

Original article

Treatment decision-making by men with localized prostate cancer: the influence of personal factors

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Abstract

Objectives: For many men with localized prostate cancer, there is no definite answer or unequivocal choice regarding treatment modality. This high-stakes treatment decision is made in the context of great uncertainty. The purpose of this study is to systematically document meaningful and relevant aspects of treatment decision-making reported by men with localized prostate cancer. **Methods:** Focus groups and individual interviews were conducted with 44 men who were within 6 months of a diagnosis of localized prostate cancer. Using content analysis and grounded theory analytic techniques, major aspects and processes of men's treatment decision making are identified and described. **Results:** The participants reported their experiences beginning with influential personal history factors, followed by detailed descriptions of information gathering and the important influence of expected treatment outcomes and other individuals' cancer histories and/or shared opinions. Twenty of the 44 (45%) participants relied heavily on the influence of another's opinion or history to finalize a decision, yet only 10 of the 44 (22.7%) reported this individual to be their physician. A common process, "making the best choice for me" was explicated. **Conclusion:** Clinicians assume that men are making rational treatment decisions based on reliable information, yet this study documents a different reality. Patient education about medical therapies and the patients' own medical factors is not enough. A clinic visit dialogue that brings personal factors to the conversation along with medical factors can guide a man to making his "best choice" for localized prostate cancer. © 2003 Elsevier Science Inc. All rights reserved.

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Introduction

¹No other disease condition with the incidence of prostate cancer has so many treatment alternatives with so few certainties in outcome. Controversy dominates the health care discourse regarding which treatment delivers the best outcomes [1]. Localized prostate cancer (LPC) can be treated with one or more of several modalities including observation alone, surgery, cryosurgery, hormonal therapy, brachytherapy, or external beam radiation therapy. Efficacy

and complication rates vary widely even within treatment modalities [2]. Randomized trials comparing treatments are at least a decade away from meaningful results and even then may not demonstrate significant differences in survival [3]. Compounding the problem is the fact that prostate cancer has been a disease of elderly men, and many men with this malignancy will die of other diseases. However, today men are being diagnosed with prostate cancer at younger ages, thereby increasing the number of years of living with treatment outcomes and complications [4].

This high-stakes treatment decision is made in the context of great uncertainty. Men and their family members worry and anguish over the "right thing to do" both before the decision, after it has been made, and even when therapy has been implemented [5,6]. For many men, there is not a

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definitive answer or unequivocal choice regarding treatment modality. The notorious complications of prostate cancer treatment: bladder, bowel, and sexual dysfunction cannot easily be compared between treatment modalities.

Individual and shared decision-making are active fields of study promoted by patient consumerism, ethical practice and research issues, development of clinical practice guidelines, and health-care resource issues [7–9]. Understanding the patient's perspective is a necessary endeavor in order to proceed with testing of patient-centered clinical interventions [7]. When the dimensions of men's perspectives and decision-making processes are identified and described, then the fit and relationships with other medical factors and demographic characteristics can be examined relevant to treatment decisions for LPC. Previous research addressing the decision making process of men with LPC has not occurred in a setting that provided a variety of treatment modalities [10]. The purpose of this study is to systematically document meaningful and relevant aspects of treatment decision-making in men with LPC.

2. Methods

2.1. Design

Within a descriptive, cross-section design, an inductive study was implemented as the method of data generation. Content analysis [11,12] and Grounded Theory [13] methods of data production and analysis informed the approach.

2.2. Sample

The study was reviewed and approved by the institutional Human Subjects Division, current from October 1997 to present. Men who received a diagnosis of LPC (Stage I or II) and had or had not yet made treatment decisions within the last 6 months were invited by both clinician invitation at three urology clinics and by community media (flyer and newspaper) announcements. All participants were able to read, speak, and write English. Of the 68 eligible study candidates, contact was actually established with 50 referred men. Four men declined participation in the study and 2 men were later found ineligible, resulting in a total enrollment of 44. All participants provided written informed consent. The investigator suspended interviews in December 1999 when theoretical saturation of coded categories was established. No enrolled participants withdrew from the study. The sample had a mean age of 64.8 (SD=9.3) and included 7 (16%) men of color. Table 1 lists all demographic information collected.

