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Factors Associated with Prostate Cancer Patients' and their Spouses' Satisfaction with a Family-based Intervention

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Abstract

Issue—Only a few programs are designed to help couples to cope with the effects of prostate cancer, and typically only their intervention outcomes are reported. The purpose of this study was to assess prostate cancer patients' and their spouses' satisfaction with an efficacious supportive-educative, family-based intervention, and factors associated with their satisfaction. We assessed the relationship of overall satisfaction with the intervention to 1) the patients' and spouses' appraisal and the resource and quality of life baseline scores and 2) changes in those scores after completing the intervention.

Findings—Results showed participants were very satisfied with the program. Patients who had higher scores on baseline measures, indicating more positive appraisal of their illness, better use of resources (e.g., coping, self-efficacy), and higher overall quality of life, reported more satisfaction with the intervention. For spouses, few baseline measures were related to their satisfaction; however, spouses who reported positive changes following intervention (less negative appraisal and uncertainty, better communication) reported higher satisfaction with the program.

Conclusion—Although satisfied with the program, factors associated with patients' and spouses' satisfaction differed. In order to translate effective interventions to clinical practice settings, it is important to assess participants' satisfaction with program content and delivery as well as program outcomes.

Despite the fact that prostate cancer is the second leading cause of cancer death in men [1], patients are living longer with this disease because of scientific advancements. However, treatment options for prostate cancer are accompanied by troubling side effects including bowel, bladder, and sexual problems which continue into survivorship,[2, 3] and negatively affect quality of life (QOL).[2–7] Studies have shown a reciprocal relationship exists between men and their spouses where, as men's problems increase, spouses' quality of life decreases.[5, 8–10] In spite of these difficulties, there are few programs designed to help couples cope with the effects of prostate cancer and even fewer that evaluate couples' satisfaction with intervention programs.

The purpose of this study was to assess *prostate cancer patients' and their spouses' satisfaction* with a supportive-educative, family-based intervention and associated factors. The FOCUS program was originally developed by Northouse and colleagues in 2002 for women with advanced breast cancer and their family caregivers and was positively evaluated.[11] Subsequently, Northouse et al. adapted the FOCUS program for men with prostate cancer and their spouses to cross-validate the outcomes with the breast cancer study

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in a randomized clinical trial (RCT) in 2007.[12] That study determined if participants' satisfaction was maintained when the program was offered to patients and caregivers who differed in gender, type of cancer, and phase of illness.

In the current study the specific aims were 1) to examine patients' and spouses' satisfaction with intervention content and delivery by role (i.e., patients versus spouses) and phase of illness (i.e., newly diagnosed, biochemical recurrence, advanced); 2) to determine if appraisal variables (appraisal of illness/caregiving, uncertainty, hopelessness), resource variables (self-efficacy, communication, coping strategies), and quality of life variables (generic and cancer-specific) were related to patients' and spouses' satisfaction with the program; and 3) to determine if *patients' and spouses' perceived need for intervention* was associated with the program's assessment of satisfaction. These analyses can provide information to tailor programs to other cancer patients and their family caregivers.

Conceptual Framework and Review of Literature

The stress-coping model adapted from Lazarus and Folkman served as the theoretical framework that guided the development of the program and overall study.[13] According to this framework, a series of pre-existing personal and illness-related factors influence how patients' and spouses' appraise their illness or the caregiving experience associated with it. In combination, these pre-existing factors (e.g., demographics, phase of illness, relationship role) and appraisal factors, as well as their resources to manage the illness, subsequently affect patients' and spouses' quality of life. The supportive-educative, family-based intervention was designed to reduce patients' and spouses' negative appraisals, enhance resources, and help them to maintain their quality of life.

Effects of Prostate Cancer on Patients and Spouses

Prostate cancer has been referred to as a "relationship disease" because of the effect it has on both patients and their spouses.[14] Spouses play a central role in helping men make treatment decisions,[15] cope with the illness, and maintain their quality of life.[16, 17] However, this central role can create stress for spouses. Spouses report more emotional distress associated with a diagnosis of prostate cancer, greater uncertainty, and less support than do their husbands.[4, 5, 16]

Prostate cancer and the resulting treatments can cause problems with normal body functions and interpersonal relationships that can significantly disrupt the lives of patients and their spouses.[2, 4,9] Treatment side effects, including urinary incontinence, erectile dysfunction, loss of libido, and overwhelming fatigue are accompanied by an array of distressing emotional reactions that affect the lives of both patients and spouses.[5, 9] Adjustment to treatment-related side effects places demands on couples' physical and mental resources, and can diminish their quality of life.[3, 9]

Psychosocial Intervention Studies for Prostate Cancer Patients and Spouses

A number of studies have been conducted with prostate cancer patients during diagnosis, treatment[18–24] and post-treatment, [25–30] but few have included spouses. [23, 31–34] These interventions have varied in length, method of delivery (video, audiotape, computer, telephone, and group), and evaluation results. Interventions that provided information about the disease, treatment, and/or side effects were viewed positively by patients and often resulted in less disruption to daily life.[20, 21, 24, 26, 27, 32] Studies designed to improve patients' ability to manage treatment side effects showed improved coping abilities,[19, 22, 23, 25, 28, 31, 33, 35] while efforts to increase physical activity of the men following treatment generally showed no significant results.[30]

