

Couples' Experiences With Prostate Cancer: Focus Group Research

Janet Harden, RN, MSN, Ann Schafenacker, RN, MSN, FNP,
Laurel Northouse, PhD, RN, FAAN, Darlene Mood, PhD, David Smith, MD,
Kenneth Pienta, MD, Maha Hussain, MD, and Karen Baranowski, RN, MSN, NP

Purpose/Objectives: To explore the experiences of couples living with prostate cancer, the impact of the illness on their quality of life, their ability to manage symptoms, and their suggestions for interventions that would help them to improve their daily experiences.

Design: Descriptive, qualitative.

Setting: Six focus groups were used to obtain the data; two were patient-only groups, two were spouse-caregiver groups, and two were dyad groups. The focus groups were conducted at two comprehensive cancer centers in the midwestern region of the United States.

Sample: 42 participants: 22 men with prostate cancer and 20 spouse-caregivers.

Methods: Focus group discussions were tape-recorded, and the content was analyzed.

Main Research Variables: Quality of life, symptom experience, and areas for intervention.

Findings: Four major themes emerged from the data: enduring uncertainty, living with treatment effects, coping with changes, and needing help.

Conclusions: Participants had a need for information and support. Both men and spouse-caregivers felt unprepared to manage treatment effects. Symptoms had a broad effect on couples, not just men. Positive effects of the illness, as well as negative effects, emerged from the themes.

Implications for Nursing: Attention needs to be given to methods of providing information and support to couples coping with prostate cancer. Both patients and partners need to be included in discussions about the effect of the illness and treatments so that both can feel more prepared to manage them.

Cancer of the prostate is the most common form of cancer among men over 55 years of age (Jemal, Thomas, Murray, & Thun, 2002). Because of the inherent nature of the illness, cancer of the prostate frequently affects the self-esteem and sexual function of men. Treatment side effects, including urinary incontinence, erectile dysfunction, loss of libido, and fatigue, affect not only the patient but also his spouse. These symptoms can drastically alter the established role of each member of the husband-wife dyad, resulting in feelings of frustration and stress. Changes in the marital relationship can further affect the quality of life of the couple. How couples live with a diagnosis of prostate cancer

Key Points . . .

- Prostate cancer creates a great deal of uncertainty in the lives of men and their spouses.
- Both patients and spouses want information about treatment effects, particularly incontinence, hormone alterations, fatigue, and sexual difficulties, and ways to manage them.
- Spouses play a major role in helping men manage the illness and need to be included in programs of care.
- Patients and spouses need the opportunity to voice their concerns and receive support from healthcare professionals caring for them.

and manage treatment effects is not well defined in the literature. The specific aims of this study were to explore (a) the experiences of couples living with prostate cancer, (b) the impact of the illness on their quality of life, (c) their ability to manage symptoms, and (d) their ideas for interventions that would help them to improve their daily experiences. As healthcare professionals gain a better understanding of couples' experiences, they will be able to design programs of care to meet the physical and

Janet Harden, RN, MSN, is a lecturer in the College of Nursing at Wayne State University in Detroit, MI, and a doctoral student in the School of Nursing at the University of Michigan in Ann Arbor; Ann Schafenacker, RN, MSN, FNP, is the project manager in the School of Nursing at the University of Michigan; Laurel Northouse, PhD, RN, FAAN, is a Mary Lou Willard French Professor of Nursing in the School of Nursing at the University of Michigan; Darlene Mood, PhD, is a professor in the College of Nursing at Wayne State University; David Smith, MD, is an associate professor in the Department of Internal Medicine at the University of Michigan; Kenneth Pienta, MD, is a professor in the Departments of Internal Medicine and Surgery at the University of Michigan; Maha Hussain, MD, is an associate professor of internal medicine at Wayne State University; and Karen Baranowski, RN, MSN, NP, is a nurse practitioner at Karmanos Cancer Institute in Detroit. This project was funded by a John and Suzanne Munn Endowment Idea Grant from the University of Michigan Comprehensive Cancer Center (L. Northouse was the principal investigator.). (Submitted November 2000. Accepted for publication March 28, 2001.)

Digital Objective Identifier: 10.1188/02.ONF.701-709

psychological needs of dyads living with prostate cancer and support them in their day-to-day struggles.

Conceptual Framework

Men and their spouses use a variety of coping resources to deal with the biopsychosocial stressors associated with living with prostate cancer. A cognitive-appraisal model of stress, used in previous research involving couples dealing with a cancer diagnosis, guided this research (Northouse, Mood, Templin, Mellon, & George, 2000; Northouse, Templin, & Mood, 2001). In this model, personal characteristics, social resources, and illness-related factors are antecedent conditions that affect individuals' cognitive appraisal of their illnesses and their use of coping strategies; these mediators subsequently affect patients' and family members' quality of life. The model also specifies a reciprocal relationship between patients' and family members' quality of life; each affects the other. In the current study, the researchers were interested in focusing on those aspects of the model pertaining to patients' and spouses' quality of life and illness-related factors (e.g., treatment effects, symptoms) and identifying the kinds of nursing interventions needed by couples experiencing prostate cancer.

