

# Provision of Individualized Information to Men and Their Partners to Facilitate Treatment Decision Making in Prostate Cancer

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**Purpose/Objectives:** To determine if providing individualized information to men who are newly diagnosed with prostate cancer and their partners would lower their levels of psychological distress and enable them to become more active participants in treatment decision making.

**Design:** Quasiexperimental, one group, pretest/post-test.

**Setting:** The Prostate Centre at Vancouver General Hospital in British Columbia, Canada.

**Sample:** Convenience sample of 74 couples. 73 men had early-stage prostate cancer. Mean age of the men was 62.2 years, and mean age of the partners was 58.1 years. The majority (> 50%) had received their high school diplomas.

**Methods:** Respondents completed measures of decision preferences and psychological distress at the time of diagnosis and four months later. All participants used a computer to identify their information and decision preferences. Computer-generated, graphic printouts were used to guide the information counseling session.

**Findings:** Patients reported assuming a more active role in medical decision making than originally intended, partners assumed a more passive role in decision making than originally intended, and all participants had lower levels of psychological distress at four months.

**Conclusions:** Evidence supports the need to provide informational support to couples at the prostate cancer diagnosis to facilitate treatment decision making and lower levels of psychological distress. Future research is needed to evaluate this type of approach in the context of a randomized clinical trial design.

**Implications for Nursing:** The personalized, computer-graphic printouts can provide clinicians with an innovative method of guiding information counseling and providing decisional support to men with prostate cancer and their partners.

Prostate cancer poses a significant health concern for men and their families. Currently, prostate cancer is the most commonly diagnosed nonskin malignancy and second most common cause of male cancer-related deaths in North America (Jemal, Thomas, Murray, & Thun, 2002; National Cancer Institute of Canada, 2002). Etiology remains unknown, optimal treatment is controversial, survival rates vary, and all prostate cancer therapies have an impact on quality of life (Brawley & Barnes, 2001; McPherson, Swenson, & Kjellberg, 2001; O'Rourke, 2001). The diagnosis often is unexpected and particularly stressful for men and their partners as they first adjust to the cancer diagnosis and try to make sense of the various treatment options. Although the majority of oncology healthcare professionals believe that patients with cancer should be involved in making informed treatment choices, a significant number of men are presenting to physician offices for treatment discussions with little to no knowledge of the dis-

## Key Points . . .

- ▶ The Patient Information Program computer program provides clinicians with a method of assessing and providing information to men who are newly diagnosed with prostate cancer and their partners.
- ▶ Evidence indicates that such an individualized information decision support intervention assists men in becoming more active participants in treatment decision making.
- ▶ Provision of individualized information at the time of diagnosis lessens the psychological distress of couples after a definitive treatment decision has been made.
- ▶ Further research is needed to explore how partners use information and how satisfied they are with their reported level of involvement in treatment decision making at the time of diagnosis.

ease or potential treatment options (Onel et al., 1998). Treatment choices often are made as a response to lay information or a result of a bias toward surgery as a cure (O'Rourke & Germino, 1998). Informal sources such as family, friends, and men with prostate cancer remain the most frequently cited sources of information used by men and their partners (Davison & Degner, 1997; Davison, Degner, & Morgan, 1995).

Men with prostate cancer have been shown to prefer to participate in treatment decision making with their physicians (Davison & Degner, 1997; Wong et al., 2000), but the extent

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to which partners wish to participate in treatment decisions and the influence they have on the final treatment decision currently is unknown. Data exist to indicate that older female spouses tend to ask more questions than their partners and assume a more active role in medical encounters (Beisecker & Moore, 1994). However, information is limited regarding how younger or same-sex partners wish to be involved in medical decision making. Investigators have demonstrated that providing information to men who are newly diagnosed with prostate cancer does result in benefits such as increased participation in treatment decision making, decreased levels of anxiety, and improved communication of illness-related information to family (Davison & Degner). The benefits of providing information to partners are unknown.

## Literature Review

Davison and Degner (1997) measured the effect of providing self-efficacy information to a group of men who were newly diagnosed with prostate cancer and measured an assumed-decisional role as the primary patient outcome. Men received either a written information package or an intervention that consisted of a written information package with discussion, a list of questions they could ask their physicians, and an opportunity to have their medical consultations audiotaped. Because the majority of men were married, they were encouraged to have their partners present during the treatment discussion with their physicians. The intervention resulted in lowering men's levels of state anxiety at six weeks following the treatment decision and men assuming more active roles in treatment decision making than originally preferred. Men reported that all three parts of the intervention were important. Married men from both groups reported that their wives read all or most of the information package. This information intervention was shown to be effective in helping men to assume a more active role in treatment decision making. The authors suggested that further efforts be made to include spouses in all treatment-related information sessions and to study how partners wished to be involved in the treatment decisions with their spouses.