2.3. Procedures

2.3.1. Focus Groups

Fifteen men in total participation in 5 focus groups held in the Western Washington area. Two participants were

Table 1
Demographic information for all 44 participants

Characteristic	n (%)
Age Mean 64.8 (SD = 9.3)	
Employment	
Retired	22 (50)
Full-time	14 (31.8)
Part-time	7 (15.9)
Missing	1 (2.3)
Partner Status	
Single	3 (6.8)
Partner/Married	31 (70.5)
Divorced	8 (18.2)
Widowed	2 (4.5)
Education	
Through grade 12	5 (11.4)
2 year college	9 (20.5)
4 year college	11 (25.0)
Graduate degree	19 (43.2)
Income	
Under \$10,000	5 (11.5)
\$11,000–\$20,000	3 (6.8)
\$21,000–\$30,000	1 (2.3)
\$31,000–\$40,000	7 (15.9)
\$41,000–\$50,000	3 (6.8)
Over \$50,000	22 (50)
Missing	3 (6.8)
Ethnicity	
White/Hispanic/non-Hispanic	37 (84.1)
African American	6 (13.6)
Asian American/Pacific Islander	1 (2.3)
Religion	
Catholic	6 (13.6)
Protestant	20 (45.5)
Jewish	1 (2.3)
Other	16 (36.4)
Missing	1 (2.3)

later determined ineligible due to progressive disease. The principle investigator (DB) led the first 4 groups and began with an opening statement, "Please discuss your treatment decision, including all important aspects and concerns and how you made your decision." All groups were audio-taped. The fifth focus group consisted of previous interviewed participants who had not reached a treatment decision at the time of their initial interview. These men were asked by a research nurse to discuss their decision since the last interview or group.

2.3.2. Individual Interviews

Thirty-one individual unstructured interviews were conducted in the Seattle area. Interviews were audiotape recorded. Five of the six African-American participants were contacted and interviewed by a male, African American research assistant. All other interviews were conducted by either the principal investigator or research nurse, both middle-aged, white women. Each interview began with a statement, "Tell me about your decision for treatment of the prostate cancer, including all aspects and concerns you are

considering or have considered.” During the interviews that were held in the latter half of data collection, if the participant did not spontaneously address previous identified recurrent topics, the interviewer prompted the participant regarding these topics.

2.4. Analysis

Content analysis [11–14] was the method of data analysis for the focus groups. The anonymous raw data were entered into the code-based data analysis software package, NUD*IST® (Non-numerical Unstructured Data Indexing Searching and Theorizing). Common components of the participants’ experiences discovered in the data were identified and coded for the first 4 groups.

The constant comparative method of Grounded Theory data analysis described by Glaser and Strauss [15] and Strauss and Corbin [13] was applied to the individual interview data. Each incident or concept was compared to previous coded incidents for similarity and differences. The components and categories of codes discovered in the focus groups were addressed in each individual interview, either spontaneously by the participant or by interviewer query. Codes were grouped together to fit the previous categories or to build new ones. Relationships between codes and categories were explored through the many cross-referencing analytic techniques available in NUD*IST4®. Finally, the explication of the core set of categories that composed the “basic social process,” [15] the major theme of the data, was accomplished.

The following dependability and confirmability strategies were implemented in the analysis of the focus group and interview data: (a) an audit trail of data and analysis utilizing on-screen coding and memo writing in the software; (b) interrater reliability of coding thematic measures on 10% of the transcripts conducted by co-investigators; and (c) participant evaluation of results through member checks [16].

The co-investigators’ inter-rate work resulted in an initial 80% agreement for coding of one core variable (the *influential other*). Differences in coding were discussed until full consensus was achieved between investigators. Out of 13 randomly selected participants, 10 evaluated a mailed description of the findings (including a graphic [Fig. 1] of the decision activities). The responses received confirmed the analysis with written statements indicating the findings were consistent with the participants’ experiences.

