

# 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.<sup>[1]</sup> 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,<sup>[2-4]</sup> impact upon life satisfaction, and reduce mental and social well-being.<sup>[5,6]</sup> While prostate cancer is exclusively a male disease, it is also argued that, for partnered men, it could be considered a "relational disease"<sup>[7]</sup> due to the significant impact that the physical and psychosocial consequences may have on intimate relationships. In addition, Galbraith *et al.*<sup>[8]</sup> 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.<sup>[6,9-11]</sup> 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.<sup>[12-16]</sup> In terms of the types and perceived importance of unmet needs for patients with prostate cancer, Boberg *et al.*<sup>[12]</sup> 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.<sup>[12]</sup>

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.<sup>[6,7,9,17,18]</sup> Hawes *et al.*<sup>[11]</sup> 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.<sup>[7]</sup>

One avenue through which unmet needs may be addressed is illness self-management. Fenlon and Foster<sup>[19]</sup> 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).<sup>[20]</sup> While the self-management literature for prostate cancer is developing,<sup>[21]</sup> early evidence suggests that self-management can be an effective way to manage both physical and psychological symptoms associated with the disease.<sup>[22-24]</sup>

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.<sup>[25-31]</sup>

Despite the apparent benefits of obtaining adequate information, studies continue to find that the informational needs of patients and partners may be unmet.<sup>[9,10,26,32]</sup> This may be partly explained due to the complexity of the information seeking concept, which goes beyond simply the provision of information.<sup>[33]</sup> 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.<sup>[29,33]</sup> 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.<sup>[26]</sup>

Another variable that may be pertinent regarding health information seeking in the cancer context is satisfaction with information received. Davies *et al.*<sup>[34]</sup> 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.*<sup>[35]</sup> 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*)<sup>[36]</sup> 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.<sup>[37]</sup>

## 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  $\geq 4$  on the distress thermometer;<sup>[38]</sup>
- 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.<sup>[39]</sup> 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.<sup>[25]</sup> 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,<sup>[40]</sup> Revised Impact of Event Scale.<sup>[41]</sup> Assessment of Quality

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

## 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.<sup>[36]</sup> 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.<sup>[37]</sup>

## 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.<sup>[25]</sup> Item means were obtained for SupportScreen<sup>[39]</sup> 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.<sup>[37]</sup>

## 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,<sup>[39]</sup> 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 20<sup>th</sup> for patients and 16<sup>th</sup> 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,<sup>[25]</sup> and reduction in distress, anxiety and depression.<sup>[28,52]</sup> 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.*,<sup>[53]</sup> 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.<sup>[52,54-58]</sup>

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,<sup>[59-62]</sup> sleep disturbances/fatigue,<sup>[61]</sup> and lower quality of life.<sup>[59]</sup> Consequently, Galbraith *et al.*<sup>[8]</sup> 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,<sup>[34]</sup> facilitate involvement in decision making,<sup>[63]</sup> increased use of adaptive coping strategies,<sup>[33]</sup> and enhance vitality and positive mental health.<sup>[64]</sup> 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<sup>[32]</sup> 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.<sup>[34,64]</sup> 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.<sup>[65,66]</sup> 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<sup>[39]</sup> 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.

## References

1. Cancer Australia. Prostate Cancer Statistics; 2014. Available from: <http://canceraustralia.gov.au/affected-cancer/cancer-types/prostate-cancer/prostate-cancer-statistics>. [Last accessed on 2015 May 25].
2. Broom A. Prostate cancer and masculinity in Australian society: A care of stolen identity? *Int J Mens Health* 2004;3:73-91.
3. Fergus KD, Gray RE, Fitch MI. Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer. *J Health Psychol* 2002;7:303-16.
4. Klaeson K, Sandell K, Berterö CM. Sexuality in the context of prostate cancer narratives. *Qual Health Res* 2012;22:1184-94.
5. Sharpley CF, Birsika V, Denham JW. Factors associated with feelings of loss of masculinity in men with prostate cancer in the RADAR trial. *Psychooncology* 2014;23:524-30.
6. Weber BA, Sherwill-Navarro P. Psychosocial consequences of prostate cancer: 30 years of research. *Geriatr Nurs* 2005;26:166-75.
7. Street AF, Couper JW, Love AW, Bloch S, Kissane DW, Street BC. Psychosocial adaptation in female partners of men with prostate cancer. *Eur J Cancer Care (Engl)* 2010;19:234-42.