Men with prostate cancer and their partners experience a variety of stressful events at the time of diagnosis that could place them at risk for poor psychological and emotional adjustment. Fear of cancer contributes to anxiety, helplessness, and loss of control. In a literature review by Northouse and Peters-Golden (1993) about the impact of cancer on spouses, three specific concerns were identified as universal to spouses of patients with cancer: dealing with the fear and threat associated with a cancer diagnosis, helping partners to deal with the emotional repercussions of the cancer, and managing changes and disruptions of daily life brought on by disease. Additional concerns included lack of information, obstacles encountered when seeking information to make a treatment decision, perceived lack of time physicians spent explaining treatment options, difficulties getting second opinions from physicians other than urologists, and lack of information at the time of discharge to deal with symptoms (Heyman & Rosner, 1996; Oberst & James, 1985; Oberst & Scott, 1988; O'Rourke & Germino, 1998).

The immediate postoperative period has been identified as the most stressful for men with prostate cancer and their families (Moore & Estey, 1999). Spouses and family members

have been identified as the two most important and available sources of support. However, spouses should not automatically be regarded as the natural support system because evidence suggests that a mutuality of psychological response between patients with cancer and their family members exists (Baider, Ever-Hadani, & De-Nour, 1995; Cassileth et al., 1985). The degree of psychological distress also has been shown to vary throughout the course of the illness. The crisis of a cancer diagnosis and treatment is not resolved for patients or their spouses, even at three to six months postdischarge (Oberst & Scott, 1988). In fact, the crisis has been shown to worsen at the time of treatment and in the palliative care phase (Cassileth et al.). Oberst and Scott reported that all surgically treated patients with cancer in their study reported severe distress at 10 days postdischarge, with spouses' levels of anxiety being significantly higher than patients' during hospitalization and the pre-discharge period. In addition, Oberst and James (1985) reported that the incidence of spouses reporting illnesses and somatic complaints was increased 30–90 days after discharge, as concerns shifted to their own health and the impact of cancer on their life. Costello and Kiernan (1993) also identified admission for surgery and time of discharge as extremely anxiety provoking for men with prostate cancer. Currently, research is unclear as to whether assessing and providing information to patients with cancer and their partners at the time of diagnosis will lessen psychological distress.

Certain sociodemographic and disease-related variables have been reported to be associated with levels of psychological distress experienced by patients with cancer and their partners. Edlund and Sneed (1989) reported that although the youngest group (< 50 years of age) experienced the most distress in learning of their diagnosis, the oldest group (> 70 years of age) experienced significantly less psychological distress than all other age groups. Baider et al. (1995) indicated that male patients and their partners reported minimal amounts of distress and appeared to be better adjusted than couples where the patients were female. Stage of illness also has been reported to be correlated significantly with adaptation among patients' significant others, with spouses being more distressed by the frequency of physical symptoms and role limitations (Ell, Nishimoto, Mantell, & Hamovitch, 1988). More specifically, partners of men with prostate cancer have been reported to have significantly greater levels of psychological distress when their husbands' disease was more advanced (Kornblith, Herr, Ofman, Scher, & Holland, 1994). In contrast, Cassileth et al. (1985) reported that variables such as age, sex, time since diagnosis, and clinical factors did not have an influence on levels of anxiety, mood disturbance, or global mental health of patients with cancer.

## Conceptual Framework

Lazarus' Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) provided a framework to explain how men and their partners cope with the stress and uncertainty of a prostate cancer diagnosis. Individuals use cognitive appraisal to (a) evaluate how such an event affects their well-being (primary appraisal or stress), (b) assess available resources or options to deal with or mediate the situation (secondary appraisal or coping), (c) evaluate how effective specific actions have been (reappraisal or modifications), and (d) subsequently adjust to the stimulus-stressor (adaptation or

outcome). Information seeking is identified as the most frequent method individuals use to cope with and maintain control over a stressful life event (Cohen & Lazarus, 1979). Information is conceptualized as a form of cognitive control because it provides individuals with a way to interpret events and take action to lessen the threat or impact of the event. The model is transactional because individuals constantly are interacting with their environment and making decisions based on personal and situational factors. Study hypotheses empirically tested how providing individuals with the type of information they preferred would help them to cope with the stress of a prostate cancer diagnosis (as indicated by levels of psychological distress) and the extent to which they chose to assume control in making a treatment decision. Lazarus and Folkman suggested that to adequately measure coping, individuals must be assessed at several points over time. Empirical testing of how such an information intervention affects reappraisal and adaptation will be tested in a future longitudinal study.

## Study Purpose and Hypotheses

The purpose of the current study was to determine whether providing individualized information to men who were newly diagnosed with prostate cancer and their partners would lower their levels of psychological distress and enable them to be more actively involved in treatment decision making. Researchers hypothesized that at four months following the individualized information counseling session, patients and their partners would report lower levels of state anxiety and depression, patients would report they had assumed a more active role in medical decision making than they originally had preferred to play, and partners would report that they had assumed a more active role in their spouses' treatment choice than they originally had preferred to play.