Five prior studies have included spouses, either alone or with their husbands. One involved a psycho-educational group intervention for spouses, covering six specific topics related to coping.[31] The intervention group reported improved coping skills, but showed no change in distress. Another study evaluated spouses' preparedness for the caregiving role and found that when caregivers are better prepared for their role, they experience less distress.[33] A third study, which included both patients and spouses, offered a single presurgical intervention to improve couples' interpersonal communication and their communication with the medical team, but had limited effectiveness.[32] Fourth, a pilot study that included patients and their partners used a telephone-based intervention focusing on coping skills; this resulted in better communication between partners and increased problem-solving abilities.[23] Finally, a study that included both patients and spouses used Advanced Practice Nurses to deliver an intervention (8 home visits, 8 telephone calls) and addressed three key areas: symptom management during surgical recovery, restoration of urinary continence, and promotion of marital communication and psychosexual function.[34] Results showed a modest effect on marital interaction and sexual function for both patient and spouse.

Typically, in prior studies, only intervention outcomes have been examined with no evaluation of participants' satisfaction with the program. However, in order to translate interventions to clinical practice settings, it is important to assess participants' satisfaction with program content and delivery as well as intervention outcomes. This type of assessment, referred to as a process evaluation,[36] provides valuable information about the acceptability of the program to participants, and may identify aspects of program content or delivery that need to be revised before further implementation. This type of evaluation provides information on ways to refine interventions to achieve a format and length that will best satisfy the needs of recipients.

Methods

A process evaluation was conducted as part of a large RCT to test the effects of a supportive-educative, family-based intervention on prostate cancer patients' and their spouses' quality of life and other factors. Primary study outcomes have been reported previously.[12] This current process evaluation examines patients' and spouses' satisfaction with program content and delivery.

Design

A descriptive-correlational design was used to describe patients' and spouses' satisfaction with the intervention. Comparisons between participants' satisfaction with the intervention by role and phase of illness were examined. Relationships between appraisal, resource, and quality of life variables, measured at baseline prior to the intervention (Time 1), as well as changes in those variables from baseline to completion of the intervention about four months later (Time 2), were correlated with patients' and spouses' satisfaction following the intervention. Satisfaction data were collected at one time point approximately two weeks after the completion of the intervention. In addition, the study examined the relationship between patients' and spouses' perceived need for intervention and satisfaction with the intervention.

Sample

Prostate cancer patients were eligible for this RCT if they were in one of three phases of prostate cancer: newly diagnosed, biochemical recurrence (following primary treatment), or advanced. Spouses were eligible if they were ≥ 21 years and were identified by patients as their primary support person for this study. The final sample for the RCT (N=235 couples), consisted of 112 couples in the intervention group and 123 couples in the control group.

Only the 112 couples who participated in the intervention were eligible for this process evaluation that assessed their satisfaction with the intervention.

The 112 couples who completed the intervention program and both the baseline and post-intervention data collections were mailed individual copies of the Satisfaction Questionnaire to complete. Of the 112 couples, 86 complete dyads (both patient and spouse) responded to the questionnaire (76.8% of eligible dyads). The remainder had only one respondent per dyad or did not respond after three attempts to reach them. The average age of respondents was 63.7 years for patients; 59.6 years for spouses. This sample was largely Caucasian (85%), well educated (71% had college degrees) and the majority of families (54%) had an income of $75,000 or more. The sample distribution by phase of illness consisted of 66% of the patients in the newly diagnosed phase, 15% in the biochemical phase, and 19% in the advanced phase. These 86 dyads (i.e., the process evaluation sample) did not differ significantly on any of these characteristics from other dyads in the intervention group that did not complete the Satisfaction Questionnaire.

Program Development

The supportive-educative, family-based intervention was called the FOCUS Program. It addressed five core content areas: Family involvement, Optimistic outlook, Coping effectiveness, Uncertainty reduction, and Symptom management, and was delivered in five sessions (3 home visits, 2 telephone calls) by an advanced practice nurse. Supplementary materials, such as symptom management cards and an optimism brochure outlining self-care behaviors, were used to provide information to participants. The FOCUS Program was originally developed for advanced breast cancer patients and their family caregivers, and it was found to be effective in reducing hopelessness and negative appraisal of illness in patients and reducing the negative appraisal of caregiving in family caregivers.[37, 38] Breast cancer patients and caregivers reported high satisfaction with this original program.[38]

Modifications to Original FOCUS Program

The program was adapted for men with prostate cancer to determine if the program could produce positive outcomes in patients who differed in gender and type of cancer from the original sample. Adaptation of the program was based on an extensive review of the prostate cancer literature, recommendations for modifications in either the content or delivery of the program from the original intervention nurses, and data obtained from six focus groups with prostate cancer patients and their spouses: two couples-only groups, two patient-only groups, and two spouse-only groups.[9] Focus group participants reported a need for information and support and said they felt unprepared to manage treatment-related side effects.

