

Do men with prostate cancer and their partners receive the information they need for optimal illness self-management in the immediate post-diagnostic phase?

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ABSTRACT

Objective: To (a) determine whether the information provided to men with prostate cancer and their partners in the immediate postdiagnostic phase met their needs; and (b) examine patient and partner satisfaction with the information received.

Methods: Pre-intervention survey data from a pilot randomized controlled trial of a self-directed coping skills intervention involving 42 patients with prostate cancer, and their partners were collected to examine their psychosocial concerns/needs.

Results: The main concerns for patients and partners were psychosocial in nature such as managing emotions, concern about the future, and losing control. Overall, patients and partners received most information about tests and treatment options.

Partners reported receiving significantly less information about support services ($P = 0.03$) and self-care strategies ($P = 0.03$) compared to patients. Partners also reported being significantly less satisfied with the information they received ($P = 0.007$).

Conclusions: Whereas medical information is routinely given, patients and partners may benefit from greater information about psychosocial issues arising from cancer. Despite increased recognition of partner's information needs these still remain unmet.

Key words: Prostate cancer, information seeking, psychosocial needs, partners/caregivers, satisfaction with information

Introduction

Prostate cancer is the most common cancer in Australian men, and approximately 92% of the patients survive beyond 5 years.^[1] While surviving cancer treatment, prostate cancer survivors may experience long-term treatment side effects

(e.g., incontinence, sexual dysfunction) that challenge the patient's sense of masculinity and identity,^[2-4] impact upon life satisfaction, and reduce mental and social well-being.^[5,6] While prostate cancer is exclusively a male disease, it is also argued that, for partnered men, it could be considered a "relational disease"^[7] due to the significant impact that the physical and psychosocial consequences may have on intimate relationships. In addition, Galbraith *et al.*^[8] have demonstrated the strong interrelationship between patient and partner health-related quality of life for couples experiencing prostate cancer, suggesting mutuality in response to the disease and its treatment, and therefore highlighting the need to consider both members of a dyad throughout the cancer journey.

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Although there is increasing recognition of the importance of psychosocial issues in cancer care and survivorship, many patients with cancer and their partners report unmet psychosocial needs.^[6,9-11] Research examining the unmet needs of patients with prostate cancer have found that fear of cancer spread, concern about the impact of cancer on others, changes in sexual functioning, managing side effects or treatment complications, and adjusting to changes in quality of life are issues that are potentially unmet in routine care and treatment.^[12-16] In terms of the types and perceived importance of unmet needs for patients with prostate cancer, Boberg *et al.*^[12] concluded that patient's most important needs (i.e., care delivery needs) were generally met; however, their support needs (e.g., dealing with side effects, addressing emotional issues) were perceived as less important and generally unmet. In terms of information needs, patients reported having unmet needs regarding recurrence and treatment-related side effects.^[12]

There is also growing evidence of the numerous psychosocial challenges for partners dealing with prostate cancer, including emotional distress, psychosexual and relational changes, assisting the patient to adjust to treatment-related side effects and an altered view of the future.^[6,7,9,17,18] Hawes *et al.*^[11] identified that the partners of patients with prostate cancer reported both personal challenges such as maintaining a balanced life and emotional well-being, but also patient-related challenges such as dysfunctional communication and fear of the patient developing depression. There is also evidence to suggest that partners of patients with prostate cancer who are themselves depressed or anxious demonstrate lower coping skills and poorer adaptation to the diagnosis compared to patients.^[7]

One avenue through which unmet needs may be addressed is illness self-management. Fenlon and Foster^[19] define cancer self-management as the "awareness and active participation by the person in their recovery, recuperation, and rehabilitation, to minimize the consequences of treatment, promote survival, health and well-being." Self-management interventions typically aim at addressing information needs (knowledge focus) and/or development of new, adaptive skills to address cancer-related challenges (training focus).^[20] While the self-management literature for prostate cancer is developing,^[21] early evidence suggests that self-management can be an effective way to manage both physical and psychological symptoms associated with the disease.^[22-24]

One strategy for enhancing self-management and meeting the psychosocial needs of men with prostate cancer and their partners is through information provision;

either received from their health care professionals, or independently acquired (e.g., internet searches). Evidence suggests that appropriate information can reduce anxiety, facilitate a sense of control and coping, increase treatment adherence, improve engagement in shared decision-making, and enhance self-care self-efficacy.^[25-31]