## Methods

### Participants

A consecutive sample of 80 couples referred to the Prostate Centre at Vancouver General Hospital was recruited for the study. Several urologists practicing in greater Vancouver currently refer patients to the center at the time of diagnosis to access informational resources. Criteria for study participation included patients who were aware of their diagnosis, had their initial treatment consultation, were able to read and speak English, showed no evidence of mental confusion, and were in an ongoing relationship. "Ongoing relationship" was defined as men who were married, living with common-law partners, or living in same-sex relationships. Partners also were required to speak and read English.

### Instruments

The **Patient Information Program (PIP)** is a computer program that was developed to measure information and decision preferences of men with prostate cancer and their partners. This was the first time PIP was used with patients and their partners. PIP consists of two tools previously used to measure decision and information preferences of men newly diagnosed with prostate cancer (Davison & Degner, 1997; Davison et al., 1995). A detailed description of the analytic procedures involved in the development of PIP recently has been published (Davison et al., 2002).

The first part of PIP uses a computerized version of the **Control Preferences Scale (CPS)**, a card sort developed by Degner and Sloan (1992) to elicit patients' preferences for control over treatment decision making. The tool consists of five statements about different roles that individuals can assume in treatment decision making. The five statements are presented in fixed-order pairs to participants who are asked to select their preferred choice. Previous use of CPS demonstrated that 82% of the decisional preferences of men who were newly diagnosed with prostate cancer fell into the psychological dimension of a preference about keeping, sharing, or giving away control of treatment decision making to their physicians (Davison & Degner, 1997). Statements used to measure partners' preferred roles in decision making were derived from the original CPS statements (see Figure 1). All statements were changed to the past tense, and a "pick one" methodology was used to measure the roles patients and their partners reported they had assumed in the treatment decision-making process. For example, the statement "I prefer to leave all decisions regarding my treatment to my doctor (partner)," now read "I left all decisions regarding my treatment to my doctor (partner)."

The second part of PIP consists of a computerized version of a paper-and-pencil **survey questionnaire** previously developed and used by Davison et al. (1995) to assess the information needs of a group of men who were newly diagnosed with prostate cancer. The nine categories and descriptive statements include prognosis (likelihood of cure), stage of disease (spread and extent of cancer), side effects (possible side effects of treatment), treatment options (treatments available), social activities (impact on work, daily activities, and social life), family risk (hereditary risks of prostate cancer), home self-care (healthcare needs during and following treatment), impact on family (helping family members deal with cancer diagnosis), and sexuality (treatment options and counseling for sexual concerns). The information categories were presented in pairs using a Thurstone methodology (Thurstone, 1974) and in a fixed order using Ross's matrix of optimal ordering (Ross, 1974). Participants selected the one information category from each pair that was most important that day. Davison et al. (1995) previously had reported that this questionnaire demonstrated moderate agreement among profiles of men who were newly diagnosed with prostate cancer as indicated by Kendall's coefficient of agreement ( $W = 0.248$ ).

The **Spielberger State Anxiety Inventory (STAI-Y Form)**, a 20-item self-report (Spielberger, Gorsuch, & Lushene, 1970), was used to measure how participants were feeling "at that moment." Reliability coefficients in the alpha

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#### Active

- I prefer to make the final treatment decision.
- I prefer to make the final treatment decision after seriously considering my doctor's (partner's) opinion.

#### Collaborative

- I prefer that my doctor (partner) and I share responsibility for deciding which treatment is best.

#### Passive

- I prefer that my doctor (partner) makes the final treatment decision but seriously considers my opinion.
  - I prefer to leave all treatment decisions to my doctor (partner).
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**Figure 1. Statements in the Control Preferences Scale for Patients and Partners**

coefficient range of 0.83–0.94 have been reported in studies conducted with surgically treated patients with cancer (Oberst & Scott, 1988), patients newly diagnosed with prostate cancer (Davison & Degner, 1997), and patients being asked about their prostate cancer screening preferences (Davison, Kirk, Degner, & Hassard, 1999). Mean state anxiety scores for working male and female subjects between the ages of 50–69 years have been reported as 35.72 (SD = 10.34) and 32.2 (SD = 8.67), respectively (Spielberger et al.).

The **Center for Epidemiologic Studies Depression Scale (CES-D)**, a 20-item self-report, was used to measure levels of depression. Originally developed to measure depressive symptoms in the general population, CES-D has been used in research on the psychosocial health of patients with cancer. Each item is scored on a four-point scale (0–3), with higher scores indicating more severe symptoms. The total score can range from 0–60. Radloff (1977) recommended that respondents scoring more than 16 should be screened for a diagnosis of major depression. An internal consistency reliability of 0.87 was reported in a 1998 study that was conducted to examine the psychometric properties of this scale in patients newly diagnosed with cancer (Beeber, Shea, & McCorkle, 1998). A sociodemographic questionnaire was used to gather personal data and record disease-related information.

