of Death</li> </ul>	<ul style="list-style-type: none"> <li>● Where widow reported her husband as being very anxious during his last 3 months of life, 2–4 years later she has relative risk of 2.5 of depression, and 3.4 of anxiety</li> </ul>
Valdismarsdottir <i>et al.</i> (2004)	<ul style="list-style-type: none"> <li>● Retrospective</li> <li>● Questionnaire regarding awareness of time of husband's impending death</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 379</math> widows of men who died of PCA or bladder cancer 2–4 years earlier</li> <li>● Women identified from Swedish National Register of Causes of Death</li> </ul>	<ul style="list-style-type: none"> <li>● The shorter the widows' awareness of time of husband's impending death the higher the risk of her having subsequent psychological morbidity</li> </ul>

with the terminal phase, and as a function of the diverse treatments applied.

Bearing these issues in mind, of the studies examining partners' psychosocial distress, those of Kornblith *et al.* (2001), Cliff and Macdonagh (2000) and Banthia *et al.* (2003) are the most methodologically rigorous. In a prospective examination of the psychosocial impact on patient and partner of treatment for hormone-refractory advanced PCA, the Kornblith group (2001) found that the latter's anxiety diminished over time, with partners of well-functioning patients feeling less emotionally burdened. A good response to chemotherapy was associated not only with a decline in the partner's anxiety and depression, but also with enhanced positive feelings.

The study is typified by several strengths. One is stipulation of stage of PCA and modality of treatment, enabling clinicians to determine the relevance of the findings for their practice. The design also allows insights into what is essentially a psychological journey for a couple as they face the effects of the diagnosis and treatment of PCA. Artefacts related to cross-sectional inquiries are therefore minimised. Use of standardised instruments makes the study eminently reproducible. Furthermore, the same measure of distress used in patient and partner facilitates direct comparison between them.

The researchers achieved an 80% response rate by partners at the 2 month point but this fell substantially thereafter, illustrating the dilemma for investigators—long-term follow-up data are invaluable but often incomplete, and therefore prone to bias. As in many PCA studies, the sample was homogeneous with respect to ethnicity and socio-economic status, and thus representative of only part of the general clinical population.

Cliff and Macdonagh (2000) examined psychosocial morbidity in patients and partners cross-sectionally. Half the women, compared to only one in five men, manifested abnormal findings; partners were also more concerned about pain and physical limitations arising from treatment; conversely, patients were more worried about sexual function. Impressively, the 135 pairs were administered questionnaires in their homes.

Banthia *et al.* (2003) also conducted a cross-sectional survey, covering quality of couples' relationships, coping and mood. They found that where couples had a robust relationship, the

patient was buffered from depression but the partner was not. What is more, where the partner reported feeling distressed or described reactions to the cancer of avoidance, over-involvement or hyper-arousal, the couple's relationship was worse. The team, like Cliff and Macdonagh, recruited a decent-sized sample (154 partners), but reliance in part on recruitment through the media may have increased the likelihood of bias.

Five other studies merit attention. In an earlier study, Kornblith *et al.* (1994) found partners reporting greater levels of psychological distress than patients. Urinary difficulties as reported by the patient were particularly related to partners' distress. Since the sample was derived from attendees at health education lectures, it is conceivable that more motivated and cohesive couples were recruited. Secondly, Baider *et al.* (2003) examined psychological distress and perceived family support in patients in remission and their partners. Distress, in contrast to the above studies, was lower for partners compared to patients. A couple reporting elevated distress noted less family support. Perez *et al.* (2002) surveyed sexual function and quality of life in partners of patients who had undergone radical prostatectomy and found that partners' ratings of their sexual satisfaction predicted their quality of life, but not patients' medical or sexual status post-surgery.

Valdimarsdottir's team (Valdimarsdottir *et al.*, 2002) scrutinised psychosocial data of women whose husbands had died of PCA or bladder cancer and were identified in the Swedish National Register. Widows who reported their partners as highly anxious during their last 3 months of life had a relative risk of 2.5 of depression and a relative risk of 3.4 of anxiety 2–4 years after the death. In a subgroup (Valdimarsdottir *et al.*, 2004), widows learning of their husbands' impending death less than 24 hours before it occurred were most at risk of psychological morbidity. Although cross-sectional and retrospective, drawing the sample from a national register is a strength. On the other hand, it is impossible to tease out PCA from bladder cancer patients, since they were studied as a single group. With both bladder cancer and PCA affecting the male lower urogenital tract, the overall psychosocial impact on patient and partner may be assumed to be very similar, although there may be discrepancies in the types of treatments employed.