Literature Review

The quality of life of men with prostate cancer is a major consideration, yet quality-of-life issues in this group of men have been studied less than in other forms of cancer (Herr, 1997). Litwin et al. (1995) found that men with prostate cancer reported significantly worse sexual, urinary, and bowel function than men without prostate cancer, even after controlling for general sexual and urinary problems reported by older men. Studies of men with localized prostate cancer, typically treated by prostatectomy or radiation therapy, indicate that men's general quality of life improves during the first year following diagnosis, but their disease-specific problems (e.g., incontinence, sexual difficulties) often persist over time (Braslis, Santa-Cruz, Brickman, & Soloway, 1995; Helgason et al., 1996; Litwin et al.; McCammon, Kolm, Main, & Schellhammer, 1999; Stanford et al., 2000). Studies of men with advanced prostate cancer, who typically receive an orchiectomy or hormone treatments, indicate that these treatments can cause a loss of libido, fatigue, or hot flashes that can interfere with men's quality of life (Albertsen, Aaronson, Muller, Keller, & Ware, 1997; Clark et al., 1997; Esper, Hampton, Smith, & Pienta, 1999; Trachtenberg, 1997). In one study, men with recurrent prostate cancer reported significantly more pain, more anger, a greater lifestyle change, and a greater need to discuss their illness than did men with localized disease (Fitch, Gray, Franssen, & Johnson, 2000).

Although considerable research has been conducted on the effect of cancer on partners of patients with cancer (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Given & Given, 1992; Lewis, Woods, Hough, & Bensley, 1989; Northouse, Dorris, & Charron-Moore, 1995; Oberst & James, 1985), a notable paucity of family-based research in the prostate cancer literature exists, even though family members play a central role in men's choice of treatment (Volk et al., 1997) and in maintaining men's quality of life (Jakobsson, Hallberg, & Loven, 1997). From the few studies that have been performed, findings indicate that spouses play a central role in the lives

of men with prostate cancer. Spouses are the major providers of emotional and physical care to these men (Heyman & Rosner, 1996; Jakobsson et al.; Kornblith, Herr, Ofman, Scher, & Holland, 1994; O'Rourke & Germino, 1998; Stetz, 1987; Volk et al.). In one qualitative study, patients with prostate cancer reported that their wives were the first to compensate for problems that they had carrying out their day-to-day activities and also were their primary source of support (Jakobsson et al.). Gray, Fitch, Phillips, Labrecque, and Fergus (2000) found that it was rare for men with prostate cancer to disclose information about their illness to anyone but their wives. Some men in that study relied on their wives to disclose information about their cancer to other people, thereby saving the men from having to answer awkward follow-up questions that could arise. Other investigators have reported that wives often are the communication conduit between their husbands and healthcare professionals, serving as key advocates for their husbands (Heyman & Rosner).

This central role of primary support person or caregiver, however, has emotional costs for spouses. Kornblith et al. (1994) found that spouses of patients with prostate cancer reported more emotional distress associated with the illness than did their husbands with the disease. These investigators also found a reciprocal relationship in the problems reported by patients and spouses. As men's problems increased, especially in areas related to fatigue and urinary problems, a subsequent decrease in spouses' quality of life occurred. Gray, Fitch, Phillips, Labrecque, and Klotz (1999) found that signs of anxiety were evident in both patients and spouses even though the anxiety was not always acknowledged openly.

For the most part, prior research on the quality of life of men with prostate cancer has focused primarily on the men and specifically on the extent to which they experience physical symptoms associated with treatment. Although these symptoms are important to address, other psychosocial aspects of the illness, such as dealing with uncertainty, maintaining support, or managing other life changes associated with the illness, have received little attention in the prostate cancer literature. Furthermore, research on the experiences of spouses is limited—especially in view of the integral role that spouses play in maintaining the health and well-being of men with prostate cancer. Therefore, in the current study, the researchers examined the quality of life of men with prostate cancer and their spouse-caregivers, the symptoms the men were experiencing and their ability to manage them, and the men's ideas about the kind of interventions that would help them manage the illness.

Methods

Design

Focus group discussions were used in this qualitative study to explore the dyad's experience of living with prostate cancer. Sessions were held in private conference rooms located near the site that the men received their treatments. After a careful review of the literature, the team who would be assessing the couples' ability to cope with the cancer experience developed interview questions. Trained interviewers using semistructured interview questions collected data. The questions that were used were purposely broad and open-ended to encourage participants to share their own perspectives. More focused questions were asked during the discussion to clarify information or guide the participants back to the topic.

Sample

Six focus groups were used in this study: Two groups were comprised of men only ($n = 14$), two groups were spouses only ($n = 12$), and two groups were couples ($n = 8$ couples). O'Rourke and Germino (1998) recommended the use of separate focus groups to obtain the individual versus shared perceptions of patients with prostate cancer and their spouse-caregivers. Within the spouse-only group, four of the spouses were married to men who participated in the men-only group.

Purposeful sampling of participants was obtained from two comprehensive cancer centers in the Midwest. Men aged 40–90 years were eligible for the study if they had a confirmed diagnosis of prostate cancer and were in one of the following three phases of illness: newly diagnosed phase (between one month to two years postdiagnosis), postprimary treatment phase with rising prostate-specific antigen (PSA), and metastatic phase including hormone-sensitive and hormone-refractory disease. Efforts also were made to obtain a mix of patients who had received a variety of treatments including prostatectomy, radiation, or hormone therapy. A total of 22 men and 20 spouse-caregivers participated in the six groups ($N = 42$). The response rate was 81% for participants referred by staff at a university hospital compared to 50% for those referred by staff from an inner-city hospital, resulting in an overall response rate of 64%.

Instruments

The instruments used in this study included a demographic and medical history questionnaire and a semistructured interview guide. The focus group topics explored the effects of living with prostate cancer on the quality of life of the men and their caregivers, symptom management, level of confidence in managing symptom issues related to the disease, and the type of interventions that would most benefit the couples in their day-to-day lives (see Figure 1).