Table 1 provides the primary session topics for the core F-O-C-U-S areas that were delineated in more detail in the protocol manual. Four major modifications were made to the original FOCUS content. First, symptom management content was expanded to include treatment-related side effects that prostate cancer patients experience, such as urinary incontinence, sexual problems, and hormone imbalance. The two original symptom management cards on urinary incontinence and sexual difficulties were modified to address more specifically these symptoms for prostate cancer patients. For example, the card dealing with sexual problems was revised to include more information on causes of erectile dysfunction and its management, such as Viagra, MUSE, and penile implants. In addition, a new card on symptom management of hormone imbalance was developed to address men’s problems with hot flashes, changes in libido, and fatigue that accompany androgen deprivation treatments.

Second, we tailored sections of our protocol manual to address the issues of couples in the various phases of illness (newly diagnosed, biochemical recurrence, advanced) because our original FOCUS Program was conducted only with breast cancer patients and their caregivers in the advanced phase. As a result of these modifications, the protocol manual increased from 17 pages to 21 pages. Third, whereas the family caregivers for the original sample included a heterogeneous group of caregivers such as spouses, parents, siblings, and children, family caregivers in the prostate study were limited to spouses (including cohabitating sexual partners) because of the elevated distress they report and the negative effects of prostate cancer on couples' intimate relationships. Finally, we modified the program delivery based on feedback from intervention nurses in the original study. Although nurses in both studies had five contacts with each dyad (three face-to-face home visits; two telephone contacts), nurses from the original study reported that using a phone session for the final meeting with dyads was inadequate and made it difficult to achieve closure with the dyad. In the prostate program, the phone contacts were interspersed between home visits, making the final session a more appropriate face-to-face home visit. Table 1 lists the content for each session and the amount of contact time planned for each session.

Process Evaluation Measures

Satisfaction Questionnaire—Patients' and spouses' satisfaction with the intervention was measured separately using a 17-item Satisfaction Questionnaire, administered approximately two weeks after participants completed the intervention. The first eight items of the scale assessed participants' satisfaction with the core content areas of the FOCUS Program and its delivery; these items were used to create an overall satisfaction score (see Table 2). In our original breast cancer study, only six items were used to measure program satisfaction resulting in high internal consistency reliability alphas for patients (0.89) and family caregivers (0.93).[38] In the current study, two additional items (# 7 and 8) were added to the satisfaction scale (see Table 2). This eight-item satisfaction scale had high internal consistency reliability alphas for prostate cancer patients (0.87) and their spouses (0.89). The remaining items on the satisfaction questionnaire assessed participants' satisfaction with program structure (items 9–11), their perceptions of the value of the program to themselves and to other couples in the future (items 12–13), and their retrospective self-perceived need for intervention (item 14) (see Table 3). The final three questions (15–17) were open-ended, asking participants to identify the most and least beneficial aspects of the program along with anything they would have added.

Variables Associated with Satisfaction

To determine if patients' or spouses' satisfaction with the program was associated with selected psychosocial variables, instruments used in the RCT to assess appraisal, resource, and quality of life variables were examined for their relationship to participants' satisfaction scores. All instruments were used in prior research with cancer patients and their spouses and had excellent psychometric properties. Satisfaction scores were also compared with participants' perceived need for the intervention, measured by a single item of the Satisfaction Questionnaire. Patients and spouses completed all questionnaires independently.

Appraisal variables—Appraisal variables included appraisal of illness or caregiving, uncertainty, and hopelessness. Appraisal of illness/caregiving was measured using the Appraisal of Illness scale for patients and the Appraisal of Caregiving scale of spouses.[39, 40] Each 27-item scale assesses the degree of threat related to the illness or tasks of caregiving. Uncertainty was measured with Mishel's 28-item Uncertainty in Illness Scale.[41] Hopelessness was measured with the 20-item Beck Hopelessness Scale.[42]

Resource variables—Resource variables consisted of patients' and spouses' level of self-efficacy to manage the illness or caregiving, their ability to communicate with one another about the illness, and use of active versus avoidant coping strategies. Self-efficacy was measured using the 17-item Lewis Cancer Self Efficacy Scale to assess respondents' confidence in their ability to manage the effects of cancer.[43] Communication about the illness was measured using the 32-item Lewis Mutuality and Interpersonal Sensitivity Scale.[43] Coping strategies were measured with the Brief COPE [44] that was factor analyzed in a previous study into active and avoidant strategies.[45]

Quality of Life (QOL)—Cancer-specific quality of life was measured using the 39-item Functional Assessment of Cancer Therapy (FACT-G, version 4) which assesses physical, social/family, emotional, functional, and overall quality of life.[46] Spouses completed a modified version of the FACT-G in which they reported on their own quality of life. A second measure of physical and mental health, the Medical Outcomes Study Short Form Health Survey (MOS SF-12), was used as a measure of general (non-illness related) quality of life.[47]

Need for Intervention—Patients' and spouses' perceptions of their own need for intervention was measured with Item 14 of the Satisfaction Questionnaire (see Table 3). Participants were asked to consider, now that the intervention was completed, how much they felt they needed to talk about the topics raised by the intervention nurse, using a 5-point scale (1 = low; 5 = high).