### (B) Coping patterns of partners of PCA patients

Approaches used in research on coping patterns in the partners of PCA patients vary considerably (see Table 2 for a summary of all the quantitative studies discussed below). Superior studies specify stage of cancer and treatment modality, and use validated instruments. Only by using validated instruments can studies be adequately compared and replicated. In another vein, longitudinal qualitative work can generate valuable insights into the experience of couples confronted by PCA and its treatment. Moreover, future psychosocial interventions could well draw on the findings of such work.

Many limitations typify the less rigorous studies in this area: stage of PCA not defined, excessive ranges in time since diagnosis, low response rate of partners compared to patients, failure to specify what proportion of participating family members of PCA patients were spouses and the use of unvalidated instruments with inadequate description of their content.

Nevertheless, in this category, studies by Campbell *et al.* (2004), Germino *et al.* (1998), Ptacek *et al.* (1997) and Gray *et al.* (1999) on coping patterns of partners impress in terms of methodological rigour and sophistication.

Campbell and colleagues (2004) examined the link between patients' and partners' self-confidence, mood and quality of life in the wake of receiving the diagnosis. More self-confident partners were, not surprisingly, less depressed, anxious and fatigued, experienced less strain in the role of caregiver and felt better able to help the patient. Sampling was restricted to men with early stage PCA, most of whom were treated surgically. Recruitment aimed at including subgroups of each of the main treatments would have been more informative.

Ethnicity is rarely examined in this context. Unusually, Germino *et al.* (1998) looked at coping in White and African-American patients and their 'family care providers' (mostly partners). The greater the uncertainty in partners of White patients, but not in African-Americans, the greater their doubts about the patient's medical treatment. Uncertainty also correlated with poor problem solving and feelings of inadequate support, again in partners of White but not African-American patients.

Inter-ethnic comparison of coping is an interesting aspect but would be more complete were the

Table 2. Coping patterns of partners of patients with prostate cancer

Study	Design	Characteristics of the sample	Major findings
Campbell <i>et al.</i> (2004)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Profile of Mood States-Short Form, Caregiver Strain Index, Self-efficacy for Symptom Control Index (modified for partners)</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 40 partners (39 female, 1 same-sex) of African-American PCA patients treated without recurrent disease</li> <li>● Convenience sample of attendees at urology specialty clinics, members of a regional tumour registry and from the community</li> </ul>	<ul style="list-style-type: none"> <li>● Partners who reported greater confidence in their ability to help patients cope with PCA symptoms reported less depression, anxiety and fatigue</li> <li>● Partners who reported more overall confidence in their ability to help the patient with symptoms reported less caregiver strain</li> </ul>
Germino <i>et al.</i> (1998)	<ul style="list-style-type: none"> <li>● Cross-sectional (baseline data from a three arm RCT)</li> <li>● Psychological Adjustment to Illness Scale</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 200 partners of either post-prostatectomy or pre-radiation treatment PCA patients (132 partners of White men and 68 partners of African-American men)</li> <li>● Convenience sample of attendees at specialist urology clinics and private practice</li> </ul>	<ul style="list-style-type: none"> <li>● The more uncertainty White partners experience, the less positive they feel about the helpfulness of different kinds of treatment and strategies for coping with cancer</li> <li>● The more uncertain White partners feel, the less positive they feel toward the patient as they recover from PCA treatment</li> </ul>
Piacek <i>et al.</i> (1997)	<ul style="list-style-type: none"> <li>● Retrospective comparison of partners of PCA patients and partners of breast cancer patients</li> <li>● Ways of Coping Checklist-Revised, Social Provisions Scale, Dyadic Adjustment Scale, Mental Health Inventory and an unvalidated instrument to measure cancer-related stress</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 57 partners of PCA patients who have completed radiotherapy within previous 3 years</li> <li>● Participants consecutive attendees at two specialist clinics</li> <li>● Study also included 38 partners of breast cancer patients, 95 breast and PCA couples in total.</li> </ul>	<ul style="list-style-type: none"> <li>● Partners of PCA patients reported receiving more social support than partners of breast cancer patients and were more satisfied with that support</li> <li>● Stressed partners of PCA patients reported seeking less social support</li> </ul>
Malcarne <i>et al.</i> (2002)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Profile of Mood States, Social Problem-Solving Inventory-Revised</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 32 partners of PCA patients</li> <li>● Convenience sample recruited from physicians, support groups, media coverage and community organisations</li> </ul>	<ul style="list-style-type: none"> <li>● Partners of PCA patients with better problem-solving skills (positive problem orientation and rational problem solving) reported less distress, partners with worse skills (avoidance, impulsivity, negative problem orientation) reported more distress</li> </ul>
Davison <i>et al.</i> (2002)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Patient Information Program</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 80 partners of early stage PCA patients</li> <li>● Convenience sample recruited by several urologists</li> </ul>	<ul style="list-style-type: none"> <li>● Patients rated importance of information on sexuality higher than partners</li> <li>● Partners rated importance of home care higher than patients</li> </ul>