Procedures

The university human investigation committee approved the study protocol prior to the identification of eligible participants. The names of potential subjects were identified by clinic staff who contacted the patients or caregivers and asked

them if they were willing to learn more about the study. Those individuals willing to have their names released to the investigators were contacted by a member of the research team who explained the study in greater detail.

Willing participants were scheduled for one of the focus groups depending on their time or availability. The same leader and coleaders were employed for each group. Prior to the start of the focus group, participants signed a consent form and completed demographic and medical history questionnaires. As the group discussion was initiated, the leader and coleaders reassured participants that their comments would be kept anonymous and confidential. The same semistructured interview guide was followed in each group, with slight modification of wording depending on whether the question was being directed to members of the patient-only, spouse-only, or dyad group. Each group was interviewed for approximately 90 minutes. Focus group members were paid \$15 for their participation.

During the interview, participants were asked to describe their perceptions of the experience of living with prostate cancer. Recapitulation, a brief restatement of what was said, was used to lead participants back to earlier points to clarify and fill in gaps. This process provided clearer descriptions. Clarification was used frequently to facilitate a fuller understanding of the stated message. All focus groups were tape-recorded, and the tapes were transcribed. Following transcription of the interviews, accuracy was checked by comparing the transcripts with the tapes and with observers' notes (Huberman & Miles, 1994).

Data Analysis

Descriptive statistics were used to report the demographic and medical characteristics of the sample. Focus group data were analyzed to identify themes using established qualitative phenomenologic techniques (Holstein & Gubrium, 1994).

The process of theme development was emergent. Each interview was read in entirety by the investigators to determine the lived experiences provided by the participants. During the second and third readings, coding was used to identify threads and the various dimensions of the experience. Data were condensed by investigators into descriptive categories that formulated meaning in areas of the lived experience. The investigators revisited the data independently and compared results. Categories were organized into clusters based on similarities of meaning.

Themes, the abstracted entities that provide meaning and give identity to recurrent experiences of participants, emerged. These themes captured the nature of the experience and provided a meaningful whole (De Santis & Ugarriza, 2000). Explicit quotes were extracted from the transcripts to provide a basis for understanding the themes and their unifying properties.

Results

Sample Characteristics

The average age of men with prostate cancer was 63.7 years. The majority of men were Caucasian (64%), some were African American (32%), and one man was Native American (4%). The men reported a wide range of educational backgrounds, although most had some education beyond high school ($\bar{X} = 14.4$ years, $SD = 3.2$). The majority were married (86%) and had family incomes greater than \$50,000 per year (67%). Fifty-five percent of the men were retired.

1. What effect has the prostate cancer had on your quality of life and the quality of life of your spouse? By "quality of life" we mean your physical, psychological, and social health.
2. What symptoms/complications have you experienced that are troubling to you or your spouse? How do you manage them? What information or help would you like from health-care professionals?
3. When you think about all the things that you have to manage related to this illness, what areas do you feel the most confident about handling? Which areas do you feel less confident about?
4. If you were to develop an ideal or special program to help men live effectively with prostate cancer, what would you like to see in the program? What would you include to help family caregivers? When during the illness would this be most helpful?
5. Is there anything further that you would like to share with us that would be helpful for us to know about your experience?

Figure 1. Focus Group Questions

The caregivers, who averaged 60.5 years in age, all were spouses of men with diagnosed prostate cancer. The majority of caregivers were Caucasian (75%); however, 25% of the caregivers were African American. The caregivers also reported diverse educational backgrounds (\bar{X} = 13.7 years, SD = 2.2), and although the majority were retired or homemakers (65%), 35% were working outside of the home.

Men in this study were from one of three phases of illness: newly diagnosed postprimary treatment phase (18%), postprimary treatment with a rising PSA phase (biochemical recurrence) (23%), or metastatic phase (59%). Ten men reported having a prostatectomy (46%), nine (41%) had radiation therapy, 10 (46%) had hormone treatment, and five (23%) reported other types of treatment. None of the men reported following a “watchful waiting” approach. At the time of the focus groups, most of the men were receiving treatment (82%), and about two-thirds indicated that they had a recurrence of their prostate cancer (biochemical or clinical evidence). On the medical information sheet, men also identified symptoms they were experiencing: 13 (59%) reported sexual problems, 13 (59%) experienced urinary problems, 10 (46%) reported fatigue, 5 (23%) had bowel problems, and 3 (14%) had emotional problems. Sixty-seven percent of the men reported having other health problems, such as heart disease and arthritis. In addition, 40% of the caregivers reported having health problems of their own, such as hypertension or diabetes.

Themes

The major findings of this study pertain to the themes that were abstracted from the comments of focus groups participants. They reflected the physical and psychological impact of living with prostate cancer. Their experiences clustered into four major themes: enduring uncertainty, living with treatment effects, coping with changes, and needing help.

Enduring uncertainty: The theme of enduring uncertainty emerged from the following subthemes: struggling with choices, interruption in life, and emotional roller coaster (see Figure 2).

Struggling with choices: Participants described the confusion they felt in struggling with treatment options and the disability that accompanies various options. Several talked of the need to keep abreast with new developments to help in the decision process. Couples frequently were presented with opposing views by the healthcare professionals they consulted. They expressed difficulty in trying to sort out choices when the diagnosis was newly made. Participants felt overwhelmed. Many expressed difficulty processing the information given to them. One couple described the experience in this way.