## Procedure

The present study used a one-arm, quasi-experimental, pre-test/post-test design. Data collection commenced following ethical approval of the study protocol by the appropriate institutional review committees. The first author provided an explanation of the purpose of the study and obtained written consent from each participant who had made an appointment at the Prostate Centre to access information. The first author conducted all interviews. Two couples who met the study criteria refused to participate in this study. Six of the original 80 participating couples dropped out of the study. This article reports on data from 74 couples who completed interviews at the time of diagnosis and again at four months.

At the first interview, each participant completed the socio-demographic questionnaire, STAI, and CES-D measures and was assisted in using the computer program. Patients completed one arm of the computer program that included measurement of preferred role in making a treatment decision with their doctors, preferred role in making a treatment decision with their partners, and information preferences. Partners completed another arm of the computer program that included two sections: preferred role in making a treatment decision with patients and information preferences. Although couples completed the paper questionnaires and computer program in the same room, every effort was made to ensure all participants completed the study protocol without input from their spouse or partner. For example, while patients completed questionnaires, their partners used the computer program.

Graphic printouts of each part of the computer program were used to guide the individualized information counseling session with each couple. For example, patients received a graphic printout of the role they wished to play in making a treatment decision with their physicians, the role they wished to play in making a treatment decision with their partners, and a hierarchical profile of the information categories they considered most important to discuss that day. Partners received graphic printouts displaying the role they wished to play in

patients' treatment decision and a hierarchical profile of information categories they thought were most important to them that day. Different roles patients could play in making a treatment decision with physicians were discussed in the context of patients' preferred role. Preferred role expectations of each member of the couple also was discussed.

Information categories identified by each participant as being the most important were identified, compared, and confirmed. The type and amount of information provided in the counseling session differed according to individual couples' information profiles. Information was discussed within the context of each patient's specific disease characteristics. The physician referral information included treatments recommended, prostate-specific antigen (PSA) blood test result at the time of diagnosis, histologic grade of cancer (Gleason score), clinical stage of disease, and biopsy results. For example, if side effects was chosen as a main information category, side effects associated with each of the physician-recommended treatment options were identified, described, and discussed within the context of how each would affect patients' and their partners' future lifestyles. All participants also were asked to identify other methods they wished to use to access additional information. Method choices included written information and videos, as well as lists of suggested Internet sites, questions to ask physicians, and local prostate support groups. These supplemental resources were provided to couples at the end of the counseling session. Participants were encouraged to call their physicians to discuss specific questions relating to their disease and treatment.

All couples were telephoned by the first author approximately three months following the initial interview to arrange second interviews at the center. At the second interview, participants completed the STAI, CES-D, and CPS (pick one statement) measures.

## Data Analysis

SPSS 9.0® (SPSS Inc., Chicago, IL) was used to analyze the data. The study's directional hypotheses were tested on a one-tailed basis. Thurstone scaling data analysis was conducted using the Statistical Analysis System® (SAS Institute, Inc., Cary, NC). A 0.05 critical value of alpha was used to determine statistical significance.

Coombs' (1976) unfolding theory was used to confirm that patients and their partners did perceive their decision preferences along a single dimension. This scaling method is based on the theory of preferential choice. Participants were asked to rank the statements in terms of their proximity to their personal preference. Individual preference orders were unfolded to determine whether they were consistent with the existence of an underlying psychological dimension, providing a direct test of the hypothesis that participants do have systematic preferences about the degree of control they want in treatment decision making, ranging from no control to complete control. Preference orders fell on the dimension if they were in a sequence that captured the hypothetical rank order of the decisional roles and the midpoints between them. The combination of the five decisional roles and their midpoints produced a dimension with 12 possible sets of 11 response patterns each. Coombs set the criterion for accepting the dimensionality of any particular scale at 50% plus one of observed preference orders having unfolded onto the dimension. Several articles have been published to provide a detailed description of

the analytic methods (Degner, Sloan, & Venkatesh, 1997; McIver & Carmines, 1991).

Men's preferred roles with physicians and partner's preferred roles with patients were found to be valid (according to Coombs' [1976] criterion) at 62% and 81%, respectively. However, only 45% of men's preferred roles with partners were found to be valid. When an invalid sequence was identified on the computer printout, participants were presented with a list of the five statements of the CPS, and they were asked to pick the role they preferred. This choice was the same as the computer-generated first choice in the majority of preferred role selections; patients with physician (86%), patients with partners (88%), and partners with patients (100%). For example, 36 of the 43 invalid "patients' preferred role with partners" were the same as the statement selected from the CPS.

Preferred and assumed decisional categories were collapsed into active (A, B), collaborative (C), and passive (D, E) for analysis. Chi-square tests were used to measure differences between patients' and partners' preferred and assumed roles. Chi-square tests also were used to identify differences in decision preferences (assuming a less active role than originally preferred, the same role, or a more active role than originally preferred) according to study demographic variables (age, education, stage of disease, and treatment status).