Rees <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Miller Behavioural Style Scale, Family Inventory of Needs (adapted for use with partners)</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 39</math> partners of PCA patients</li> <li>● Convenience sample from a PCA charity</li> </ul>	<ul style="list-style-type: none"> <li>● Partners of PCA patients have a high level of need for information about treatments</li> </ul>
Feldman-Stewart <i>et al.</i> (2001)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Unvalidated instrument</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 22</math> family members or friends of recently diagnosed PCA patients (unclear how many were female partners)</li> <li>● Convenience sample</li> </ul>	<ul style="list-style-type: none"> <li>● Partners of PCA patients worry about how long it is safe to take a decision about treatment</li> </ul>
Srirangam <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Unvalidated instrument</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 82</math> partners of early stage PCA patients</li> <li>● Convenience sample</li> </ul>	<ul style="list-style-type: none"> <li>● Information gathering and emotional support the most important roles for partners</li> </ul>

ethnicity of partners also reported. Nevertheless, the findings suggest clinically pertinent ethnic differences in couples' coping. To date, these are the only comparisons of ethnic groups, but in view of a recognised higher incidence of PCA in African-Americans (Hsing *et al.*, 2000) this aspect warrants further attention.

Ptacek *et al.* (1997) looked retrospectively at coping in wives of men who had successfully completed a course of external beam radiotherapy compared to husbands of women who had received radiotherapy for breast cancer. Both spousal groups sought out similar amounts of social support but wives of PCA patients were more satisfied than husbands of breast cancer patients with the support they received. The PCA spouses were also more satisfied with support received from siblings, children, other relatives and physicians. Breast cancer husbands reported receiving greater support from their wives than PCA wives reported receiving from their husbands.

Gray and colleagues (1999) have reported various findings from their 1 year longitudinal qualitative study using semi-structured interviews with 34 PCA patients undergoing surgery and separate interviews with their partners. Although the diagnosis came as a shock to couples, this waned over time. The reality of the PCA led, in most couples, to a sense of renewed commitment to their relationship, a search for information to guide decisions about treatment and facing the question of with whom to share the news and how much detail to divulge. Couples sought a semblance of normality in their lives once treatment decisions had been made but experienced anxiety (in one or both) as surgery loomed.

Two months later, couples felt well connected through establishing routines of care despite some continuing irritability and depression in the men. Women comforted men with impotence by reassuring them that there was more to their relationship than sex (Phillips *et al.*, 2000). However, 1 year after surgery, wives hesitated to offer the same level of support lest this undermine their husbands' quest for self-reliance (Gray *et al.*, 2000a).

The men were influenced by their partners' attitudes to disclosure of the diagnosis (Gray *et al.*, 2000b). Many wives supported their husbands' preference to limit disclosure, but saw sharing with others as a positive step (Gray *et al.*, 2000b). A proportion of women persuaded their spouses to disclose more than the latter were inclined to do;

some were grateful for the nudge. The wife's initial compliance with her husband's wishes was often re-negotiated over time. Patients supported their partners by minimising ill-effects of the cancer, being aware of their emotional interdependence and expressing care toward the spouse (Fergus *et al.*, 2002).

Five other studies, conducted by Malcarne *et al.* (2002), Davison *et al.* (2002), Butler *et al.* (2000), Harden *et al.* (2002) and Lavery and Clarke (1999), are also worthy of note, although they have smaller sample sizes than the aforementioned studies or are narrower in their area of inquiry.

Malcarne and colleagues (2002) found that partners positively oriented to difficulties related to their spouse having PCA, and applying rational problem-solving skills, were less distressed. In Davison and colleagues' (2002) survey of partners of patients with early PCA, sexuality was of greater cogency to patients than to partners.

Butler and colleagues (2000) found that many partners of men who had undergone prostatectomy claimed the surgery had not affected their relationship. However, a proportion felt isolated if patients did not recruit their help to decide on treatment. Interruption to life was a key theme emerging from focus groups of couples facing PCA conducted by Harden and colleagues (2002). Couples struggled to keep abreast of developments in treatment, trying to reconcile contradictory views of health professionals and finding themselves unable to plan coherently for their future.

Using a transactional model to differentiate between individual and interpersonal coping, Lavery and Clarke (1999) concluded from couple interviews that patients used a diverse range of strategies relative to their partners. However, the latter engaged more actively in decision-making and other problem-solving activities relevant to the cancer.