If you go to a surgeon, they want to cut you open, and if you go to an oncologist, they will want chemo . . . so everybody's got their own approach. As we said earlier, we wanted to have some closure on it. Just tell me what to do, but they don't say.

-
- Struggling with choices
 - Interruption in life
 - Emotional roller coaster
-

Figure 2. Theme: Enduring Uncertainty

Another man said,

The thing you need to do is keep up [on information] and know what's happening and what [new treatments] they keep coming up with. . . . Somebody's got to make a decision, which will be me . . . I've got to come up with my own decision on this. But I don't know . . . I don't know what I'll do.

Interruption in life: Participants described a sense of annoyance with disrupted plans and changes in life roles. For many, the diagnosis resulted from a routine examination when the men were feeling well. For others, the diagnosis was delayed until treatment options were narrowed. For all, the diagnosis and treatment was disruptive to their lives and routines. Caregivers expressed concern about leaving their partners alone. For several caregivers, their attendance at the focus group meeting was the first “social” event they had been to in quite some time. Dyads talked about the changes in household responsibilities that resulted after diagnosis. Life plans were set aside, at least temporarily, while they dealt with the current situation. Life was turned upside down. One caregiver described her situation.

Both of us are retired, and we certainly had hopes of being this wonderful little old couple that would just . . . you know, be lively and walk into the sunset together. And do all the things you'd planned. And you find that you can't do all that.

Emotional roller coaster: Although couples living with prostate cancer described efforts to maintain quality in their daily lives, they frequently referred to a constant worry. They described a decrease in their sense of future security. The month-to-month wait to determine whether the result of the next PSA would be good or bad always loomed ahead. As the time for testing drew near, the worry intensified, overshadowing everything. When the results were good, they were reassured until next time. Couples felt less able to make long-term plans, and many expressed a sense of urgency, saying “you can't waste a moment.” Even when the results of testing were good, they felt an emotional drain. One couple expressed the feeling this way.

Emotionally, we were going along on a high plateau, and then a couple of months later, we went back to the doctor and found out that the PSA had gone back up . . . so it is kind of an emotional up and down.

A caregiver related the following.

After the surgery, they said everything would be okay. . . . Then they came back and they said, “No . . . everything is not okay . . . now you need to have radiation” . . . and then they tell us there is no cancer. But it's a roller coaster ride . . . first good, then bad . . . then we wonder, what is it?

Living with treatment effects: The second major theme, living with treatment effects, emerged from the following subthemes: losing urinary control, sexual difficulties, hormonal alterations, and overwhelming fatigue (see Figure 3).

Losing urinary control: All groups related difficult experiences in dealing with the loss of urinary control. Severity of this loss varied from little to total. Men still in the work force talked of planning their schedule around the availability of restrooms. The need to urinate more frequently, coupled with

- Losing urinary control
- Sexual dysfunction
- Hormonal alterations
- Overwhelming fatigue

Figure 3. Theme: Living With Treatment Effects

the inability to control this need, was a great source of frustration. Men chose aisle seats at every opportunity to allow for ease of leaving. Trips were short or planned with frequent stops. As a result of treatment, some men had total urinary incontinence, which left them dependent on incontinence pads. The worry about the return of function was constant. One man said,

A lot of times you feel like you have the urge to go to the bathroom. When I was younger, I could control it until I got a chance . . . now I can't. . . . I think that's the hardest part for me. It's all of a sudden; I don't have as much control over myself as I used to.

Another man (postprostatectomy) felt unprepared for the symptoms he was going to encounter.

The catheter comes out and they say, "Okay, go on. I'll see you in a couple of weeks when you need your PSA drawn." Nobody tells you about the diapers. Nobody tells you how to protect your skin. These are very important issues. Physicians deal with the disease, but they don't deal with the consequences of the disease.

Sexual dysfunction: For many of the men, surgery, chemotherapy, or hormone therapy dramatically affected their erectile function and libido. Male group members talked about feeling incomplete; men grieved the loss of an integral part of their marriage. Some couples made adjustments in how they had sexual relations; others had not had relations in quite some time. One man stated his feelings very clearly.

You go to sleep holding hands; it's the best you can do. You sleep in the same bed, and you're afraid to hold each other because somehow you feel like you are starting something that you can't finish, and she's the same way.

Another man also expressed his concern about his loss of sexual prowess.

You're harmless. . . . My wife puts up with it okay. She never bugs me about it [intercourse]. I know she misses it . . . but you don't realize what an integral part of your marriage it is . . . now there's something missing [cries].

Women group members acknowledged the distress their partners felt related to sexual dysfunction; however, their concerns more frequently centered on their own struggles with the possibility of losing their mates. Many said they could handle the sexual dysfunction because at least they still had their husbands. Some couples said that they did not receive much help with sexual changes. These changes were seldom discussed by couples with healthcare professionals, and healthcare professionals seldom asked about sexual concerns.

Hormonal alterations: Men who received hormone therapy as treatment for their prostate cancer experienced fluctuations in mood that were confusing for the couple to recognize and then manage. Episodes of crying and anger were accompanied by hot flashes and weight gain. Men complained about feeling depressed and crying easily. Most said they were unpre-

pared for these symptoms of treatment. One wife stated it this way.

I never expected my husband to get hot flashes and [menstrual] cycling. . . . He was angry at being angry, and he was angry because of not knowing what was really going on. . . . His sister visited us. After 48 hours of watching his behavior, she said to me, "Oh my God! Is he PMS-ing on you?" She could see right away what was going on. But before her comment, I couldn't see it. . . . There should be a note when you take these hormones saying, "This is what can happen; these are the symptoms."