Procedures

Baseline data were obtained prior to randomization (Time 1). The first post-intervention follow-up data collection session was completed four months later (Time 2). After patients and spouses completed the Time 2 data collection, each person was mailed a copy of the Satisfaction Questionnaire and a stamped, return envelope. They were instructed to complete their satisfaction questionnaires separately. No data were collected during the three-month intervention period. In order to control for potential sources of bias that can interfere with the accuracy of satisfaction measures, participants were asked to complete the Satisfaction Questionnaire in their own home (setting), in the absence of any research staff (no coercion), after all intervention contacts had been completed (timing), and returned to the Project Director (someone other than their own intervention or data collection nurse).

Data Analysis

Descriptive statistics were used to examine demographic data and individual items on the satisfaction questionnaire. To assess the influence of role (patient, spouse) and phase of illness (newly diagnosed, biochemical recurrence, and advance disease) on satisfaction, a 2 × 3 ANOVA was conducted, with role treated as a within-subjects factor, and phase of illness treated as a between-subjects factor. This allowed us to assess the influence of role, phase of illness, and any possible interaction between role and phase. For the categorical questions (items 9–13), chi-square analyses were conducted. Correlations were used to determine the relationship of total satisfaction scores with baseline appraisal, resource and quality of life variables as well as change in those variables between baseline (Time 1) and post-intervention (Time 2). To assess change, we conducted partial correlations with satisfaction scores and follow-up appraisal, resource, and quality of life variables, controlling for baseline scores. In addition, we assessed the correlation among satisfaction and patients' and spouses' evaluations of their need for intervention. Qualitative responses elicited by the three open-ended questions were content-analyzed for major themes by research staff.

Results

Description of Satisfaction by Role and Phase of Illness

Table 2 provides descriptive information about patients' and spouses' responses to eight items that comprised the overall satisfaction score on a five-point scale ranging from 1 (low) to 5 (high) satisfaction. There was no relationship between patients' or spouses' demographic characteristics (e.g., age, education, income) and their overall satisfaction with the intervention. There also were no differences by role (patient versus spouse) (all $ps > .05$) or by phase of illness (all $ps > .05$) on any of the individual items or the overall 8-item satisfaction score. In addition, there were no significant role by phase interactions (all $ps > .05$). Both prostate cancer patients and their spouses reported high satisfaction with the program (all mean scores >4.01), with the exception of patients' rating (3.87) of the supplementary materials (e.g., brochures, pamphlets) (see Table 2). Furthermore, the small standard deviations obtained for items on the satisfaction scale indicated high consistency in participants' responses (see Table 2).

To determine if the satisfaction scores of prostate cancer patients and their spouses obtained in this study differed from the satisfaction scores of breast cancer patients and their family caregivers in the original study, independent t-tests were computed for the six individual satisfaction items that were used in both studies, and the overall six-item satisfaction score. There were no significant differences between prostate cancer patients and breast cancer patients on items pertaining to family involvement in discussions, assistance in maintaining a positive attitude, or in the way in which questions were answered. However, prostate patients reported significantly less satisfaction than breast cancer patients on items pertaining to information on coping ($M = 4.42$ vs. 4.58, $p = .05$), information on symptom management ($M = 4.33$ vs. 4.52, $p = .02$), understanding of intervention nurses ($M = 4.67$ vs. 4.90, $p = .001$), and the overall sum of the first six satisfaction items ($M = 27.2$ vs. 28.1, $p = .016$).

A nearly opposite pattern was found in the satisfaction scores of spouses in the prostate study and the scores of family caregivers in the breast study. Spouses of prostate patients reported significantly higher satisfaction on items pertaining to assistance in maintaining a positive attitude ($M = 4.49$ vs 4.23, $p = .004$), way in which questions were answered ($M = 4.58$ vs. 4.34, $p = .001$), information on symptom management ($M = 4.37$ vs. 4.15, $p = .01$), and the overall sum of the first six satisfaction items ($M = 27.1$ vs. 26.0, $p = .009$). No differences were found for spouses of prostate cancer patients and family caregivers of breast cancer patients on items pertaining to family involvement in discussions, information on coping, or understanding of intervention nurses.

Table 3 provides descriptive data for prostate cancer patients' and their spouses' satisfaction with program structure and value. The majority of patients (85%) and spouses (74%) reported that the number of home visits and telephone calls was about right. The majority of patients (75%) and spouses (74%) also reported that the content of the FOCUS Program did not duplicate information that they received from cancer center staff. Of those participants who reported some duplication, many of these respondents added comments indicating that the duplication was helpful because it reinforced information that they received from clinic staff. The majority of prostate cancer patients (71%) and their spouses (73%) reported that the FOCUS Program helped them to cope with the cancer diagnosis, treatment, and post-treatment experiences. Many of the remaining couples said that they were coping well on their own prior to receiving the program and/or were not in need of help. The majority of patients (90%) and spouses (85%) said that they would recommend the program to another couple who was coping with prostate cancer.

We also assessed whether participants' responses to these additional items on the satisfaction questionnaire (items 9–13) differed by role or phase of illness. There was no significant role effect, indicating no difference in the responses of patients and spouses on these items. Significantly more patients in the biochemical recurrence phase of illness (55%) felt the FOCUS Program duplicated content obtained from cancer center staff than did newly diagnosed (22%) or advanced patients (13%) ($\chi^2_{(df=2)}=6.43$, p=.04). There were no other differences by phase of illness.