Six further studies, by Rees *et al.* (2003), Feldman-Stewart *et al.* (2001), Srirangam *et al.* (2003), Pinnock *et al.* (1998), O'Rourke and Germino (1998) and Feltwell and Rees (2004) touch on partner coping patterns within their study designs. The Rees team (2003) found that partners wanted comprehensive information about treatment. In this study, the stage of PCA was not defined, time since diagnosis ranged from 4 months to 9 years, and the response rate for partners was low. Feldman-Stewart *et al.* (2001) identified widespread concerns about risks in delaying decisions about treatment among patients and

family members/friends facing the recent diagnosis of PCA and an eagerness to learn about treatment options if the initial treatment proved unsuccessful. Unfortunately, this study was marred by poor recruitment, compounded by not specifying how many of the family members were spouses. Srirangam *et al.* (2003), also studying newly diagnosed patients and partners, found that cogent tasks for partners were to obtain information and to muster support; many partners were found, however, to shy away from influencing the patient's decision about treatment. Unfortunately, in this case an unvalidated and poorly described instrument to measure the need for information was used.

Pinnock and colleagues (1998) conducted focus groups composed of men with general urological health problems, including PCA, together with their partners. The latter often played a key role in obtaining a professional consultation. O'Rourke and Germino (1998) also used focus groups, but confined to PCA patients and their partners. They concluded that misconceptions about surgery and radiotherapy hampered couples making informed treatment decisions. Feltwell and Rees (2004) reported much diversity in information-seeking, some partners seeking copious details about treatment, others eschewing contact with experts altogether.

### *(C) Impact of PCA on the couple relationship*

Focus group research, such as that by O'Rourke and Germino (2000), reveals a wealth of material to generate hypotheses for further research into the impact of PCA on the couple relationship (see Table 3 for a summary of all the quantitative studies discussed below). Attempts to measure the impact of PCA on couples' relationships are a welcome development too and augur well for the field. In a sense, the couple's relationship is a 'third party' for clinicians and researchers to address since discordance in perspectives between patient and partner appears to be common, with possible adverse repercussions for their well-being. Instruments like the Dyadic Adjustment Scale can yield insights into tensions that may affect this 'third party'. Whether such measures can also predict psychological distress in the patient and/or partner in the aftermath of diagnosis and treatment is a promising line of inquiry.

The research on the impact of PCA on the relationship based, at least in part, on data



Table 3. Impact of prostate cancer on the couple relationship

Study	Design	Characteristics of the sample	Major findings
Piacek <i>et al.</i> (1999)	<ul style="list-style-type: none"> <li>● Retrospective</li> <li>● Dyadic Adjustment Scale, Ways of Coping Checklist -Revised</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 57 partners of PCA patients who have completed radiotherapy within previous 3 years</li> <li>● Patients consecutive attendees at two specialist clinics</li> </ul>	<ul style="list-style-type: none"> <li>● Partners believe that patients experience more stress than the patients themselves report</li> <li>● Patients who feel supported also report good marital satisfaction</li> </ul>
Neese <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Cross-sectional</li> <li>● Unvalidated instrument</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 164 partners (including one same-sex partner) of PCA patients</li> <li>● Patients attendees at a specialised clinic</li> </ul>	<ul style="list-style-type: none"> <li>● Most partners report at least some dissatisfaction with their current sexual relationship</li> </ul>
Galbraith <i>et al.</i> (2005)	<ul style="list-style-type: none"> <li>● Prospective</li> <li>● Dyadic Adjustment Scale, Medical Outcomes Study General Health Survey, Quality-of-Life Index</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 126 partners of early stage PCA patients</li> <li>● Convenience sample</li> </ul>	<ul style="list-style-type: none"> <li>● Up to 4.5 years after treatment for PCA the patient and partner's marital satisfaction and health-related quality of life are closely linked</li> </ul>
Carlson <i>et al.</i> (2001)	<ul style="list-style-type: none"> <li>● Cross-sectional comparison of partners of PCA patients and partners of breast cancer patients</li> <li>● Partners completed Profile of Mood States as patient proxies, unvalidated instrument assessing social support</li> </ul>	<ul style="list-style-type: none"> <li>● <i>N</i> = 15 partners of PCA patients attending a radiation therapy unit, diagnosed with PCA within previous year</li> <li>● Convenience sample</li> <li>● Study also included 8 partners of breast cancer patients</li> </ul>	<ul style="list-style-type: none"> <li>● Partners of PCA patients had a more accurate understanding of patients' experience than partners of breast cancer patients</li> </ul>

collected from the partner is represented best by four studies by Ptacek *et al.* (1997, 1999), Neese *et al.* (2003), O'Rourke (1999) and Boehmer and Clark (2001a, b).

Ptacek and colleagues' (1997) study, which we dealt with in part in Section B, represents the most methodologically rigorous work in this category. The study incorporated a measure of couple satisfaction, as well as spouse's level of stress and pattern of coping. Satisfaction and social support were strongly correlated in patients but not their partners. When the team turned the focus onto the PCA couples exclusively, they found that patients and partners disagreed on the extent of patient distress, partners consistently reporting that the patients experienced more distress than the patients themselves reported (Ptacek *et al.*, 1999). Given the discrepant retrospective ratings, we can see that reliance on patients' reports alone may not reflect the entire picture. Gaining the perspectives of both members of the couple is an obvious advantage. This study benefited from a well-defined and good-sized sample and focus on one treatment group (radiotherapy).