The lack of preparation for the possible occurrence of these symptoms was a source of distress for men and their wives.

Another area distressing to men and their partners was the change they experienced in their self-identity and feelings of masculinity as a result of the hormone alterations. One man reflected,

You don't have that [sexual] power anymore. It's sad fooling yourself. . . . I used to go out with female friends and tease them . . . say anything so I would feel masculine. That was the power I had. Now I can't flirt anymore . . . because of that medicine [hormones].

Overwhelming fatigue: The fatigue resulting from treatment was described as one of total exhaustion, especially by men with advanced disease. This fatigue limited the ability of many men to do the things required at work and at home. They expressed distress because their wives now were doing things the men had done previously. Men complained of not being able to spend quality time doing things together because "it seems like I'm sleeping all the time." They discussed how they wanted to do the things that they always had done before the illness but now could not. One man said,

I've always been a hard charger. I exercised on a daily basis. I could always get along on five or six hours of sleep . . . put in long hours at work and still always did all my own work around the house. . . . But over the last month, I just sort of ran into a brick wall. And I'm exhausted.

Fatigue was a very distressing symptom for many men who said that they could push through their tiredness in the past but were not able to do so now.

Coping with change: The third major theme, coping with change, emerged from subthemes of drawing together, shifting roles, facing anger, controlling the situation, and sharing with others (see Figure 4).

Drawing together: Living with prostate cancer and its treatments brought out a renewed family experience for many of the men and their wives. Couples who had been very active socially before the diagnosis found less desire for those types of encounters. Because of the consequences of treatment, couples became more selective in the social engagements they

- Drawing together
- Shifting roles
- Facing anger
- Controlling the situation
- Sharing with others

Figure 4. Theme: Coping With Changes

accepted. Frivolous social activity seemed less important to them. Families drew closer together, and the members shared feelings of love and concern more freely. Adult children changed vacation plans to spend more time at home with their fathers. Many couples felt the cancer experience drew the family together. Just being there to support each other and share time was integral in their relationships. One man shared this.

My brother decided to tell me that he loved me. It sort of brings the family together because you figured it couldn't happen to us . . . but it did, and now my brothers and sisters call me regularly.

Shifting roles: Many of the treatment options left the male participants severely fatigued. Their inability to complete normal household duties resulted in a shifting of responsibilities. Some couples struggled to keep up with the chores as they always had done, whereas others utilized outside services to help with task completion. In some cases, this resulted in friction between partners. One man explained his experience.

My wife tries to do too much. It's physically exhausting for her and very, very difficult. But at the same time, I don't know how to change it. I think that's her way of coping.

Facing anger: Hearing the diagnosis of prostate cancer was devastating for participants and their families. Couples expressed anger and shock at this unexpected intrusion in their lives and dreams. Some expressed anger at a delayed diagnosis that made the prognosis less promising, and their anger was pointed at physicians for not having done a thorough screening earlier. Some caregivers directed anger at themselves for not knowing that screening should be performed, not asking more questions, and not prodding their husbands more to get an annual physical. Some felt anger at the lack of fairness because they already were dealing with illnesses of other kinds. Many expressed anger because of the helplessness they felt. One wife shared these feelings.

They said my husband's cancer was advancing so fast that they had to treat it aggressively, and they did. He lost 70 pounds in four and a half weeks. So, I'm dealing with my anger. . . . I had anger at the beginning because the doctor forgot to check his prostate twice . . . and I'm angry at myself for not knowing.

Some men found the best way to cope was to put the cancer out of their minds and continue to live. They believed that doing otherwise would create negative energies that would impede their recovery.

Controlling the situation: People handle stressful situations differently. Some participants found a need to control who knew about their diagnoses. Children, mothers, and other family members were not told. These couples struggled in supporting each other. One wife expressed frustration because she was not allowed to ask the doctor any questions. Another wife was not sure what treatment her husband was receiving because he did not want to discuss this with her. Although this disturbed the wives, they quickly added that this was how their husbands wanted it. They just tried to support them. One caregiver discussed her concern about her husband's unwillingness to share his symptoms and pain with his doctor. Her husband admitted that he was reluctant to discuss his problems with the doctor and said,

You know a man never tells another man he's having problems or is in pain. . . . Men don't show their vulnerability to other men.

Sharing with others: Some participants found it helpful to discuss their situation with others. One wife expressed dismay because her husband told everybody he met, especially at church. She added that when they respond, "I'll pray for you," he finds great comfort. A few men and wives talked of gathering strength from their religious communities and prayer life. They found support in the sentiments offered by fellow members at their places of worship.

One wife told about her husband's constant need to discuss his operation and treatment. "That's all he talked about for weeks. And it drove everyone crazy, but it helped my husband deal with it." One participant encouraged his children to develop a family tree of relatives and the diseases they may have encountered for future reference. Frequently, couples shared concerns for their sons and encouraged them to have prostate cancer screening early and regularly.

Needing help: The fourth major theme, needing help, emerged from the subthemes of professional caring, tailored information, and peer reassurance (see Figure 5).

Professional caring: Participants all too often found health-care personnel "professional," but distant. They felt that dealing with hundreds of people every day made staff less compassionate. One couple reported filling out questionnaires periodically, expressing the same grave concern over and over without anyone asking about the issue. One wife called her social worker asking for help for her husband in dealing with his disease, but no one followed up. One man was told, in a matter-of-fact manner, that he was not going to live very long. He needed support at that point, but none was provided. Some participants said this lack of professional concern could be the result of dealing with patients' problems day after day with no reprieve. One man summarized his need.