Two measures of reliability were used in the analysis of the computerized version of the information preferences questionnaire (Davison et al., 2002). Kendall's coefficient of agreement demonstrated moderate agreement among profiles of men ( $W = 0.31$ ) and partners ( $W = 0.29$ ) in their paired comparative judgments. However, participants' individual responses, as measured by the Gulliksen and Tukey reliability measure, indicated high reliability for men ( $R^2 = 0.938$ ) and partners ( $R^2 = 0.946$ ).

The STAI and CES-D are unidimensional scales and were considered to have interval levels of data. The internal consistency values of these scales, as measured by Cronbach's alpha were as follows: (a) STAI-pretest (patients = 0.934, partners = 0.931), post-test (patients = 0.859, partners = 0.902), (b) CES-D pretest (patients = 0.881, partners = 0.911), post-test (patients = 0.923, partners = 0.94). Student-paired *t* tests were used to identify differences between the pre- and post-test scores of men and their partners. One-way analysis of variance statistical procedures were used to measure differences in levels of anxiety and depression according to participants who assumed a less active role than originally preferred, the same role, or a more active role than originally preferred.

## Results

### Patient Characteristics

Seventy-four of the original 80 couples who agreed to participate in this study completed both sets of questionnaires (see Table 1). The second set of questionnaires was mailed in a self-addressed envelope to 20 couples who were unable to travel to the center. One of the six couples that withdrew from the study had a marriage breakup, and the other five did not return calls or questionnaires. Couples that withdrew were not remarkably different from the other couples.

The mean age of patients was 62.2 years ( $SD = 6.9$ ) with a range of 41–79 years. Fifty-four percent of patients had more than a high school diploma, and 51% were employed on a full-time or part-time basis. Partners ranged in age from 29–

**Table 1. Participant Characteristics**

Variable	Men (N = 74)		Partners (N = 74)	
	n	%	n	%
<b>Age (years)</b>				
$\bar{X}$	62.2		58.1	
SD	6.9		8.8	
40–49	2	3	12	16
50–59	23	31	27	37
60–69	41	55	29	39
70–79	8	11	6	8
<b>Education</b>				
< High school	14	19	8	11
High school	20	27	22	30
> High school	40	54	44	60
<b>Employment status</b>				
Full-time	34	46	15	20
Part-time	4	5	14	19
Retired	36	49	31	42
Unemployed	–	–	14	19
<b>Residence</b>				
Urban	56	76	–	–
Rural	18	24	–	–

*Note.* Because of rounding, not all percentages total 100.

76 years with a mean age of 58.1 years ( $SD = 8.8$ ), and 60% had greater than a high school diploma. The majority (61%) of partners were not working outside the home. Ninety percent of couples were married, and 10% were cohabiting. The sample included one same-sex couple.

Seventy-three patients had clinical stage T1 or T2 prostate cancer, 70% had Gleason scores of 6 or 7, and 70% had PSA scores of less than 10. Radical prostatectomy was the treatment of choice for approximately three-quarters of patients. Fifty-one percent of patients had received definitive treatment at the time of the second interview. Range of time to second interviews was 3.5–5 months.

### Preferred and Assumed Roles in Treatment Decision Making

**Patients with physicians:** The majority of patients had a preference to play either an active (51%) or collaborative (42%) role in decision making with their physician. However, a significantly higher proportion of patients reported assuming a more active role in making their treatment decision than originally intended ( $\chi^2 [2, n = 74] = 15.02, p < 0.001$ ) (see Table 2). Age ( $< 60$  years versus  $\geq 60$  years) ( $\chi^2 [2, n = 74] = 2.30, p > 0.1$ ), level of education ( $\leq$  grade 12 versus  $>$  grade 12) ( $\chi^2 [2, n = 74] = 4.84, p > 0.1$ ), and status of definitive treatment at time of second measurement (completed versus not completed) ( $\chi^2 [2, n = 74] = 1.15, p = 0.56$ ) were not found to be predictive of assuming a more or less active role in treatment decision making than originally intended.

**Patients with partners:** Forty-seven percent of patients wanted to either make the treatment decision alone (10%) or after seriously considering their partners' opinions (37%), and 54% wanted to share the decision making with their partner. The roles that patients preferred their partners to play in their treatment choice and the roles they thought their partners had played were not significantly different from one another ( $\chi^2 [2, n = 74] = 2.76$ ) (see Table 2). Definitive treatment status

**Table 2. Preferred and Assumed Roles in Treatment Decision Making**

Control Preferences Scale Statement <sup>a</sup>	Active		Collaborative		Passive	
	n	%	n	%	n	%
<b>Patient with doctor</b>						
Preferred	38	51	31	42	5	7
Assumed	58	78	10	14	6	8
<b>Patient with partner</b>						
Preferred	34	46	40	54	–	–
Assumed	44	60	30	41	–	–
<b>Partner with patient</b>						
Preferred	2	3	41	55	31	42
Assumed	–	–	12	16	62	84

N = 74

<sup>a</sup> See Figure 1.