Turning to sexual aspects, Neese *et al.* (2003) explored these in a telephone survey of a large cohort of couples. A third of the wives were dissatisfied with their sexual relationship and a half of the wives felt that although problems prevailed they were uninterested in obtaining help. A fifth of couples were receiving sex therapy; another fifth had found it unhelpful and dropped out.

As mentioned above, O'Rourke (1999) investigated treatment decision-making and its impact on the couple using a longitudinal, qualitative approach. Interviews, conjoint and individual, were held within 6 weeks of diagnosis but before a choice of treatment, and later at 3 and 12 months. Partners and patients alike turned to people who had experienced PCA and other types of cancer to make sense of treatment options but the women approached family and friends whereas the men considered the views of celebrities through the media. The women de-emphasised impotence, citing their own menopause-based changes. They highlighted, instead, the duration of the relationship as a key factor in dealing with these changes. Despite the different outlooks, the men and women described moving from their individual perspectives of treatment options to a negotiated couple choice (O'Rourke and Germino, 2000).

Treatment decision-making was also examined by Boehmer and Clark (2001a). Separate focus

groups for patients (undergoing hormonal therapy) and their partners revealed that communication about the cancer and its treatment was limited (Boehmer and Clark, 2001b). Most patients informed their partners about physical symptoms they had but the latter also had to rely on non-verbal cues. The women refrained at times from asking their spouses about progress lest they stir things up. Partners articulated their despair more readily than patients, the latter downplaying the implications of the cancer. The women consistently described how devastating the loss of sex was for their husbands; they felt it necessary to build up the men's self-esteem and reassure them of their masculinity.

By conducting separate focus groups for patients and partners, Boehmer and Clark (2001a) ascertained that the process of doctor, patient and partner making a decision concerning treatment could be categorised into: partner excluded, doctor-initiated inclusion of partner and spousal alliance. When the partner was excluded, the patient directed his attention to the doctor. In the doctor-initiated inclusion of partners, men were passive in involving the spouse. In a spousal alliance, all aspects of the PCA and its treatment were openly canvassed and discussed.

Five further studies, by Rosner *et al.* (1997), Jacobs *et al.* (2002), Maliski *et al.* (2002), Galbraith *et al.* (2005) and Carlson *et al.* (2001) are worth noting. The Rosner team (1997) interviewed patients and their partners, both individually and in focus groups, at various stages of the disease. Partners supported the patient as he regained a sense of control by seeking information from the doctor. The couples' experiences clustered meaningfully into early and late phases (Heyman and Resner, 1996). Fear of cancer in patient and partner dominated early, the couple feeling pressed to decide about treatment promptly. Later, partners felt that sexual intercourse and intimacy were not synonymous; feelings of love expressed by their husbands in other ways were just as pertinent.

Jacobs and colleagues (2002) asked newly diagnosed patients, their partners and doctors, what aspects of PCA had led to difficulty. Partners regarded fear of the unknown higher than patients; other problem categories were deciding about treatment, fear of being left alone, erectile dysfunction and incontinence. Rankings of the men and women correlated highly.

Maliski *et al.* (2002) interviewed couples together after prostatectomy and identified loss of

control, need for information and the quest for best surgical treatment and 'top' surgeon as key issues. The couples embarked on a 'crash course' which led, in most cases, to a more sanguine view of PCA as a relatively 'good cancer', although still in need of prompt treatment. Armed with this knowledge, couples felt confident handing over the levers of control to the surgeon. Along the way, wives supported the men by putting impotence into perspective and reassuring them and establishing routines together that enhanced the men's sense of control (Maliski *et al.*, 2001).

Galbraith and colleagues (2005) surveyed couples several years after PCA treatment by surgery, radiotherapy or watchful waiting regarding their marital function and health-related quality of life. Patients' and partners' quality of life and marital satisfaction were closely associated 4 years after initial treatment.

Carlson and colleagues (2001) administered a measure of mood to PCA and breast cancer patients and their partners, with an instruction to partners to respond as if they were the patient. Perceptions of support and the cancer process were also assessed. Wives of PCA patients had a more accurate understanding of their partners' experience than the husbands of breast cancer patients had of their partners' experience. Patient and partner perceptions of support were more congruent in PCA than in breast cancer couples.