People in that office see hundreds of patients every day. And they become hard to it. And I understand that. But being on the other end [as a patient] . . . it's tough enough at that time. You're trying to sort things out because you've just been told you have cancer.

Other participants shared stories of one nurse in a particular practice who took the time to know each of them and answer their questions. She would call them at home to follow up on concerns they had expressed or just to see how they were doing. Her concern for them as individuals made them feel supported. These participants agreed that this nurse was special because she really cared.

Tailored information: All participants agreed that the need for information was great. However, each needed different information or needed it in a different way than others. Participants, initially shocked by the diagnosis, absorbed little information and left the doctor's office with many unasked questions. At their appointments, they had a list ready, but when the doctor gave them their PSA results, their emotional reactions

-
- Professional caring
 - Tailored information
 - Peer reassurance
-

Figure 5. Theme: Needing Help

took over and the questions were unasked again. These patients viewed their doctors and the office nurses as very busy. Many felt they could not bother a busy nurse with questions. Participants felt it would have been helpful for someone trained in the causes and treatments of prostate cancer to spend time with them, gather information about them, and answer any questions they might like to ask. Participants wanted someone to listen to their specific needs and fears and help them find answers or just review information. They wanted someone to tell them that what they were experiencing was normal for this stage of treatment—someone who knew them and would listen to them. They agreed among themselves that their issues would be easy to clear up but could get blown out of proportion when no one listened to their concerns.

Peer reassurance: Participants frequently wondered about the course of treatment they selected, about the symptoms they were experiencing, and whether these symptoms should be expected. Many felt that having a person to talk with, call, or ask a specific question would be beneficial. Participants felt a type of sponsor or buddy system with someone who has “been there” would be helpful. This resource could review information and help patients understand what to expect based on past experiences or could help reassure them that what was happening was normal at this stage. One couple described the need for reassurance.

A person you could talk to would help . . . 90% of the time I function really, really well, but there's that 10% when all the dark, awful thoughts run through your mind. If there was just somebody you could call and ask a question, a specific question such as, “Is this normal for somebody going through this treatment?”

Discussion

The lives of people living with prostate cancer are influenced greatly by their experiences. Their daily lives and plans have been disrupted and often set aside. This study suggests that living with prostate cancer is a daily struggle to balance the anxiety caused by constant uncertainty and manage the treatment effects and day-to-day responsibilities. The themes discussed in the focus groups are interlaced. The lived experience is a multidimensional phenomena influenced by the effects of the disease process and personal expectations.

The overwhelming need for information was a thread that ran through each theme, a finding that has been reported in the literature (Heyman & Rosner, 1996; Robinson et al., 1999). Beginning at the time of diagnosis, dyads were faced with the need to make a decision regarding treatment choices. Many expressed concern about making an informed choice at a time when they were overwhelmed with fear associated with a cancer diagnosis. The fear they experienced diminished their ability to concentrate and process information. Only one couple from the focus groups was satisfied with the information they received. This couple had been given a videotape that explained treatment options, and they were able to take the video home, watch it repeatedly, and share it with their adult children. Managing uncertainty was a major theme that pervaded each group and was related to participants' need for information to make informed decisions.

Many participants felt unprepared for recognizing and managing treatment effects. Although they had been told about possible outcomes, such as incontinence and impotence, health-

care providers rarely spent time discussing the impact of these effects on patients' daily lives. The limitations imposed by the treatment effects threatened the quality of life of the men and their partners. Furthermore, although a number of previous studies have mentioned problems with urinary incontinence and sexual dysfunction (Stanford et al., 2000), less attention has been given to hormone alterations, which were particularly problematic for some couples in this study. For men, the hormone treatment affected their sense of “power” as sexual beings. For wives, it affected their sense of femininity or sexual attractiveness because their husbands showed less interest in them as a result of the effects of the hormones.

The findings of the focus groups indicated that spouses in this study assumed an active role in their husbands' illness; they were the ones who encouraged their husbands to seek treatment, were their husbands' primary source of support, and frequently were the communication conduit between their husbands and their physicians and nurses. Other investigators also have reported these findings (Gray et al., 2000; Heyman & Rosner, 1996; O'Rourke & Germino, 1998). Wives were the ones who felt angry or guilty when important diagnostic symptoms were missed or their husbands delayed seeking treatment.

Partners were affected by men's illnesses and symptoms, especially the symptoms related to urinary, sexual, and hormonal changes. Even though these symptoms are thought of as *men's* symptoms, in reality, they are symptoms that *couples* experience. For example, incontinence often was a problem that couples dealt with, not just men. Wives frequently helped their husbands strategize how to handle incontinence problems in work and social situations. This is not to minimize the primary effect of these symptoms on men, but rather to suggest that these symptoms have a broader effect on couples. These findings are consistent with the conceptual framework used to guide this study, which stated that illness-related factors (e.g., symptoms) affect the quality of life of both patients and their spouses.

Coping with change was another theme that pervaded the focus groups. Within focus groups and even within couples, considerable diversity was present in the strategies used to cope with the illness. Some had the desire to be very open, whereas others preferred to be more guarded about their disease. For certain couples, coping with role changes was stressful. Most couples, however, were able to identify beneficial aspects of the illness in their lives. Many discussed the ways that the illness had drawn them closer together, allowed them to become more selective in how they spent their time, and drawn a great deal of support from others. These positive aspects of the illness have been reported by patients in other studies as well (Ferrans, 1994; Pelusi, 1997). The ability to identify positive and negative aspects of the illness appeared to be an important coping mechanism that helped some of these couples find meaning in the illness.