Factors Related to Satisfaction

We assessed the relationship of overall satisfaction with the intervention 1) to patients' and spouses' baseline scores, and 2) to changes in their appraisal, resource, and quality of life scores following the intervention (see Table 4). As shown in Table 4, prostate cancer patients who at baseline had less negative appraisal of illness, less uncertainty, use of less avoidant coping, more self-efficacy about managing the illness, and higher overall quality of life reported higher satisfaction with the FOCUS Program. At follow-up assessment, after controlling for baseline scores, patients who reported an increase in their self-efficacy after completing the intervention also reported higher satisfaction with the program.

In contrast, for caregivers, only one baseline factor--higher self-efficacy-- was associated with caregivers' higher satisfaction with the FOCUS Program in comparison to the multiple baseline factors associated with patients' satisfaction. Further, after controlling for baseline scores, caregivers who reported significant changes on multiple outcomes following the intervention (i.e., lower negative appraisal of caregiving, less uncertainty, and improved interpersonal communication) reported higher satisfaction following the intervention.

Need for Intervention and Satisfaction

The overall need for prostate cancer patients to talk about the content of FOCUS Program was 2.9 (SD=1.4) on a 5-point scale, comparable to 3.1 (SD=1.4) for their spouses. There were no significant differences in participants' perceived need for intervention by role (p = .52) or by phase of illness (p = .55). Approximately one-third of the prostate cancer patients (33%) and their caregivers (39%) rated themselves as having a high need (4 or 5 on the scale) for the intervention. Patients and caregivers who reported a higher need for the intervention were significantly more satisfied with the FOCUS Program (r = .27 and .26, respectively).

Qualitative Findings

Two items on the Satisfaction Questionnaire gave dyads the opportunity to comment on the elements of the program they found most beneficial and least beneficial. In addition, one item asked for suggestions about anything they would have added to the program.

Most beneficial aspects of program—Under the topic of most beneficial, both patients and spouses had many comments to share (110 comments for patients and 121 for spouses). Of these, three main themes emerged: 1) interactions with the nurse, 2) including spouses in discussions, and 3) altruism.

Interactions with the nurse: In response to the question "What was the most beneficial aspect of the FOCUS Program?" most patients and spouses identified their supportive interactions with the nurse. One patient commented, "I really appreciated being able to discuss any emotional or physical problem one-on-one with a nurse". One spouse appreciated, "…an opportunity to communicate openly with a professional. It helped us raise issues we had been avoiding." Often the discussions in the home opened up areas that the couple had not felt comfortable talking about on their own. The gentle probing of the advanced practice nurse enabled both patient and spouse to vocalize concerns they had not previously shared. In addition, patients felt they could openly discuss any emotional or physical problem with this nurse who understood the impact of their situation. Spouses appreciated being included in the discussions and having the opportunity to talk about feelings related to cancer, sexuality, and psychosocial aspects of their situation. Dyads appreciated the information provided by intervention nurses who could answer questions about all aspect of managing a prostate cancer illness, and discuss questions specific to their individual type of treatment.

Including the spouse: Another beneficial theme identified was including the spouse in the intervention sessions. One patient stated that one of the most helpful aspects of the intervention was “being able to understand my spouse’s feelings.” Including the spouse validated the effort that both the patient and the spouse were each contributing to the recovery process. Bringing the spouse into the conversation on all levels provided additional knowledge and support for the couple. Further, it opened discussions about physical and emotional problems, giving permission to discuss concerns that might not have previously been discussed. One spouse commented, “Just talking to someone who listened to our problems and tried to help provide support…. Support is everything.”

Altruism: Many couples felt that by participating in the study they were able to help others who might be experiencing similar situations. One spouse stated very succinctly, “I liked the thought that if we proceeded with the study, then maybe we were helping others.” For many couples, participation in the study was a way of finding meaning and purpose by helping others and therefore their participation was a part of their feeling satisfied with the intervention.

Least Beneficial Aspects of Program—Under the topic of least beneficial, 15 dyads did not comment and an additional 17 dyads stated that everything was useful. Of the dyads that did respond, two main themes emerged: 1) timing of the program, and 2) printed materials.

Timing: Some couples experiencing a new diagnosis of cancer have the greatest need for support at the initial time of diagnosis. This was reflected in couples’ comments. A few of the participants felt that the program should have been offered earlier, just after diagnosis, when they first learned about the cancer. A spouse commented, “It is hard to face the reality of what could happen.” They felt that placing the intervention earlier would better help those in crisis at diagnosis.

Printed materials: Several of the participants commented that the printed materials were not as beneficial as other aspects of the program, stating, “books and tapes cannot replace a human contact.” These comments were made more often by patients than by caregivers.

Suggestions for additions to the program—In response to the question that asked “What would you like to see added?” most couples did not respond. The few couples that responded suggested two areas that could be added: 1) more follow-up and 2) a “spouse alone” session.