3. Results

Although the initial interviewer statement was generic to include any aspect of decision making for prostate cancer, the participants consistently told their story through the following components: personal history including the detection and diagnosis experience, the information they had

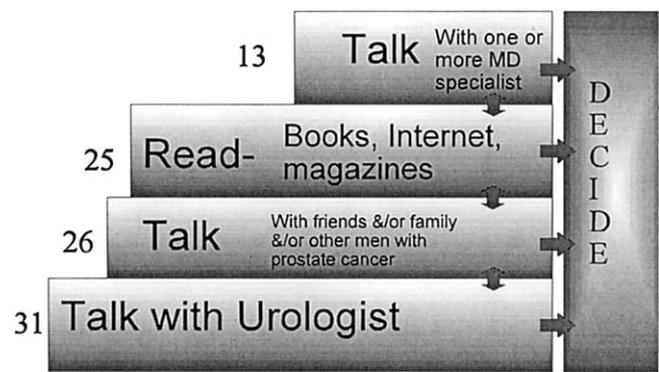


Fig. 1. The process of information gathering and numbers of 31 individual interview participants who reported each activity.

come into contact with, influential factors and issues of importance to their decisions and conversations with a variety of people. A core process of “Making the best choice for me” was developed through the analysis of the components of the participants’ experiences.

3.1. Personal history, detection, and diagnosis experiences

The participants typically began with a story about their detection and diagnosis, including the details of learning about an elevated PSA and the shock and surprise of hearing the diagnosis. Embedded in this initial story, the majority of men told us about who they are and what they do (or did) for a living (Table 2).

3.2. Gathering information

All participants recounted something about their visit to the urologist for the “options talk.” An analysis of the 31 individually interviewed participant transcripts indicated that the men also described various combinations of reading books, magazines, and Internet web-sites with talking to friends and family members. A smaller number (13) sample visited additional physicians for second opinions. The order in which these information gathering activities occurred varied widely with many men re-visiting each source several times during the decision making process. Fig. 1 illustrates the relative numbers of participants describing various information activities.

Only 6 participants stated that they did not read any written material. Notable, all 6 were men of color, one first generation Asian-American and 5 African American men. They all stated they were able to read and write English during eligibility screening and there was no indication that they had difficulty reading the consent information for the study. Six different urologists had advised these participants. An individual interview was conducted with each participant and the query was made about reading information with each to confirm the absence of that component in

Table 2

Personal factors with which participants (N = 44) described themselves plus definitions, exemplar quotes, and the percent of the participants describing themselves with each category

	Definition	Exemplar quotes	%
Age	Men who described themselves as being a particular age and this age having influenced their treatment decision.	“But knowing that you can live a more normal life and enjoy what you have left, theoretically. Because at age 66, you don’t know anyway how much you got left.”	52%
What I do	This includes men who identified themselves by their occupation and/or other things that they do.	“I was told by Dr. [] that I could lift anything for 6 weeks . . . that would interfere with my job. . . . I don’t have 6 weeks of vacation. It’s a very physical job, I lift buckets of dirty mop water. . . . I vacuum a huge library.”	52%
Priorities	Men described the issues that were most important to them when they contemplated the treatment options. Quality of life and family burden were frequent issues.	“. . . with the thought that maybe I can cure it with surgery, then that took precedence. So, getting all the cancer cells is important—more important to me know than getting. . . . preserving sex life.”	50%
Health Status	The impact that current health status or previous health care experiences has on a man’s perception of what treatment is best for him.	“Well, I’ve had a number of surgeries. I’ve had seven hip surgeries and a heart surgery in the past 10 years. I’m saying . . . let’s go ahead and get this done.”	43%
Personality	The impact that a man’s personality has on his view of why a particular treatment does or does not suit him.	“Some guys are procrastinators. I’m a direct action dude. I’m a guy who wants—I’m very impatient. I’m a Type A personality. I want stuff resolved. For good or for bad I want it taken care of.”	36%
Lifestyle	Men related their treatment decisions to the way in which they live their lives.	“But my lifestyle, you know hiking, and spending all weekends outdoors and . . . I walk to work and back, and all these things, and constantly walking and peeing, and it [surgery] seems terribly incompatible for me . . .”	27%
Experiences	Influence life experiences that men spoke of when they related their decision making process.	“Well I just lost a friend to prostate cancer, he had the aggressive type, he was gone in 18 months. He’d just had a physical. So I thought I think I’ll go . . .”	25%
Philosophy	Views on life and death as well as spiritual beliefs are factors that men speak of in relation to their decision making process.	“I mean, some people are scared, and my philosophy is that I’ve had sixty six, almost sixty seven good years, and, uh you’re born, you’re going to die sooner or later.”	23%
Ethnicity	Some men described themselves as belonging to a particular ethnic group and the impact that their ethnicity plays on their approach to health care or their risk of developing cancer.	“I guess the percentage of African American males that have it is just so astronomical compared to the rest of the population.” “Some of the factors they didn’t know about me is that I heal very fast. In fact I hardly bleed at all . . . You know this is kind of genetic-Scandinavians.”	11%

his story about the decision. The text box provides exemplar quotes from African American participants.