8. Galbraith ME, Pedro LW, Jaffe AR, Allen TL. Describing health-related outcomes for couples experiencing prostate cancer: Differences and similarities. *Oncol Nurs Forum* 2008;35:794-801.
9. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The supportive care needs of men with advanced prostate cancer. *Oncol Nurs Forum* 2011;38:189-98.
10. Girgis A, Lambert SD, McElduff P, Bonevski B, Lecathelinais C, Boyes A, *et al.* Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psychooncology* 2013;22:1557-64.
11. Hawes S, Malcarne V, Ko C, Sadler G, Banthuaia R, Sherman S, *et al.* Identifying problems faced by spouses and partners of patients with prostate cancer. *Oncol Nurs Forum* 2006;33:807-14.
12. Boberg EW, Gustafson DH, Hawkins RP, Offord KP, Koch C, Wen KY, *et al.* Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Educ Couns* 2003;49:233-42.
13. Lintz K, Moynihan C, Steginga S, Norman A, Eeles R, Huddart R, *et al.* Prostate cancer patients' support and psychological care needs: Survey from a non-surgical oncology clinic. *Psychooncology* 2003;12:769-83.
14. O'Brien R, Rose P, Campbell C, Weller D, Neal RD, Wilkinson C, *et al.* "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Educ Couns* 2011;84:200-7.
15. Rivers BM, Gonzalez B, Hussin M, Jacobsen PB. Unmet psychosocial and educational needs of men treated for prostate cancer: A preliminary assessment. *Ann Behav Med* 2012;43:S13.
16. White K, D'Abrew N, Katris P, O'Connor M, Emery L. Mapping the psychosocial and practical support needs of cancer patients in Western Australia. *Eur J Cancer Care (Engl)* 2012;21:107-16.
17. Kent EE, Arora NK, Rowland JH, Bellizzi KM, Forsythe LP, Hamilton AS, *et al.* Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. *Patient Educ Couns* 2012;89:345-52.
18. Roth AJ, Weinberger MI, Nelson CJ. Prostate cancer: Psychosocial implications and management. *Future Oncol* 2008;4:561-8.
19. Fenlon D, Foster C. Self management support: A review of the evidence. Macmillan Research Unit, University of Southampton; 2009.
20. McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, *et al.* Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011;61:50-62.
21. Paterson C, Jones M, Rattray J, Lauder W. Identifying the self-management behaviours performed by prostate cancer survivors: A systematic review of the evidence. *J Res Nurs* 2015;20:96-111.
22. Cockle-Hearne J, Faithfull S. Self-management for men surviving prostate cancer: A review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances. *Psychooncology* 2010;19:909-22.
23. Hsiao CP, Moore IM, Insel KC, Merkle CJ. Symptom self-management strategies in patients with non-metastatic prostate cancer. *J Clin Nurs* 2014;23:440-9.
24. Oliffe JL, Davison BJ, Pickles T, Mróz L. The self-management of uncertainty among men undertaking active surveillance for low-risk prostate cancer. *Qual Health Res* 2009;19:432-43.
25. Arraras JI, Greimel E, Sezer O, Chie WC, Bergenmar M, Costantini A, *et al.* An international validation study of the EORTC QLQ-INFO25 questionnaire: An instrument to assess the information given to cancer patients. *Eur J Cancer* 2010;46:2726-38.
26. Feltwell AK, Rees CE. The information-seeking behaviours of partners of men with prostate cancer: A qualitative pilot study. *Patient Educ Couns* 2004;54:179-85.
27. Fernsler JI, Cannon CA. The whys of patient education. *Semin Oncol Nurs* 1991;7:79-86.
28. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Ann Oncol* 2011;22:761-72.
29. Lambert SD, Loiselle CG. Health information seeking behavior. *Qual Health Res* 2007;17:1006-19.
30. McCaughan E, McKenna H. Never-ending making sense: Towards a substantive theory of the information-seeking behavior of newly diagnosed cancer patients. *Cancer Nurs* 2007;16:2096-104.
31. McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: A systematic literature review of randomized controlled trials. *J Public Health Med* 2001;23:227-34.
32. Echlin KN, Rees CE. Information needs and information-seeking behaviors of men with prostate cancer and their partners: A review of the literature. *Cancer Nurs* 2002;25:35-41.
33. van der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *Eur J Cancer Care (Engl)* 1999;8:238-44.
34. Davies NJ, Kinman G, Thomas RJ, Bailey T. Information satisfaction in breast and prostate cancer patients: Implications for quality of life. *Psychooncology* 2008;17:1048-52.
35. Gilbert SM, Sanda MG, Dunn RL, Greenfield TK, Hembroff L, Klein E, *et al.* Satisfaction with information used to choose prostate cancer treatment. *J Urol* 2014;191:1265-71.
36. Lambert SD, Girgis A, Turner J, McElduff P, Kayser K, Vallentine P. A pilot randomized controlled trial of the feasibility of a self-directed coping skills intervention for couples facing prostate cancer: Rationale and design. *Health Qual Life Outcomes* 2012;10:119.
37. Lambert SD, McElduff P, Girgis A, Levesque JV, Regan TW, Turner J, *et al.* A pilot, multisite, randomized controlled trial of a self-directed coping skills training intervention for couples facing prostate cancer: Accrual, retention, and data collection issues. Submitted *J Support Care Cancer* [In Press].
38. National Comprehensive Cancer Network. Distress Management Clinical Practice Guidelines: Version 1; 2014. Available from: [http://www.nccn.org/professionals/physician\\_gls/pdf/distress.pdf](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf). [Last accessed on 2015 May 25].
39. Loscalzo M, Clark K, Dillehunt J, Rinehart R, Strowbridge R, Smith D. SupportScreen: A model for improving patient outcomes. *J Natl Compr Cancer Netw* 2010;8:496-502.
40. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361-70.
41. Weiss DS, Marmar CR. The impact of event scale — Revised. In: Wilson JP, Keane TM, editors. *Assessing Psychological*