#### *(D) Psychosocial interventions for partners of PCA patients*

Randomised controlled trials targeted at partners of patients with specified PCA stages and treatments and using well-defined interventions are warranted but it would appear that more intensive and far-reaching programmes: are needed to establish worthwhile benefits for partners of men diagnosed with PCA (see Table 4 for a summary of all the quantitative studies discussed below). Based on a review of partners' distress, coping patterns and impact of the cancer on the couple relationship it would appear that the timing of the intervention and the thematic areas tackled need careful consideration. Of the three studies under review in this section, that by Manne *et al.* (2004) is the most apposite in this regard.

Manne and colleagues (2004) tested the effectiveness of a closed psycho-educational group, led by a trained leader, on distress, coping, personal

growth in, and communication between, partners. Participants randomly assigned to treatment met weekly for 6 sessions whereas control couples received 'standard care'. Information about PCA and its treatment, stress management, coping skills, optimal communication and support, intimacy and sexual concerns were covered. The programme also incorporated presentations by a radiation oncologist, psychologist and social worker, complemented by group discussion and homework assignments. Audiotaped sessions were rated for treatment adherence. At 1 month follow-up, positive reappraisal of the situation and personal growth were higher, and denial lower, in treated partners. However, the two groups did not differ on levels of distress and communication.

The trial used sound methodology including valid outcome measures, and is eminently reproducible. Unfortunately, it was under-powered and did not include a control for time and attention given to the intervention group. Furthermore, an acceptance rate of 57% of eligible couples suggests possible bias. The authors themselves acknowledge these shortcomings but they are to be commended for executing this pioneering project.

In a quasi-experimental study performed by Davison *et al.* (2003) using recruits from a study of coping styles reviewed in Section B (Davison *et al.*, 2002), the researchers provided information about PCA to newly diagnosed men and their partners to determine if this would lower psychological distress and promote patients' and partners' involvement in treatment decision-making. Respondents completed measures of decision preferences and distress at the time of diagnosis and 4 months later. Interestingly, participants were given print-outs derived from their questionnaire responses, which were then used to guide counselling with each couple.

It is clearly difficult to draw any conclusions without controls and randomisation. At follow-up, patients who assumed a more active role tended to have partners who played a more passive role than they had predicted for themselves. All participants, patients and partners, had lower levels of distress at the 4 month point.

Giarelli *et al.* (2003) randomly assigned partners to either usual care or an intervention group. The intervention group received teaching from a nurse about strategies to help their husbands manage their physical symptoms following surgery, and to promote communication and sexual intimacy.

Table 4. Evaluation of psychosocial interventions for partners of patients with prostate cancer

Study	Design	Characteristics of the sample	Major findings
Manne <i>et al.</i> (2004)	<ul style="list-style-type: none"> <li>● Randomised Controlled Trial comparing a closed structured psychosocial group intervention against a control group of usual treatment</li> <li>● Mental Health Inventory, Impact of Events Scale, COPE, Post-traumatic Growth Inventory, Communication Patterns Questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 60</math> partners of PCA patients of various stages and treatments (29 randomly assigned to intervention group and 31 assigned to control group)</li> <li>● Patients identified from medical records at a large cancer centre</li> </ul>	<ul style="list-style-type: none"> <li>● Positive reappraisal and growth was higher among the intervention partners compared to the controls</li> <li>● Denial was lower among the intervention wives compared to controls</li> <li>● The intervention did not result in changes in psychological distress compared to controls</li> </ul>
Davison <i>et al.</i> (2002)	<ul style="list-style-type: none"> <li>● Quasi-experimental (non-randomised), one group, pre-test post-test study comparing partners' psychological distress and decision-making before and after an individualised information session</li> <li>● Patient Information Program, State Anxiety Inventory, Centre for Epidemiological Studies-Depression</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 74</math> partners of early stage PCA patients (one same-sex partner) interviewed at time of diagnosis and 4 months later</li> <li>● Attendees at a prostate centre at a general hospital</li> </ul>	<ul style="list-style-type: none"> <li>● At follow-up 4 months after diagnosis, partners reported assuming a more passive role in decision-making than originally intended</li> <li>● All patients and partners had lower levels of psychological distress at 4 months</li> </ul>
Giarelli <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>● Randomised Controlled Trial comparing partners receiving a standardised nursing intervention with those who received usual care</li> <li>● Preparedness for Caregiving Scale</li> </ul>	<ul style="list-style-type: none"> <li>● <math>N = 110</math> partners of PCA patients preparing for radical retropubic prostatectomy (57 in intervention group and 53 in control group) and 3 and 6 month post-surgery</li> <li>● Attendees at a urology clinic at a medical centre</li> </ul>	<ul style="list-style-type: none"> <li>● Both intervention and control group partners rated themselves as well prepared to take care of physical and emotional needs of patients</li> <li>● Both groups preparedness improved at 3 and 6 months post-surgery</li> </ul>

Using both quantitative and qualitative methodology to gauge partner responses, partners in both intervention and control groups were found to become better equipped to take care of the physical and emotional needs of the men at 3 and 6 month follow-up.