3.2.1. Exemplar quotes from African American men

62 yo: “I felt like I was rushed . . . into an operation. I don’t blame the doctors, I blame myself. Because, instead of me saying, well I would look into this I just accepted the doctor’s word.”

75 yo: “I felt that I had enough information from the doctor that I didn’t need to do a lot of additional research of my own to, you know, make a decision.”

64 yo: (Responding to query about reading or gathering other information) “No I haven’t . . . I was going to tell that doctor I want to go with the best that they had. . . . [which] would be the best for me.”

These men provided some insight into why they did not receive any informational material. Several African American men described the sense of urgency in receiving the treatment, for fear of tumor spread. To these men, accepting what they understood to be the first treatment recommen-

dation meant greater likelihood of stopping the disease (see Outcomes section below).

3.3. Influential factors

Men spontaneously talked about the factors that influenced their treatment decision. A set of related, meaningful factors was spoken about including a self-description of themselves, a variety of potential treatment outcomes, past experience with cancer, and influential individuals.

3.4. Outcomes

The importance of survival and/or its relationship to quality of life was addressed by all focus group participants and by 26 of the 31 individually interviewed men. Interestingly, of the 26 individually interviewed men who addressed survival as an issue, 14 made a point to talk about another individual with cancer and their circumstances of the others’ survival. Not surprisingly, the participants ad-

Table 3
The effect of the influential other reported by 20 participants and the decisions each at the time of their interview or focus group.

Treatment Decision	Effect of the Influential Other			
	Widened horizons	Moved toward a certain decision	Moved away from a certain decision	
Prostatectomy	0	4	6	
Brachytherapy	1	5	6	
Watchful waiting	1	0	1	
Complementary/ alternative therapy	1	1	1	
Hormonal	0	0	0	
Undecided	1	3	2	
Totals	4	13	16	33*

* Some participants reported more than one effect.

dressed both incontinence and sexual dysfunction more often than any other treatment complication. The next most commonly addressed outcome was spread of the disease, with 6 of 7 men of color expressing this concern and 5 of 24 white men speaking specifically about spread of disease. Of interest is that the 6 men of color are the same participants who did not read any written or electronic material as part of information gathering. One African-American participant stated, “I felt that I had enough information from the doctor that I didn’t need to do a lot of additional research of my own to, you know, to make a decision. I’ve had a couple of friends that have died of prostate cancer, and I didn’t know a lot about it. What I did not know is that if you neglect it and let it go you’re pretty much signing your own death warrant because once it starts to spread it’s like any other cancer, once it starts spreading you have a more difficult time trying to get rid of it.”

3.5. The influential other

The majority of participants (43 of 44) described hearing about or speaking with other men who had a diagnosis of prostate cancer ($n = 41$) and/or told a story about someone else with another type of cancer ($n = 22$). Interpretations of the others’ experiences varied, however 20 of the participants relied on the stories or experiences from *influential others* to widen their horizons, or move toward or away from a specific treatment modality. For the purposes of this study, the influential other is defined as an individual whose illness experience and/or story had explicit influence on the participant’s treatment decision. Table 3 lists the ways that these experiences or stories influenced the participants.

3.5.1. The doctor as the influential other

Ten of the 44 men talked about the specific influence of a doctor with whom they visited. Five of these men described receiving a recommendation from the doctor that was not directly solicited. For example, “But I felt more comfortable with him, he made his case a little better, let’s

say, he seemed to be a little more persuasive, a little more understanding to me.” In contrast, 5 other men recounted that they requested a specific recommendation from one or more doctors. All 5 used similar language to make the request, involving some version of “if you were men, what would you do?”

3.5.2. The lay influential other

Friends, business associates, family members and celebrities were described by participants as influential others. Intimate partners and wives were not typically identified as influential others, but were most often discussed as having minimal input into the actual decision ($n = 9$). Only 2 participants specified their wives as having significant input into the decision. The typical role for wives was addressed as information gatherers and processors and supporters.