More follow-up: A few patients felt that a follow up visit one or two years after the program would help assess progress made towards goals that were discussed in the meetings. Other patients would have liked more information related to long-term erectile dysfunction. Spouses felt that more long-term support would be helpful especially if the cancer was not responding to treatment. Another spouse felt that more materials on stress reduction and positive ways to incorporate intimacy into their daily life would be very helpful.

“Spouse only” session: One spouse suggested that it would be helpful to have at least one session separate from the partner to talk about things without the partner present, stating “sometimes we tend to shield one another from some feelings.” Spouses felt it important to have someone who listened to their problems and tried to help them. Spouses in particular found this support to be very beneficial.

Discussion

This study examined prostate cancer patients’ and their spouses’ satisfaction with the content and delivery of a supportive-educative, family-based intervention, and factors associated with their satisfaction. Both patients and spouses reported high satisfaction with the content and delivery of the FOCUS Program. They rated items pertaining to the core content of the program (F-O-C-U-S) high and the majority said that the program helped them to cope with prostate cancer and the treatments for it. It is of note that 90% of the patients and 85% of the spouses said that they would recommend the FOCUS Program to other couples coping with prostate cancer.

Even though couples were classified into three different phases of prostate cancer, they still reported equally high satisfaction with the program, most likely related to the tailoring inherent in this intervention (for example, different materials were given depending on the difficulties the dyad was experiencing). Only patients in the biochemical recurrent phase thought the program duplicated the usual care in some way. Since these patients were no longer in the newly diagnosed phase requiring information on primary treatment, or in the advanced phase dealing with new treatments for metastatic disease, their need for the information may be less or different, and may account for their perception that the program duplicated more of the information they had already received.

In regard to program delivery, qualitative comments consistently indicated that prostate cancer patients and their spouses found it very beneficial to meet (together) with the intervention nurse and discuss the illness as a three-way interaction. Couples identified this as an opportunity to raise difficult issues they might not have discussed without the supportive role of the nurse. Research indicates that communicating about cancer is difficult for many couples, and that couples often hide concerns from one another or use “protective buffering” as a way to avoid discussing sensitive issues. [48] However, in the presence of the nurse who facilitated supportive interactions between patients and spouses, they were able to share issues more openly with one another and to gain more understanding of one another’s concerns.

Multiple factors influenced patients’ and spouses’ satisfaction with the intervention and these factors were not necessarily the same. For *patients*, baseline factors, which were evident prior to the intervention were more influential in patients’ higher satisfaction with the program. For *spouses*, changes that they experienced as a result of the intervention were more influential. More specifically, prostate cancer patients who had a more positive appraisal of the illness, less uncertainty, more self-efficacy, less avoidant coping and a higher quality of life at baseline were more satisfied with the program. Since many studies have documented the difficulty prostate cancer patients have discussing their illness even with their wives,[17] it is not surprising that patients who engaged in more avoidant coping and were less confident about their ability to manage the illness (i.e., self-efficacy) were less satisfied with a supportive-educative intervention that relied on the discussion of personal feelings. On the other hand, patients who reported an increase in their self-efficacy following the intervention, reported more satisfaction with the program.

The changes or positive outcomes that spouses received as a result of participating in the FOCUS Program were more highly associated with spouses' satisfaction than were their baseline scores. Research indicates that spouses of prostate cancer patients have a higher need to discuss prostate cancer,[6, 9, 49] and they have more uncertainty about the illness than do their husbands.[16] It is not surprising then that participating in a supportive-educative intervention that increased communication with their husbands also lessened their uncertainty, reduced their negative appraisal of caregiving, and was highly related to spouses' satisfaction with the FOCUS Program. Because spouses were an integral part of this intervention, they were able to discuss their questions with an advanced practice nurse who provided them with information, support, and methods to address future questions with healthcare providers. Spouses were often the persons who read the information they were given and shared it with patients. In addition, spouses were provided with positive feedback about their attempts to manage the challenges associated with the illness, which may have reduced their negative appraisal of caregiving. It is important to note that similar to patients, spouses with higher self-efficacy at baseline reported higher satisfaction with the program. This may suggest that the patients and spouses, who have some personal resources or confidence before the intervention, may find it easier to participate in the program, and they may derive more satisfaction from it.

We also assessed patients' and spouses' need for the intervention and we found that those participants who reported a higher need for the program were more satisfied with it. We found some variability in participants' need for the intervention, with approximately one-third of the patients and spouses reporting a high need for this type of supportive-educative, family-based intervention. In a time of limited resources, it may be important to tailor the dose of the intervention to participants' according to their perceived need for the intervention, or to their risk of developing poorer quality of life outcomes, based on reliable assessment guidelines.[50]

One important finding of this study was that the FOCUS Program, originally developed for advanced breast cancer patients and their family caregivers, could be modified successfully for prostate cancer patients and their spouses across various phases of illness. This suggests that core issues, such as effective family communication, optimism, active coping, reducing uncertainty, and symptom management, can cut across gender, types of cancer, and phases of illness, and these issues need to be addressed in supportive-educative programs of care. It also suggests that a family-based intervention, which facilitates communication and support, is relevant for patients and caregivers coping with both breast and prostate cancer because cancer is a "family disease." [14, 15]