Again, it is confusing as to what the intervention achieved since both intervention and control groups rated themselves as doing well. Similarly, it is difficult to interpret the meaning of partners' responses to open-ended questions in that they do not represent a measure susceptible to comparison.

Future intervention studies should deal with reluctance to disclose 'news' of PCA to family and friends who are potential sources of support, assist the couple to communicate openly, including about sexual function and intimacy, and promote mutual emotional support in couples, discouraging withdrawal and isolation by patient or partner.

## DISCUSSION

Drawing on developments in psychosocial research into breast cancer (Kissane and Bloch, 2002) and our own current work with PCA patients, their partners and their doctors, key areas of interest for future research into couples facing PCA appear to be: firstly, to develop an efficient means to identify couples and/or partners at risk of poor adjustment and likely to benefit from a psychosocial intervention; and, secondly, to devise feasible and effective ways to help such couples and/or partners.

A review of the relevant literature suggests that PCA can have marked psychosocial repercussions for the partner. With one exception (Baider *et al.*, 2003), the studies reviewed described partners emerging as more distressed than patients. Furthermore, retrospective studies suggest that while distress may diminish with time, a proportion of partners may remain adversely affected years after the death of the patient.

According to the papers reviewed, partners of PCA patients are more active in seeking information and making decisions about treatment and in supporting the patient than partners of women with breast cancer. In summarising the existing research evidence on the gender effect on psychological adjustment of couples facing cancer, Baider and Kaplan De-Nour (2000) conclude that female

patients do less well than male patients and husbands of cancer patients do less well than wives of cancer patients.

Nevertheless, in the context of the findings of the studies reviewed here, the involvement of the partner may be 'good news' for the PCA patient's well-being but does not spare the partner herself from distress. Assessing the latter's psychological status, and both patient and partner's perspective of their relationship, provides additional helpful clinical information.

It cannot be assumed that the reactions of a group of couples facing a specific cancer will be similar to couples facing a different cancer. What is more, partners of PCA patients report the patient as being more distressed than he does himself. This may have implications for the sensitivity of screening instruments administered to patients only.

A consistent theme is the concern exhibited by PCA patients regarding sexual function compared to their partners. Partners tend to reassure patients who experience impotence and do not address their own sexual needs. Conversely, urinary incontinence may have a greater adverse psychological effect on the partner than the patient.

The impact of PCA on the partner obviously continues into the phase of palliative care and beyond. Where a patient is most anxious in the months preceding death or a partner has little time to prepare for the death, there is an elevated rate of psychological difficulty which may endure for years. Psycho-educational group interventions may help partners to develop a more positive approach and lessen their tendency for denial.

Social support for female partners and their need for information, particularly from people in their own social circle who have experienced similar circumstances, is relevant. If the partner feels supported, her satisfaction with the relationship is enhanced. Hence, she is better able to shoulder the emotional burden which falls to her.

The partner's pattern of coping affects her psychological well-being. For instance, a sense that she can help the patient is likely to contribute to a more positive outlook. Partners who employ a problem-solving pattern of coping or seek social support are less distressed, whereas those who are avoidant or impulsive are more distressed. Exploring the utility of an intervention which encourages partners to adopt problem-solving strategies follows logically from this finding.

Psychosocial interventions which incorporate the partner are sorely in need of attention. The study by Manne and colleagues (2004) stands out from a minute field of clinical trials. Studies comparing a well-specified approach with a control condition are a priority. An example of such work by Scott *et al.* (2004) with couples grappling with the psychosocial sequelae of breast and gynaecological cancer is a superb model. Patients were randomly assigned to one of a control condition, coping training for patients alone or a couple-based coping programme. The effect of the last could thus be compared to conditions in which only the patient was seen. The couple and individual coping training were manualised to ensure consistency. Both included educational material, coping skills training and supportive counselling. In addition, the couple-based training included supportive communication, partner support and sexual counselling. The training in couples rather than for individuals was more effective in facilitating adaptation to cancer. This successful intervention was based on the substantial psychosocial literature examining the impact of breast cancer on patient and partner.

Insights from the research under review could be incorporated into an equivalent couple intervention for patients with PCA and their partners. In particular, it might address patient reluctance to share the diagnosis with friends and relatives, promotion of open communication in the couple, discouragement of withdrawal and isolation, recognition of patients' tendency to underestimate their own distress and that of their partner and the psychological impact on the couple of sexual and other physical problems consequent on treatment.

In this review, 44 articles covering 33 discrete samples have been identified, reporting psychosocial data gathered directly from female partners of PCA patients. This theme appears to be attracting growing research interest in psycho-oncology, with newly developing areas such as comparisons between ethnic groups (Campbell *et al.*, 2004), prospective studies of marital satisfaction (Galbraith *et al.*, 2005) and psychosocial interventions which involve partners (Manne *et al.*, 2004; Davison *et al.*, 2002; Giarelli *et al.*, 2003).