Despite the apparent benefits of obtaining adequate information, studies continue to find that the informational needs of patients and partners may be unmet.^[9,10,26,32] This may be partly explained due to the complexity of the information seeking concept, which goes beyond simply the provision of information.^[33] Specifically, information seeking and adequate provision requires the identification of the type of information needed, the desired amount, the preferred format, and under what circumstances patients and partner wish to access that information.^[29,33] For partners of patients with prostate cancer, in particular, a reluctance to seek information from health-care professionals has been identified, due to a sense of disempowerment and time pressures of the medical consultation.^[26]

Another variable that may be pertinent regarding health information seeking in the cancer context is satisfaction with information received. Davies *et al.*^[34] found that satisfaction with information was a significant predictor for all aspects of quality of life (physical, social and emotional well-being) for a sample of prostate and breast cancer patients. Satisfaction with information may also contribute to treatment decision making for patients with prostate cancer, with Gilbert *et al.*^[35] finding that discussions with the physician regarding treatment outcomes was the only satisfying source of information for men considering their treatment options. Studies specifically examining partner satisfaction with information have, to the best of our knowledge, not been conducted.

A secondary goal of the study was to assess whether men diagnosed with prostate cancer and their partners received the information they needed to address their core concerns in the early postdiagnostic phase and to examine their satisfaction with information received. The current manuscript reports on the information needs of all participants at time of entry to the study (i.e., prior to intervention randomization).

Materials and Methods

Ethics

This pilot randomized controlled trial was undertaken to explore the efficacy of a psychosocial information

resource for couples (*Coping-Together*)^[36] with approval obtained from the University of Newcastle, University of New South Wales, and South West Sydney Local Health District Human Research Ethics Committees. Findings relating to the efficacy of the intervention are reported elsewhere.^[37]

Study design

Selection and description of participants

Potential participants were referred to the study from clinicians in New South Wales and South Australia, Australia. Couples were eligible if they met the following criteria:

- Diagnosed with early stage, primary prostate cancer within the past 4 months;
- Receiving or planning to receive treatment (including active surveillance);
- Patient or partner scores ≥ 4 on the distress thermometer;^[38]
- Fluent in English;
- Cognitively able to complete surveys.

One hundred and seventy patients were referred to the study, with 57 couples not meeting the eligibility criteria, 51 declining the invitation to be part of the study and 20 unable to be contacted after referral. Forty-two couples were randomized to the study.

Measures

SupportScreen

Biopsychosocial concerns were assessed using a 48-item adapted version of the SupportScreen tool.^[39] Participants indicated the degree to which specific issues (e.g., finding reliable information about my diagnosis and treatment, feeling anxious or fearful) were a concern using a scale of 1-4, with higher scores indicating a higher level of concern or help needed.

EORTC-INFO25

Participants' perception of the information they received and their satisfaction with that information was assessed using the information module developed by the EORTC quality of life group.^[25] This module consists of 26-items, comprising subscales for information received regarding disease, medical tests, treatment, other services, places of care and self-management. Satisfaction with information was assessed using a single item.

Other measures included in the preintervention survey included the Hospital Anxiety and Depression Scale,^[40] Revised Impact of Event Scale.^[41] Assessment of Quality

of Life-8 Dimensions,^[42] Revised Dyadic Adjustment Scale,^[43] Cognitive Appraisal of Health Scale,^[44] Mishel's Uncertainty in Illness Scale,^[45] Lewis Cancer Self-efficacy Scale,^[46] Communication and Attitudinal Self-efficacy for Cancer,^[47] Brief Cope^[48] and the Dyadic Coping Inventory.^[49] Partners also completed the Caregiver Quality of Life Index^[50] and the Appraisal of Caregiving Scale.^[51] Further details regarding the measures are provided in the study protocol.^[36]

Procedures

Patients and their partners independently completed a comprehensive preintervention survey, prior to randomization, with the data from the preintervention survey pertaining to information needs and psychosocial challenges being reported here. Once the preintervention survey was returned, couples were randomized via a computer generated randomization schedule to either the *Coping-Together* intervention or minimal ethical care (MEC) condition. Couples randomized to the intervention received four *Coping-Together* booklets that propose specific coping strategies to mitigate challenges pertaining to symptom management, communication with health care professionals, providing support to partners and dealing with emotions.^[36] A relaxation CD, DVD and fortnightly Top-Tips newsletter supplemented the written materials. Couples randomized to the MEC group received the Understanding Prostate Cancer and Caring for Someone with Cancer booklets from the Cancer Council NSW and the Cancer Council Helpline brochure. A second survey identical to the preintervention survey was completed approximately 2 months after randomization. The results of the trial have been reported elsewhere.^[37]