As early in data collection as the first focus group, participants talked about the influential other as someone who was “a lot like me,” or “was my age,” or even “had a Gleason score like mine.” A total of 9 men described influential other as someone with whom they shared a belief, perspective or characteristic. This was completely unsolicited during the interviews. One participant spoke of his genetic similarity with his mother whose experience with radiation therapy and breast cancer led him to eliminate radiation as an option. “Yeah, my mom came down with breast cancer at 55, ultimately it was not what killed her, but that’s another story. The treatment killed her, radiation, a bad machine at the hospital. . . . so, gee, here I am and I’m genetically very much like my mom.” Another man spoke about his colleague and his same age (46 years). “Yeah, I think the seed implant is good—would be, in my mind, the number one option at my age.” And that was the first thing my business associate said. He said, “at our age, seed implants is what you do.”

3.6. The actual decision

Thirty-two participants chose and/or received one of the common treatments available in the Pacific Northwest: radical prostatectomy ($n = 15$), brachytherapy ($n = 15$), or watch and wait ($n = 2$). One man received androgen suppression alone and two were engaged in alternative medicine therapy. Nine men were undecided at the time of the initial 4 focus groups and individual interviews.

3.7. The core process—making the best choice for me

Through inductive analysis of the data described above, a core process of patient treatment decision making for LPC is suggested: “making the best choice for me”. Men began this process either when the prostate cancer diagnosis was expected (an elevated PSA) or the moment the biopsy results were received, even before the visit with the urologist for a discussion of the treatment options. In describing his deliberations between brachytherapy and surgery, one par-

participant stated after deciding on surgery, “I have to say that after talking to doctors, surgery usually would come to the top, not in my mind necessarily, but . . . I’m surprised with my reading that I have made the best choice for me that I could.”

The process through which participants made their own best choice began with an initial report of who I am in various aspects, placing the rest of their story in the context of their personal experience, as if this was the most fundamental part of the experience through which everything else was interpreted. They told us the detection and diagnosis experience and how they reacted. Gathering information about prostate cancer was a complex part of the process and often specific to individual men’s demographic characteristics and personal factors, again founded on “who I am.” When men discussed how they made (or were making) their treatment decision, they spontaneously considered several categories of factors. Men reported potential outcomes of various treatments and cancer itself to inform the treatment decision. Men’s interpretations of these outcomes again were based on the personal context of a particular outcome.

3.8. *Comment*

Making “the best choice for me” takes into account the medical information gained from all sources plus the personal factors that men bring to the decision process, framing the meaning of the diagnosis and treatments and guiding the treatment decision. Not only does the sequence of events in the process inform this exploration of treatment decision making, the foundation and framing of the participants’ personal experiences are the only perspectives through which we can understand this complex process if we want to understand the meaning of the diagnosis and the decision for our patients. The participants were compelled, both consciously and unconsciously to place this LPC diagnosis in the context of their own lives. The phrase used by participants, “what would you do, if you were me?” may have been yet another way the patients requested a customized and personalized recommendation. Given the uncertainty in outcome from the medical perspective, these men found their own path and decision, even when the decision was to concur with what the first doctor seen described as the first option.

Generalizing these findings is limited by the exploratory nature of this study and the sample characteristics. Drawn from another population (e.g., older men), the participants may have reported a different experience.

While few, research reports of treatment decision making for LPC contain findings consistent with the results discussed above. Holmboe and Concato [17], have used semi-structured interview methods, reported evidence of the influence of age and fear of spread on prostate cancer treatment decisions. But the findings described above are the first to include a systemic description of “who I am and what I do” as influential aspects of decision making.

The critical patient-physician dialogue during the “options talk” has not been evaluated first hand in the setting of LPC. Clearly this was the first pivotal event for most all of these study participants, even when it was during a second or third opinion visit. In a review of information needs and learning preferences of patients with cancer, Chelf and colleagues [18] concluded patients prefer obtaining information through discussion with physicians.

All participants in this study continued to gather information after the “options talk” visit, the majority relying heavily on the information for the final treatment decision. The sources of information ranged from institutional pamphlets to friends and coworkers to the electronic media on the Internet. Seventy-seven percent of the 102 participants in Holmboe and Concato’s study [17] described relying most on additional information to make their LPC treatment decision, while only 30% relied on physician recommendation. There is evidence that some cancer patients desire and require information as a prerequisite to psychological autonomy and feeling positive about proceeding with the physicians’ recommendation [19]. The use of additional information sources after the physician visit has been reported by Davison [20] to significantly reduce anxiety and enhance the level of participation in treatment decision making in 74 men with LPC.