- Trauma and PTSD. New York: Guilford Press; 1997. p. 399-411.
42. Richardson J, Khan M, Iezzi A, Sinha K, Mihalopoulos C, Herrman H, *et al.* The AQoL-8D (PsyQoL) MAU Instrument: Overview September 2009. Research paper39, Centre for Health Economics; 2009.
  43. Busby DM, Christensen C, Crane R, Larson JH. A revision of the dyadic adjustment scale for use with distressed and nondistressed couples: Construct hierarchy and multidimensional scales. *J Marital Fam Ther* 1995;21:289-308.
  44. Kessler TA. The cognitive appraisal of health scale: Development of psychometric evaluation. *Res Nurs Health* 1998;21:73-82.
  45. Mishel MH. The measurement of uncertainty in illness. *Nurs Res* 1981;30:258-63.
  46. Lewis FM. Family Home Visitation Study Final Report. National Cancer Institute, National Institutes of Health; 1996.
  47. Wolf MS, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-efficacy scale for cancer (CASE-cancer). *Patient Educ Couns* 2005;57:333-41.
  48. Carver CS. You want to measure coping but your protocol's too long: Consider the brief COPE. *Int J Behav Med* 1997;4:92-100.
  49. Bodenmann G. *Dyadisches Coping Inventar: Testmanual [Dyadic Coping Inventory: Test Manual]*. Bern, Switzerland: Huber; 2008.
  50. Weitzner MA, Jacobsen PB, Wagner H Jr, Friedland J, Cox C. The Caregiver Quality of Life Index-Cancer (CQQLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Qual Life Res* 1999;8:55-63.
  51. Lambert SD, Yoon H, Ellis KR, Northouse L. Measuring appraisal during advanced cancer: Psychometric testing of the appraisal of caregiving scale. *Patient Educ Couns* 2015;98:633-9.
  52. Mesters I, van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. *Patient Educ Couns* 2001;43:253-62.
  53. Majumder K, Brandberg Y, Johansson H, Nilsson S, Bergenmar M. Less satisfaction with information in patients with prostate cancer treated with surgery and salvage radiotherapy compared with patients treated with curative radiotherapy alone, despite similar health-related quality of life. *Clin Genitourin Cancer* 2014;12:e71-82.
  54. Adams E, Boulton M, Watson E. The information needs of partners and family members of cancer patients: A systematic literature review. *Patient Educ Couns* 2009;77:179-86.
  55. Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. Information needs and experiences: An audit of UK cancer patients. *Eur J Oncol Nurs* 2006;10:263-72.
  56. Llewellyn CD, McGurk M, Weinman J. How satisfied are head and neck cancer (HNC) patients with the information they receive pre-treatment? Results from the satisfaction with cancer information profile (SCIP). *Oral Oncol* 2006;42:726-34.
  57. Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Couns* 2005;57:342-9.
  58. Nicolaije KA, Husson O, Ezendam NP, Vos MC, Kruitwagen RF, Lybeert ML, *et al.* Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: A study from the population-based PROFILES registry. *Patient Educ Couns* 2012;88:427-35.
  59. Corà A, Partinico M, Munafò M, Palomba D. Health risk factors in caregivers of terminal cancer patients: A pilot study. *Cancer Nurs* 2012;35:38-47.
  60. Lambert SD, Girgis A, Lecathelinais C, Stacey F. Walking a mile in their shoes: Anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer* 2013;21:75-85.
  61. Romito F, Goldzweig G, Cormio C, Hagedoorn M, Andersen BL. Informal caregiving for cancer patients. *Cancer* 2013;119 Suppl 11:2160-9.
  62. Stenberg U, Cvancarova M, Ekstedt M, Olsson M, Ruland C. Family caregivers of cancer patients: Perceived burden and symptoms during the early phases of cancer treatment. *Soc Work Health Care* 2014;53:289-309.
  63. Sheehan J, Sherman KA, Lam T, Boyages J. Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction. *Psychooncology* 2007;16:342-51.
  64. Griggs JJ, Sorbero ME, Mallinger JB, Quinn M, Waterman M, Brooks B, *et al.* Vitality, mental health, and satisfaction with information after breast cancer. *Patient Educ Couns* 2007;66:58-66.
  65. Trief PM. Challenges and lessons learned in the development and implementation of a couples-focused telephone intervention for adults with type 2 diabetes: the diabetes support project. *Transl Behav Med* 2011;1:461-67.
  66. Fredman SJ, Baucom DH, Gremore TM, Castellani AM, Kallman TA, Porter LS, *et al.* Quantifying the recruitment challenges with couple-based interventions for cancer: Applications to early-stage breast cancer. *Psychooncology* 2009;18:667-73.

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