Statistical analysis

To investigate the information needs and challenges experienced by couples dealing with prostate cancer, analyses were conducted on selected measures from the preintervention survey to explore what information participants had received prior to the couple getting information resources as part of their involvement in the study. Independent *t*-tests were performed to examine differences between patients and partners on information subscales and the satisfaction with information item from the EORTC-INFO25.^[25] Item means were obtained for SupportScreen^[39] items and ranked in order of magnitude of concern for both patients and partners. Results relating to other measures from the preintervention survey are reported elsewhere.^[37]

Results

Participant characteristics

The mean age of patients was 63.8 years (standard deviation [SD] = 6.8) and partners was 59.9 years (SD = 7.5), and the average time since diagnosis was 38 days (SD = 23.72, range = 9-118 days). Demographic information about the sample is included in Table 1.

Core concerns

Psychosocial items from SupportScreen,^[39] such as managing emotions, worry about the future, and self-managing treatment side effects were the issues identified as being most problematic, although overall, the reported items means were low, suggesting a mild problem (range = 1-4). The 10 most strongly endorsed concerns of patients and partners are included in Table 2. Aside from managing side effects, medical concerns were rated by both patients and partners outside their top 10 issues (e.g., finding reliable information about diagnosis and treatment was rated 20th for patients and 16th for partners).

Information received and satisfaction

Both patients and partners reported that the most information they received was about medical tests and treatment options [Table 3]. While patients reported receiving adequate information regarding accessing support services and self-management, their partners reported receiving significantly less information on these matters.

In regards to satisfaction, patients reported a relatively high level of satisfaction with the information they received (mean = 3.26, SD = 0.68, range 1-4), whereas partners reported significantly less satisfaction overall (mean = 2.77, SD = 0.87, $P = 0.007$).

Discussion

The findings indicated that men with prostate cancer and their partners are receiving a high level of information regarding their diagnosis, tests, and treatment options. This is an encouraging finding as receiving adequate medical information can lead to greater participation in decision-making,^[25] and reduction in distress, anxiety and depression.^[28,52] Possibly, because their needs for medical information were being routinely met, both patients and partners identified their core concerns as psychosocial issues; however, they received less information on such topics. Similar findings were recently reported by Majumder *et al.*,^[53] finding that information provision

Table 1: Participant characteristics

| Characteristics | Patients (%) | Partners (%) |
|-------------------------------|-------------------|--------------|
| Relationship status | | |
| Married/de facto | 40 (95) | |
| Boyfriend/girlfriend | 1* (2.5) | |
| Mean relationship length (SD) | 33.7 years (13.6) | |
| County of birth | | |
| Australia | 37 (90) | 38 (93) |
| Other | 4 (10) | 3 (7) |
| Education | | |
| Primary/secondary school | 10 (24) | 21 (51) |
| Trade qualification | 17 (41) | 11 (27) |
| University education | 14 (34) | 9 (22) |
| Employment | | |
| Fulltime/self-employed | 17 (41) | 7 (17) |
| Part time | 4 (9.8) | 4 (9.8) |
| Pensioner | 19 (46) | 19 (46) |
| Volunteer or household duties | 1 (2.4) | 11 (27) |
| Treatment modalities | | |
| Surgery | 13 (31) | |
| Radiotherapy | 5 (12) | |
| Hormone treatment | 2 (4.8) | |
| Brachytherapy | 2 (4.8) | |
| Active surveillance | 5 (12) | |

*Demographic data are missing for one couple, all other analyses based on $n = 42$ couples. SD: Standard deviation

Table 2: Top 10 concerns of patients and partners

| SupportScreen item | Patient ($n = 41$) | | Partner ($n = 40$) | |
|--|----------------------|---------|----------------------|---------|
| | Item Mean (SD) | Ranking | Item Mean (SD) | Ranking |
| Side effects of treatment | 2.07 (0.99) | 1 | 1.72 (1.00) | 4 |
| Losing control over things that matter to me | 1.88 (0.84) | 2 | 1.60 (0.93) | 7 |
| Worry about the future | 1.85 (0.73) | 3 | 2.05 (0.83) | 1 |
| How my family will cope | 1.78 (0.76) | 4 | 1.60 (0.87) | 7 |
| Managing emotions | 1.73 (0.84) | 5 | 1.85 (0.89) | 3 |
| Being unable to take care of myself/partner | 1.61 (1.12) | 6 | 1.15 (0.53) | 26 |
| Feeling anxious or fearful | 1.59 (0.63) | 7 | 1.90 (0.93) | 2 |
| Feeling down or depressed | 1.56 (0.81) | 8 | 1.65 (0.80) | 5 |
| Feeling irritable or angry | 1.56 (0.71) | 8 | 1.63 (0.87) | 6 |
| Finances | 1.51 (0.87) | 9 | 1.50 (0.85) | 9 |
| Knowing how to support my partner | 1.51 (0.84) | 9 | 1.43 (0.71) | 13 |
| Questions and fear about end of life | 1.49 (0.75) | 10 | 1.49 (0.82) | 10 |
| Thinking clearly | 1.37 (0.73) | 12 | 1.55 (0.76) | 8 |