Even though participants in both studies reported high satisfaction with the FOCUS Program, there were differences in their levels of satisfaction within certain areas. Breast cancer patients reported higher overall satisfaction than did prostate cancer patients with the program, with prostate cancer patients reporting less satisfaction with information on coping, symptom management, and feeling understood by the intervention nurse. Since all the intervention nurses were female, it is possible that men with prostate cancer would have felt more understood discussing sexual symptoms, incontinence, and coping strategies with a male intervention nurse. It is also possible that because symptoms such as erectile function persist over time, prostate cancer patients may have needed more in-depth information on symptom management for a longer period of time. Conversely, spouses of prostate cancer patients (99% female) reported more satisfaction overall than caregivers of breast cancer patients (64 % were husbands), --specifically in maintaining optimism, getting questions answered, and obtaining information on symptom management. These differences may be related to the more active caregiving or illness-management role that female spouses of generally older prostate cancer patients adopt, versus the supportive role caregivers (primarily husbands) of breast cancer patients assume.

Patients and spouses also made helpful suggestions for the existing program. Some dyads expressed concern about the timing of the delivery of the intervention. These participants felt the intervention would be most helpful immediately after diagnosis, when they were dealing with treatment options and the new diagnosis of cancer, rather than later after treatment was completed or well under way. They also said that it would be helpful to have a longer follow-up and a “spouse only” session. These are important suggestions to consider for further program development.

It should be noted that participants’ gender was associated with their role. In the present study, as well as the earlier study of breast cancer patients and their family caregivers, it was not possible to factor out gender from role. Thus, one cannot rule out the possibility that differences in satisfaction and variables associated with satisfaction at different points of measurement may be associated with being male versus female, or even some interaction of gender and role. Future studies need to include patients with diagnoses that occur in both genders (e.g., lung, colorectal) and caregivers who also vary in gender.

Conclusion

Both prostate cancer patients and spouses reported high satisfaction with the FOCUS Program, a supportive-educative, family-based intervention.* Couples valued the opportunity to obtain information together and to discuss sensitive concerns in the presence of the nurse. Although satisfied with the program, factors associated with patients’ and spouses’ satisfaction differed. In order to translate efficacious interventions to clinical practice settings, it is important to assess participants’ satisfaction with program content and delivery as well as program outcomes.

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[*] Note: For more information on the intervention protocol and materials of the FOCUS Prostate Program, visit the National Cancer Institute’s website for Research Tested Intervention Programs (RTIPs) at: http://rtips.cancer.gov/rtips/programDetails.do?programId=102766&topicId=102270&cgId=

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Table 1

Primary Protocol Components of FOCUS-Prostate Program by Session

Content Area	F Family Involvement	O Optimistic Attitude	C Coping Effectiveness	U Uncertainty Reduction	S Symptom Management
SESSION 1 Face-to-Face 90 minutes	**1** Establish alliance **2** Assess dyad's roles & communication in family **3** Discuss impact of illness on family, identify family strengths **4** Introduce importance of teamwork & mutual support **5** Give "Taking Time" booklet	**1** Assess outlook **2** Educate about optimism benefits **3** Discuss tips to improve outlook **4** Give optimism magnet	**1** Assess dyad's coping styles **2** Educate about benefits of active vs. avoidant coping **3** Offer relaxation tape **4** Give booklets: "Facing Forward" or "When Cancer Returns" as appropriate	**1** Assess knowledge deficits **2** Educate about disease, treatments & ways to get information **3** Normalize feelings of uncertainty **4** Give informational handouts (e.g., "Treatment Guidelines," drug sheets)	**1** Assess symptoms & side effects for both patient and caregiver **2** Educate about self-care of common side effects (e.g., fatigue) **3** Give side effect cards as needed
SESSION 2 Phone Call 15–30 mins	**1** Assess how couple is currently managing **2** Problem-solve concerns as needed	**1** Reassess outlook **2** Encourage activities with a positive focus	**1** Help dyad identify feasible stress management activities **2** Reinforce active coping	**1** Provide information as needed **2** Encourage dyad to ask questions	**1** Problem-solve symptom management difficulties **2** Give positive feedback for self-care efforts
SESSION 3 Face-to-Face 90 minutes	**1** Assess family's ongoing response to cancer & any unmet needs **2** Acknowledge ways dyad has given mutual support to each other **3** Educate about communication skills, promote open sharing of concerns	**1** Reassess outlook, explore new concerns & address fears **2** Give "Fostering Optimism" brochure & discuss **3** Encourage dyad to practice their preferred optimism strategies	**1** Assess coping skills **2** Educate about stress management (e.g., relaxation techniques) **3** Encourage dyad to follow healthy living strategies (e.g., nutrition, exercise) **4** Assist dyad to select realistic strategies & encourage regular use	**1** Elicit questions & review assertiveness techniques **2** Discuss feelings of uncertainty about the future **3** Offer booklet on advance directives/ wills if appropriate	**1** Review patient's symptom management **2** Assess caregiver for symptoms & encourage self-care **3** Give permission to discuss sensitive symptoms (e.g., sexual/urinary problems) **4** Offer "Sexuality and Cancer" booklet
SESSION 4 Phone Call 15–30 mins	**1** Assess how couple is managing, reinforce combined efforts	**1** Encourage daily use of optimism strategies	**1** Reinforce recent active coping efforts	**1** Provide information as needed	**1** Problem-solve difficulties