In a broader review on the psychological dimensions of PCA (submitted for publication), we have found that most studies do not seek data directly from partners. This is a blatant omission since patients do not always admit to psychosocial problems in themselves, their partners and in their

relationship with their partner. The partner is clearly an invaluable source of information to advance our understanding of the psychosocial impact of PCA generally.

We recommend that future work focus on each of the four categories we have identified in this review to allow critical comparisons of the results obtained. This in turn will pave the way to achieve a robust series of findings to guide clinical practice.

### *Methodological issues*

A proportion of the studies reviewed report on interviews conducted with small and heterogeneous samples of partners, either on their own, in groups or with their spouses. Much of this work unfortunately is insufficiently rigorous and yields little in the way of new insights. By contrast, a few investigations, particularly the work of Gray and colleagues (e.g. 1999, 2000a, b), provide a rich account of the patient and partner's joint 'journey'. This group took care to identify a specific treatment (prostatectomy) as well as phase of illness. Welcome additions to the body of research would be equivalent longitudinal examinations of the experiences of patients and their partners where the former is treated with external beam radiotherapy, brachytherapy, hormone therapy and 'watchful waiting'. Qualitative interviews of subjects in future studies are also likely to be useful by eliciting detailed reactions to treatment, and thus complementing questionnaire-derived data.

Several quantitative studies under review used measures which have not been subjected to psychometric evaluation, and therefore are not used by other researchers. These are of limited value since it is impossible to compare findings. In many instances relevant validated instruments are available and could have been used, although at present no specific instrument exists designed to measure coping patterns in partners, as the Mental Adjustment to Cancer does in patients. The Impact of Events Scale, Mental Health Inventory, Dyadic Adjustment Scale and Profile of Mood States are well-established instruments which cover key psychosocial domains pertinent to both patient and partner and were used in three or more of the aforementioned studies.

The advent of cancer-specific quality of life and psychological adjustment measures has improved detection of distress in patients. When studying the experience of family members who may be psy-

chologically affected by cancer but are not themselves physically ill, general caregiver burden instruments can be applied, but cancer-specific measures of distress for partners and other family members are needed.

Some investigators have been vague when specifying 'partners', e.g. mentioning a 'significant adult' or a 'caregiver'. However, most patients nominated their partner in any case. An indistinct recruitment approach inhibits comparisons between studies since the patient may have a spouse or partner but suggest an adult child, sibling or friend in response to the investigator's request. It is far better to specify partners if virtually all patients will nominate their partner anyway. In this age group, at this time, this has almost invariably meant a female partner.

Inadequate sample size limits many studies. Moreover, much work is marred by the unsatisfactory practice of not discriminating for type of cancer (e.g. all urological cancers are lumped together), stage or treatment modality. Arranging more than one recruitment site is a suitable remedy to obviate these crucial limitations. Alternatively, national cancer registers as a source of patients and partners is optimal, permitting access to vast numbers of potential recruits with minimal selection bias.

Attention also needs to be paid to representativeness of samples when recruiting to reflect 'real life' clinical settings. We have seen recruitment through public, private and veterans' clinics. Representativeness could be enhanced by combining these sources of recruitment. We have also noted recruitment through attendance at educational programmes and responses to media advertisements, neither of which reflects real life clinical settings where most patients and partners encounter the doctor.

In the interest of devising an intervention for couples at risk of a poor psychosocial outcome, a longitudinal, repeated measures method is essential. Unfortunately, the problem of retention rates rears its unwelcome head, especially beyond 6 months from the baseline. This is a challenge in all psycho-oncology outcome research, especially when participants' cancer is advanced.

Linking longitudinal, observational psychosocial studies to medical and surgical PCA treatment trials is one strategy that may reduce attrition since couples are committed to treatment and will, one hopes, associate the psychosocial investigation with the patient's medical or surgical treatment.

In addition, a sophisticated comparison of physical and psychological benefits and costs for patients and partners of different forms of treatment can be established. The work of Kornblith *et al.* (2001) is exemplary in this regard.

## CONCLUSION

Research on men's reaction to an intensely 'personal' condition like PCA and its treatment without involving the partner risks overlooking a key relational dimension. Just as mastectomy and hormone therapy can challenge a woman's self-image as mother, wife and sexual partner, so prostatectomy, hormone therapy and other treatments used in PCA can shake a man's self-concept as father, husband and sexual partner. PCA like breast cancer can be construed usefully as a 'relational' condition. PCA and its treatment affect intimate aspects of bodily and psychological function in ways that only a partner appreciates; moreover, she may bear the brunt of the process. Future research into psychosocial ramifications of PCA should, therefore, incorporate the partner as well as the patient.

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