SD: Standard deviation

could be improved for areas such as other services, different places of care and things to help yourself. Together these results suggest that although there has been increasing recognition of the psychosocial needs of cancer patients and caregivers, such needs might be overlooked or viewed as secondary (i.e., to be addressed after medical concerns). This echoes the findings of other studies that have identified

Table 3: Level of information received by patients and partners

| INFO25 subscale | Mean (SD) | | P |
|---|-------------|-------------|------|
| | Patient | Partner | |
| Information about the disease | 2.63 (0.60) | 2.78 (0.80) | 0.33 |
| Information about medical tests | 3.15 (0.59) | 3.28 (0.66) | 0.35 |
| Information about treatment | 2.85 (0.68) | 2.87 (0.72) | 0.91 |
| Information about other services | 1.83 (0.77) | 1.49 (0.57) | 0.03 |
| Information about different places of care | 1.68 (0.96) | 1.41 (0.68) | 0.15 |
| Information about things to help you get well (self-management) | 2.20 (0.98) | 1.72 (0.92) | 0.03 |

SD: Standard deviation

improvements were needed in the provision of information about psychosocial matters.^[52,54-58]

The significantly lower level of information received regarding support services, and self-management of health/well-being for partners is an important finding. With an increasing trend toward cancer patients being treated through outpatient clinics and shorter postoperative hospital stays, partners are increasingly expected to provide appropriate support and care for patients. Previous research has demonstrated that cancer caregivers report high levels of anxiety and depression,^[59-62] sleep disturbances/fatigue,^[61] and lower quality of life.^[59] Consequently, Galbraith *et al.*^[8] propose that partner needs should be incorporated into treatment, care plans, and follow-up processes.

Overall, the men with prostate cancer reported a high level of satisfaction with the information they received. Previous research has suggested that satisfaction with information may enhance quality of life,^[34] facilitate involvement in decision making,^[63] increased use of adaptive coping strategies,^[33] and enhance vitality and positive mental health.^[64] The finding that partners reported significantly lower satisfaction with the information they received suggests that their information needs may be unmet. This aligns with the conclusion of Echlin and Rees^[32] who identified that despite undergoing information seeking, often more actively than patients, the partners of prostate cancer patients had unmet information needs. These findings have important implications, especially if, like patients, satisfaction with information is related to quality of life and mental health.^[34,64] This is highlighted as an area for future research.

The small sample size limits the study power and influences the type of analyses that can be performed, therefore it is suggested that the findings be interpreted with caution. Recruitment of couples into research related to health issues can be challenging, with barriers to recruitment including the patient not wanting their partner involved,

only one member of the dyad wanting to participate and declining due to time required for study commitments.^[65,66] These challenges were all encountered in the current study. However, with limited studies examining both patient and partner information needs in relation to prostate cancer, the current study provides some valuable insight that may encourage additional research in this space. The use of the SupportScreen^[39] as a research measure may also be viewed as a limitation, as it is designed as an electronic screening tool for clinical use. Finally, while we have assessed patient and partner satisfaction with the information received, we are not able to determine whether it aligns with the preferences for support (e.g., information, access to services, support groups) each member of the dyad may have wanted, and this may impact on their level of satisfaction. Future studies employing a mixed methodology to explore patient and partner preferences for support would enhance our understanding in this area.

Overall, it was found that men with prostate cancer and their partners receive adequate information regarding their treatment options and medical tests; however, they receive less information regarding psychosocial issues, despite both groups reporting that their core concerns are psychosocial in nature. The findings suggest that greater provision of psychosocial information is needed to adequately address the core concerns of both men with prostate cancer and their partners. Additional attention is required regarding the information needs of partners, particularly in ensuring that they receive information that satisfies their main concerns.

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