(completed versus not completed at time of second interview) ( $\chi^2 [2, n = 74] = 0.56, p = 0.76$ ) and level of education ( $\leq$  grade 12 versus  $>$  grade 12) ( $\chi^2 [2, n = 74] = 1.03, p > 0.1$ ) were not shown to have an influence on the roles patients assumed versus the role they originally preferred to play with their partner. The impact of patients' ages was not able to be determined because of the small sample size. However, a trend was identified for men who were older than 60 to have a preference for their partners to be more active in the treatment decision-making process.

**Partners with patients:** Partners had a preference to play either a collaborative (55%) or passive (42%) role in the treatment decision making. In the passive group ( $n = 31$ ), 23 partners wanted the patient to make the decision after considering their opinion and 8 partners wanted the patient to make the decision himself. Only two women wanted to make the decision for their husband. A significantly higher proportion of the partners reported assuming a more passive role in the treatment decision than originally preferred ( $\chi^2 [1, n = 74] = 29.42, p < 0.0001$ ) (see Table 2). Of the 62 partners who reported assuming a passive role in the treatment decision making, 52 reported that the patients had made the decision after considering their opinion, and 10 partners reported that patients had made the treatment decision themselves.

### Levels of Psychological Distress

Compared to the time of the first interview, all participants reported significantly lower levels of state anxiety and depression at the time of completing the second set of questionnaires. Partners' levels of state anxiety were slightly higher than previously reported values of employed female subjects at the time of both interviews (see Table 3). Patients' state anxiety scores were within the reported normal limits by the time of the second interview. All participants reported depression scores that were within normal limits at both interviews.

Patients' levels of psychological distress did not have a significant influence on the roles they reported assuming versus the roles they originally had preferred to play with either their physician anxiety ( $F [2, 70] = 1.03, p = 0.36$ ) and depression ( $F [2, 70] = 0.48, p = 0.62$ ) or partner anxiety ( $F [2, 70] = 1.27, p = 0.29$ ) and depression ( $F [2, 70] = 1.50, p = 0.23$ ). Similarly, partners' levels of anxiety ( $F [2, 70] = 0.28, p = 0.76$ ) and depression ( $F [2, 70] = 0.32, p = 0.73$ ) were not

found to have a significant effect on the role they preferred to play with patients in treatment decision making versus the role they actually assumed.

## Discussion

Results of this study supported the hypotheses that providing individualized information to these patients and their partners at the time of diagnosis does have potential beneficial effects, such as lowering couples' levels of psychological distress and enabling patients to participate more actively in medical decision making. The hypothesis that partners would assume a more active role in decision making than originally intended following the provision of an individualized information counseling session was not supported.

Patients in this study did report that they had assumed a more active role than originally intended. Several possible explanations could account for this finding, but the most plausible explanation is that providing information in the context of a counseling session lowered their levels of psychological distress; this enabled them to assume more control in the decision-making process. Steginga et al. (2000) also reported on the importance men with prostate cancer attach to information resources and counseling services, especially at the time of diagnosis. Similar results were reported in two randomized clinical trials conducted with men newly diagnosed with prostate cancer (Davison & Degner, 1997) and men making a prostate cancer screening decision (Davison et al., 1999). Men in these studies reported assuming more active roles in making medical decisions than originally preferred following a coaching type of information intervention. Although the finding from the current study is that the patients and their partners chose to be proactive, other factors may provide a reasonable explanation for their actions, because patients receive information from multiple sources and the uncontrolled design of this study cannot confirm this conclusion.

Approximately half of the partners in this study had a preference to play a collaborative role with their spouses in

**Table 3. Levels of State Anxiety and Depression**

Characteristic	$\bar{X}$	SD	t test <sup>a</sup>	p
<b>Men (N = 73)</b>				
State anxiety				
• Pretest	41.92	12.03	5.03	0.000
• Post-test	35.58	10.82	–	–
Depression				
• Pretest	11.49	8.21	2.42	0.018
• Post-test	9.21	7.93	–	–
<b>Partners (N = 73)</b>				
State anxiety				
• Pretest	45.10	12.23	4.60	0.000
• Post-test	38.32	12.14	–	–
Depression				
• Pretest	15.15	10.94	3.27	0.002
• Post-test	11.04	9.58	–	–

<sup>a</sup> Student-paired t test. One couple did not complete second set of questionnaires. Mean state anxiety scores for working male and female subjects between the ages of 50–69 have been reported as 35.72 (SD = 10.34) and 32.2 (SD = 8.67), respectively (Spielberger et al., 1970). Depression scores greater than 16 were considered clinically relevant (Radloff, 1977).

choosing a definitive treatment for prostate cancer. However, the majority of partners in this study reported that they had assumed a supportive role. Most partners reported that patients “made the final treatment decision after seriously considering their opinions.” The most frequent rationale given by partners for assuming this role was that it was not their body so the final choice had to be made by their spouses, as they would have to live with the consequences of the treatment chosen. Similarly, O’Rourke (1997, 1999) and O’Rourke and Germino (1998) reported that partners deferred treatment decisions to their husbands and denied having an influence on the definitive treatment choice. One explanation for this finding is that the additional information partners received made them aware of the high degree of uncertainty surrounding each treatment choice and that this knowledge resulted in them not wanting to assume responsibility for the potential consequences of such a decision. Perhaps these partners should have been asked about how they used the information to help them make sense of the treatments that are available for prostate cancer. Still another reason is that partners’ levels of anxiety precluded them from assuming more control in the decision-making process.