Content Area	F Family Involvement	O Optimistic Attitude	C Coping Effectiveness	U Uncertainty Reduction	S Symptom Management
	2 Discuss goals for final session	**2** Identify strategies most helpful for dyad	**2** Support ongoing stress reduction activities	**2** Encourage dyad to ask questions	**2** Reinforce reporting symptoms & follow-up with NP or MD
SESSION 5 Face-to-Face 90 minutes	**1** Discuss new family issues including issues with extended family & children **2** Discuss long-term ways to handle problems **3** Encourage ongoing open communication & teamwork **4** Identify gains dyad has made, review family's resources	**1** Discuss realistic goals for future **2** Reinforce daily practicing of optimism strategies	**1** Reinforce daily stress management & coping strategies **2** Encourage dyad to accept offers of help from others **3** Offer referrals for community services & support	**1** Review information-seeking strategies **2** Discuss strategies for "living with uncertainty"	**1** Review patient's & caregiver's symptom management **2** Support attempts to manage symptoms **3** Identify symptoms that are stable & improving

Table 2

Means (SD) of Eight Item Satisfaction Scale with Total Score (N = 86 patient-spouse dyads)

Items	**Patients Mean (SD)**	**Spouses Mean (SD)**
Satisfaction with…		
Content and Delivery		
1. How both patient/spouse were involved in the discussions	4.67 (.66)	4.64 (.65)
2. How you were assisted to maintain positive outlook	4.57 (.70)	4.49 (.81)
3. Information you received on coping with the illness	4.42 (.77)	4.35 (.83)
4. How your questions were answered	4.53 (.72)	4.58 (.66)
5. Information you received on managing the side effects of illness	4.33 (.76)	4.37 (.80)
6. Amount of understanding shown by FOCUS intervention nurse	4.67 (.60)	4.66 (.69)
7. Usefulness of supplementary educational materials received	3.87 (.97)	4.01 (.83)
8. Whether FOCUS program is useful for couples facing prostate cancer?	4.30 (.93)	4.35 (.89)
TOTAL	35.37 (4.0)	35.45 (4.7)

Table 3

Participants' Perceptions of Program Structure and Value of Program to Themselves and Others (N=86 patient-spouse dyads)

Items	**Patients % (N)**	**Spouses % (N)**
Satisfaction with…		
Program Structure		
9. Number of home visits (all received three)		
Number of visits about right	85% (73)	74% (64)
Would like fewer visits	12% (10)	19%(16)
Would like more visits	3% (3)	7% (6)
10. Number of phone contacts (all received two)		
Number of phone calls about right	89% (77)	88% (76)
Would like fewer phone calls	6% (5)	8% (7)
Would like more phone calls	5%(4)	4% (3)
11. Did FOCUS duplicate anything from cancer center staff?		
No	75% (65)	74% (64)
Yes	25% (21)	26% (22)
Help to self and others		
12. Did FOCUS program help you cope with the cancer diagnosis, treatment, and post-treatment experiences?		
No	11% (9)	9% (8)
Not sure	18%(16)	18% (15)
Yes	71% (61)	73% (63)
13. Would you recommend FOCUS program to another couple facing prostate cancer?		
No	1% (1)	0% (0)
Not sure	9% (8)	15%(13)
Yes	90% (77)	85% (73)
Perceived Need for Intervention		
14. Now that you have finished the FOCUS Program, how much do you feel you needed to talk about the topics brought up by the FOCUS nurse?	M=2.9 (SD=1.4)	M=3.1 (SD=1.4)

Table 4

Correlations of Total Satisfaction Score with Psychosocial Variables (N = 86 patient-spouse dyads)

Variables	**Patient**		**Spouse**	
	Baseline[a] **r**	**Follow-up**[b] **r**	**Baseline**[a] **r**	**Follow-up**[b] **r**
APPRAISAL				
Negative Appraisal of Illness/Caregiving	$-.28^{**}$	.05	−.14	$-.25^{*}$
Uncertainty	$-.36^{***}$	−.04	−.21	$-.31^{**}$
Hopelessness	−.21	.04	−.14	−.02
RESOURCES				
Communication	.19	.09	.14	$.25^{*}$
Self-Efficacy	$.35^{***}$	$.29^{*}$	$.25^{*}$	.06
Active Coping	−.06	.05	−.13	−.11
Avoidance Coping	$-.26^{*}$	−.12	−.16	.12
QUALITY OF LIFE				
Fact G: Total	$.28^{**}$	.16	.03	.05
SF 12: Physical Summary	.13	.17	.05	.10
SF 12: Mental Summary	.20	.11	.12	.20
Need for Intervention	$.27^{*}$		$.26^{*}$	

$^{***}p \le ..001$;

$^{**}p \le ..01$;

$^{*}p \le .05$

[a] Correlations (r_{xy}): x=variables assessed at baseline, y=total satisfaction assessed at 4 months

[b] Partial correlations ($r_{xy..b}$): x=variables assessed at 4 months, y=total satisfaction assessed at 4 months, b=controlled for baseline