In this study, the researchers conducted three types of focus groups: dyad, patient-only, or caregiver-only groups. The researchers initially believed that some of the issues raised in the patient-only or caregiver-only groups would be different than the issues raised in the dyad groups, where both partners were present. From the analysis of the data, however, the themes that emerged were common across all three groups. The spouses in the caregiver-only group did express more anger about the cancer and its effect on their lives than did spouses in the dyad group. Spouses in the dyad group may have wanted to protect their husbands from this anger, fearing

that their anger would add to their husbands' distress. Even though major differences across groups were not evident, the members of the patient-only or caregiver-only groups talked more freely as they shared their common experiences. This increased openness among members may be a reason for continuing to use these types of groups, as well as dyad groups, to gather information about patients' and caregivers' experiences.

Limitations

Before discussing the implications for practice, a few limitations to this study need to be mentioned. Although the sample for these focus groups had a representation of both Caucasian and African American participants, researchers were not able to categorize the comments from one ethnic group to another because of the ongoing flow of dialogue within the groups. Examining ethnic differences remains an important area for future research. Germino et al. (1998) found ethnic differences in participants' level of uncertainty and a number of quality-of-life and coping variables in a large sample of men with prostate cancer and their family caregivers. In addition, even though some differences were noted in the concerns of couples in different phases of illness (e.g., couples in the newly diagnosed phase had more concerns about incontinence and sexual changes, couples in the advanced phase had more concerns about hormone alterations), the themes that emerged from the content analysis indicated more commonalities than differences. The sample consisted of more participants from the advanced phase, which may have affected the content of some of the themes that emerged.

Qualitative data by design have limited generalizability. Findings in this study should be interpreted with the study's specific purpose in mind. The design was intended to inform thinking and provide better understanding of the daily life experiences of couples living with prostate cancer as a basis for the development of an intervention program that is meaningful for this population.

Implications for Nursing

Despite these limitations, the findings of this study indicate several potential implications for practice. First, shared experiences from the focus group members indicate that current methods used to provide support and information are limited in their effectiveness. In bustling oncology practices and clinics, the perception that everyone is extremely busy deters many clients from asking questions. Most nurses in these clinics were not seen as sources of information for the couples. In addition, the time of disease diagnosis is stressful for couples, and information given at that time often is poorly absorbed (Moore & Estey, 1999). In their study, men reported many gaps in their knowledge about catheter care, postoperative pain, incontinence, and erectile dysfunction. Alternate meth-

ods of providing information need to be explored, such as the use of home-care nurses (Robinson et al., 1999). A setting that is free from distraction and gives the perception of individualized attention would be more conducive to the intimate nature of issues that men and their partners may want to discuss. Information needs to be repeated and provided in other formats (e.g., written materials, brochures, videotapes). This would allow couples to review the information at their leisure and refer to it as they need clarification.

Second, healthcare professionals need to fully discuss the potential treatment effects that couples may face. Understanding what type of symptoms may develop following treatment and how to handle them is essential for successful management. Research has demonstrated that treatment effects, such as fatigue and urinary control, affect partners' and patients' quality of life (Kornblith et al., 1994). Being prepared for and having confidence in their ability to manage treatment symptoms will help to decrease couples' emotional distress. Nurses and other healthcare professionals can play an integral role in helping couples manage symptoms immediately before, during, and following the course of treatment. Anticipating the problems that may develop and preparing the couples for these problems will increase the couples' confidence in their daily management. Providing contact numbers and resources for information as questions develop over time will help couples feel more control over their experience.

Third, all participants spoke of feeling distressed. Life for them was an emotional roller coaster that affected all members of the family. Nurses and other healthcare professionals who work in private oncology offices or clinics need to incorporate an emotional assessment and provide referrals and resources for support to couples experiencing distress. Interventions that help couples deal with role changes within their relationships would diminish the negative stressors many couples feel. Stress reduction programs specifically designed for teaching people to live with uncertainty would benefit couples and promote emotional health.

In summary, this study provided insight into the daily struggles of people living with prostate cancer. Several themes were identified that require the development of intervention programs by healthcare professionals. Intervention programs need to focus on couples and provide information and support in treatment choice and symptom management. Programs designed for stress reduction also have the potential to improve the quality of life of men and their partners.

The authors wish to acknowledge the valuable assistance of Karin Olson, PA, Nancy Rodriguez-Galano, RN, CNS, Judith Fardig, PA, Gayle Groshko, RN, and Martha Heath, RN, who helped recruit participants for this study.

Author Contact: Janet Harden, RN, MSN, can be reached at jharden@umich.edu, with copy to editor at rose_mary@earthlink.net.

References

- Albertsen, P.C., Aaronson, N.K., Muller, M.J., Keller, S.D., & Ware, J.E., Jr. (1997). Health-related quality of life among patients with metastatic prostate cancer. *Urology*, 49, 207-217.
- Braslis, K.G., Santa-Cruz, C., Brickman, A.L., & Soloway, M.S. (1995). Quality of life 12 months after radical prostatectomy. *British Journal of Urology*, 75(1), 48-53.
- Clark, J.A., Wray, N., Brody, B., Ashton, C., Giesler, B., & Watkins, H. (1997). Dimensions of quality of life expressed by men treated for metastatic prostate cancer. *Social Science and Medicine*, 45, 1299-1309.
- De Santis, L., & Ugarriza, D. (2000). The concept of theme used in qualitative nursing research. *Western Journal of Nursing Research*, 22, 351-372.
- Ell, K., Nishimoto, R., Mantell, J., & Hamovitch, M. (1988). Longitudinal