Partners’ levels of state anxiety were lower at the time of the second interview, but still higher than working women in the general population. This finding was not surprising because almost half of the patients were recovering from surgery and many of the partners reported that they were assuming more household and daily responsibilities. At the time of the second interview, partners also expressed concerns about helping their husbands deal with the impending treatment or side effects of treatments and concealing fears of recurrence. Oberst and Scott (1988) also reported that spouses of patients with cancer had higher levels of distress from one to three months following surgery when the spouses’ concerns started to shift from the patient’s health to how the illness was going to affect their life. Perhaps another session may have been required specifically for partners to discuss their concerns and address more practical issues such as home self-care and usual timing of medical follow-up appointments. Because the current study only had one same-sex couple, making any conclusions regarding differences in how male and female partners cope with a prostate cancer diagnosis was not possible. Providing pertinent treatment-related homecare information and emotional support to partners is certainly an area that requires further study.

## Limitations

Study design, sample recruitment, and generalizability to other patient populations were identified as major limitations of this study. Without a control group, investigators cannot conclude with certainty that the benefits reported were actually the result of the information counseling session. Recruitment procedures also were biased because urologists only referred patients they thought would be interested in accessing information and willing to participate in such a study. The

inclusion of all men at the time of diagnosis from a variety of community urology practices would have been valuable, but only men who wanted more information than was already provided by their urologist came to the center. In addition, the demographic profile of couples attending this metropolitan, university-affiliated center may not be generalizable to other community urology practices. Cultural issues also were not addressed because only patients who spoke and understood English were asked to participate in the study.

## Nursing Implications

Evidence exists to demonstrate the need to provide information to patients who are newly diagnosed with prostate cancer and their partners at the time of diagnosis to facilitate treatment decision making. The PIP computer program used in this study proved useful in focusing the information counseling session and addressing questions and concerns pertaining to information priorities and related concerns on that particular day. Using this categorical approach to guide the delivery of information was found to be a reasonable and time-effective means of providing decisional support in an outpatient setting. This methodology also was able to address the variation between what information healthcare providers believe patients should receive versus what patients actually want to learn. For example, some patients ranked sexuality as the most important information need and wanted all information provided within the context of how treatment choice would affect this aspect of their lives. Additional information resources also were found to assist individuals in addressing questions or concerns that arose following the counseling session. Physicians and other oncology healthcare professionals could use this computer program to guide treatment-related discussions. The efficacy of using this approach with other newly diagnosed patients with cancer requires further study.

## Summary

In conclusion, results of this study suggest that assisting men and their partners in identifying and discussing the information they consider important at the time of diagnosis is beneficial. Counseling couples at the time of diagnosis using this type of approach enables couples to access information that is both timely and relevant. A research study currently is under way to evaluate this approach within the context of a randomized clinical trial design.

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## References

- Baider, L., Ever-Hadani, P., & De-Nour, A.K. (1995). The impact of culture on perception of patient-physician satisfaction. *Israel Journal of Medical Science, 31*, 179–185.
- Beeber, L.S., Shea, J., & McCorkle, R. (1998). The Center for Epidemiologic Studies Depression Scale as a measure of depressive symptoms in newly diagnosed patients. *Journal of Psychosocial Oncology, 16*(1), 1–20.
- Beisecker, A.E., & Moore, W.P. (1994). Oncologists’ perceptions of the effects of cancer patients’ companions on physician-patient interactions. *Journal of Psychosocial Oncology, 12*(1/2), 23–39.
- Brawley, O.W., & Barnes, S. (2001). The epidemiology of prostate cancer in

the United States. *Seminars in Oncology Nursing*, 17, 72–77.

Cassileth, B.R., Lusk, E.J., Strouse, T.B., Miller, D.S., Brown, L.L., & Cross, P.A. (1985). A psychological analysis of cancer patients and their next-of-kin. *Cancer*, 55, 72–76.

Cohen, F., & Lazarus, R.D. (1979). Coping with stress of illness. In G.C. Stone, F. Cohen, & N.E. Adler (Eds.), *Health psychology* (pp. 217–224). San Francisco: Jossey-Bass.

Coombs, C.H. (1976). *A theory of data*. Ann Arbor, MI: Mathesis Press.

Costello, D., & Kiernan, M. (1993). Patients with radical prostatectomy: Postdischarge telephone calls. *Urologic Nursing*, 13(2), 55–57.

Davison, B.J., & Degner, L.F. (1997). Empowerment of men newly diagnosed with prostate cancer. *Cancer Nursing*, 20, 187–196.

Davison, B.J., Degner, L.F., & Morgan, T.R. (1995). Information and decision-making preferences of men with prostate cancer. *Oncology Nursing Forum*, 22, 1401–1408.

Davison, B.J., Gleave, M.E., Goldenberg, S.L., Degner, L.F., Hoffart, D., & Berkowitz, J. (2002). Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nursing*, 25, 42–49.

Davison, B.J., Kirk, P., Degner, L.F., & Hassard, T.H. (1999). Information and patient participation in screening for prostate cancer. *Patient Education and Counseling*, 37, 255–263.

Degner, L.F., & Sloan, J.A. (1992). Decision-making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology*, 45, 941–950.

Degner, L.F., Sloan, J.A., & Venkatesh, P. (1997). The control preferences scale. *Canadian Journal of Nursing Research*, 29(3), 21–43.

Edlund, B., & Sneed, N.V. (1989). Emotional responses to the diagnosis of cancer: Age-related comparisons. *Oncology Nursing Forum*, 16, 691–697.

Ell, O., Nishimoto, R.H., Mantell, J.E., & Hamovitch, H.B. (1988). Psychological adaptation to cancer: A comparison among patients, spouses, and non-spouses. *Family Systems Medicine*, 6, 335–348.

Heyman, E.N., & Rosner, T.T. (1996). Prostate cancer: An intimate view from patients and wives. *Urologic Nursing*, 16(2), 37–44.

Jemal, A., Thomas, A., Murray, T., & Thun, M. (2002). Cancer statistics 2002. *CA: A Cancer Journal for Clinicians*, 52, 23–47.

Kornblith, A.B., Herr, H.W., Ofman, U.S., Scher, H.I., & Holland, J.C. (1994). Quality of life of patients with prostate cancer and their spouses: The value of a database in clinical care. *Cancer*, 73, 2791–2802.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

McIver, J.P., & Carmines, E.G. (1991). *Unidimensional scaling*. Thousand Oaks, CA: Sage.

McPherson, C.P., Swenson, K.K., & Kjellberg, J. (2001). Quality of life in patients with prostate cancer. *Seminars in Oncology Nursing*, 17, 138–146.

Moore, K.N., & Estey, A. (1999). The early post-operative concerns of men after radical prostatectomy. *Journal of Advanced Nursing*, 29, 1121–1129.

National Cancer Institute of Canada. (2002). *Canadian cancer statistics 2002*. Toronto, Canada: Author.

Northouse, L.L., & Peters-Golden, H. (1993). Cancer and the family: Strategies to assist spouses. *Seminars in Oncology Nursing*, 9, 74–82.

Oberst, M.T., & James, R.H. (1985). Going home: Patient and spouse adjustment following cancer surgery. *Topics in Clinical Nursing*, 7(1), 46–57.

Oberst, M.T., & Scott, D.W. (1988). Post-discharge distress in surgically treated cancer patients and their spouses. *Research in Nursing and Health*, 11, 223–233.

Onel, E., Hamond, C., Wasson, J.H., Berlin, B.B., Ely, M.G., Laudone, V.P., et al. (1998). Assessment of the feasibility and impact of shared decision making in prostate cancer. *Urology*, 51, 63–66.

O'Rourke, M.E. (1997). *Prostate cancer treatment selection: The family decision process*. Unpublished doctoral dissertation, University of North Carolina, Chapel Hill, NC.

O'Rourke, M.E. (1999). Narrowing the options: The process of deciding on prostate cancer treatment. *Cancer Investigation*, 17, 349–359.

O'Rourke, M.E. (2001). Decision making and prostate cancer treatment selection: A review. *Seminars in Oncology Nursing*, 17, 108–117.

O'Rourke, M.E., & Germino, B.B. (1998). Prostate cancer treatment decisions: A focus group exploration. *Oncology Nursing Forum*, 25, 97–104.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.

Ross, R.T. (1974). Optimal orders in the method of paired comparisons. In G. M. Maranell (Ed.), *Scaling: A sourcebook for behavioral scientists* (pp. 106–109). Chicago: Aldine.

Spielberger, C.D., Gorsuch, R.L., & Lushene, R.L. (1970). *STAI manual*. Palo Alto, CA: Consulting Psychologists Press.

Steginga, S.K., Occhipinti, S., Dunn, J., Gardiner, R.A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer (2000). *Psycho-Oncology*, 10, 66–75.

Thurstone, L.L. (1974). A law of comparative judgment. In G.M. Maranell (Ed.), *Scaling: A sourcebook for behavioral scientists* (pp. 81–92). Chicago: Aldine.

Wong, F., Stewart, D.E., Dancy, J., Meana, M., McAndrews, M.P., Bunston, T., et al. (2000). Men with prostate cancer: Influence of psychological factors on informational needs and decision making. *Journal of Psychosomatic Research*, 49, 13–19.

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