- analysis of psychological adaptation among family members of patients with cancer. *Journal of Psychosomatic Research*, 32, 429–438.
- Esper, P., Hampton, J.N., Smith, D.C., & Pienta, K.J. (1999). Quality-of-life evaluation in patients receiving treatment for advanced prostate cancer. *Oncology Nursing Forum*, 26, 107–112.
- Ferrans, C.E. (1994). Quality of life through the eyes of survivors of breast cancer. *Oncology Nursing Forum*, 21, 1645–1651.
- Fitch, M.I., Gray, R., Franssen, E., & Johnson, B. (2000). Men's perspectives on the impact of prostate cancer: Implications for oncology nurses. *Oncology Nursing Forum*, 27, 1255–1263.
- Germino, B.B., Mishel, M.H., Belyea, M., Harris, L., Ware, A., & Mohler, J. (1998). Uncertainty in prostate cancer. Ethnic and family patterns. *Cancer Practice*, 6, 107–113.
- Given, B., & Given, C.W. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Womens Association*, 47, 201–206, 212.
- Gray, R.E., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, 9, 273–282.
- Gray, R.E., Fitch, M.I., Phillips, C., Labrecque, M., & Klotz, L. (1999). Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice*, 7, 130–135.
- Helgason, A.R., Adolfsson, J., Dickman, P., Fredrikson, M., Arver, S., & Steineck, G. (1996). Waning sexual function—The most important disease-specific distress for patients with prostate cancer. *British Journal of Cancer*, 73, 1417–1421.
- Herr, H.W. (1997). Quality of life in prostate cancer patients. *CA: A Cancer Journal for Clinicians*, 47, 207–217.
- Heyman, E.N., & Rosner, T.T. (1996). Prostate cancer: An intimate view from patients and wives. *Urologic Nursing*, 16(2), 37–44.
- Holstein, J.A., & Gubrium, J.F. (1994). Phenomenology, ethnomethodology, and interpretive practice. In L. Denzin (Ed.), *Handbook of qualitative research* (pp. 262–272). Thousand Oaks, CA: Sage.
- Huberman, A.M., & Miles, M. (1994). Data management and analysis methods. In L. Denzin (Ed.), *Handbook of qualitative research* (pp. 428–441). Thousand Oaks, CA: Sage.
- Jakobsson, L., Hallberg, I.R., & Loven, L. (1997). Experiences of daily life and life quality in men with prostate cancer: An explorative study: Part I. *European Journal of Cancer Care (English Language Edition)*, 6, 108–116.
- Jemal, A., Thomas, A., Murray, T., & Thun, M. (2002). Cancer statistics 2002. *CA: A Cancer Journal for Clinicians*, 52, 23–45.
- 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.
- Lewis, F.M., Woods, N.F., Hough, E.E., & Bensley, L.S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. *Social Science and Medicine*, 29, 1261–1269.
- Litwin, M.S., Hays, R.D., Fink, A., Ganz, P.A., Leake, B., Leach, G.E., et al. (1995). Quality-of-life outcomes in men treated for localized prostate cancer. *JAMA*, 273, 129–135.
- McCammon, K.A., Kolm, P., Main, B., & Schellhammer, P.F. (1999). Comparative quality-of-life analysis after radical prostatectomy or external beam radiation for localized prostate cancer. *Urology*, 54, 509–516.
- Moore, K.N., & Estey, A. (1999). The early postoperative concerns of men after radical prostatectomy. *Journal of Advanced Nursing*, 29, 1121–1129.
- Northouse, L.L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41, 69–76.
- Northouse, L.L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science and Medicine*, 50, 271–284.
- Northouse, L.L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine*, 24, 115–136.
- Oberst, M.T., & James, R.H. (1985). Going home: Patient and spouse adjustment following cancer surgery. *Topics in Clinical Nursing*, 7, 46–57.
- O'Rourke, M.E., & Germino, B.B. (1998). Prostate cancer treatment decisions: A focus group exploration. *Oncology Nursing Forum*, 25, 97–104.
- Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum*, 24, 1343–1353.
- Robinson, L., Hughes, L.C., Adler, D.C., Strumpf, N., Grobe, S.J., & McCorkle, R. (1999). Describing the work of nursing: The case of post-surgical nursing interventions for men with prostate cancer. *Research in Nursing and Health*, 22, 321–328.
- Stanford, J.L., Feng, Z., Hamilton, A.S., Gilliland, F.D., Stephenson, R.A., Eley, J.W., et al. (2000). Urinary and sexual function after radical prostatectomy for clinically localized prostate cancer: The Prostate Cancer Outcomes Study. *JAMA*, 283, 354–360.
- Stetz, K.M. (1987). Caregiving demands during advanced cancer. The spouse's needs. *Cancer Nursing*, 10, 260–268.
- Trachtenberg, J. (1997). Innovative approaches to the hormonal treatment of advanced prostate cancer. *European Urology*, 32(Suppl. 3), 78–80.
- Volk, R.J., Cantor, S.B., Spann, S.J., Cass, A.R., Cardenas, M.P., & Warren, M.M. (1997). Preferences of husbands and wives for prostate cancer screening. *Archives of Family Medicine*, 6(1), 72–76. —

For more information . . .

- Prostate Cancer InfoLink
www.comed.com/Prostate
- Prostate Cancer Research Institute
www.prostate-cancer.org
- US TOO! International, Inc., Prostate Cancer Support Groups
www.ustoo.com

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.