The omission of reading about prostate during the treatment decision process by 6 of 7 men of color in this study warrants attention and further research. These same men were each concerned about the spread of the tumor. Powe [21] has reported significantly higher levels of cancer fatalism among African Americans with cancer than those of white Americans. She speculated that actual experiences with the cancers of other individuals in the community, notably friends and family members, have influence over the belief that death is inevitable when cancer is present. The sense of urgency to do something reported by men of color in this study may have precluded a thoughtful decision process in which other personal factors could be considered. This finding cannot be generalized but does encourage further study of treatment decision making in African American men.

The participants in this study were often influenced not only by the clinician’s recommendation, but by the experiences of acquaintances, relatives, and celebrities treated by one of the modalities under consideration, even though that person may have been in an entirely dissimilar clinical situation, perhaps even with a different disease. Exploratory and inductive work by O’Rourke [22,10], with 5 African American and 13 white American married couples has established a preliminary description of the process of LPC treatment decision making. The author reported that couples narrowed the options for treatment by following physician recommendation and then comparing themselves to others with similar cancer experiences, and finding personal meaning or context for the treatment options. The participants in O’Rourke’s study also told of friends and family members

treated for various cancers and how this shaped their own positive preferences for surgery and negative impressions for non-surgical intervention such as chemotherapy and radiation. However, the men in this sample may not have actually been invited to make a treatment choice, rather their choice was to accept or reject the recommendation of the urologist. The men who ultimately received external beam radiation were those whose medical factors necessitated a non-surgical approach. O'Rourke [10] stated that the biases of the region toward surgery were quite influential, along with the factor that brachytherapy was not locally available at the time of data collection. O'Rourke's [22] research also confirms our finding that men's wives primarily played a role of supporter rather than that of decision maker.

The influence of survival expectations [23] and potential treatment complications on a treatment preference [17,24] has been documented in survey type research with persons with various types of cancer and in men with prostate cancer. It is a widely held belief that treatment side effects and complications are priority considerations for both clinician recommendations and patient preferences [25], yet there are no previous reports of the framing of this influence within a context of personal experiences, particularly the stories from influential others.

Ongoing investigation of the relationship between personal and medical factors is required to then create an intervention that can customize prostate cancer patient education and decision support. The existing decision support aids for use with prostate cancer [26,27] address the medical factors such as stage, Gleason score and co-morbid conditions but does not assess or discuss personal factors that may be crucial to the patient's decision. Available electronic technology may be able to provide an interface that is user-acceptable by even low literacy patients, yet sophisticated enough (behind the scenes) to coach a patient through a personal appraisal in preparation for the clinical visit. Further investigation into the experiences of men of color with LPC and utilization of various information sources is a priority in order to enhance the understanding of all options by men who may be particularly vulnerable to misconceptions and/or disparities in health care delivery.

4. Conclusion

The growing number of treatments for LPC, the lack of randomized efficacy trials, and the large number of men being diagnosed with prostate cancer at younger ages have thrown treatment decision making for this condition into the forefront of research priorities. For many years to come, men will hear clinician recommendations but also will be given major choices about LPC treatments and asked to make critical decisions that can change their lives dramatically. Providers assume that men are making rational decisions based on reliable information, yet this study documents a different reality. Patient education about medical

therapies and the patients' own medical factors is not enough. A clinic visit dialogue that brings personal factors to the table along with medical factors can lead a man to making his "best choice." Making that choice necessitates articulating "who I am" and how those perceptions frame perceptions of all outcomes. Clinicians are in a position to help men understand, not discount, personal appraisal of information about treatment choices by communicating with them about both medical and personal factors.

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References

- [1] Montie JE. Counseling the patient with localized prostate cancer. *Urology* 1994;43:36–40.
- [2] Wasson JH, Cushman CC, Bruskevitz RC, et al. A structured literature review of treatment for localized prostate cancer. Prostate Disease Patient Outcome Research Team. *Arch Fam Med* 1993;2:487–93.
- [3] American Urological Association. Report on the management of clinically localized prostate cancer: clinical practice guidelines. Baltimore, Maryland: American Urological Association; Monograph, 1995.
- [4] Mettlin C. Impact of screening on prostate cancer rates and trends. *Micro Res Tech* 2000;51:415–8.
- [5] Berry DL. Return-to-work experiences of people with cancer. *Oncol Nurs Forum* 1993;20:905–11.
- [6] Berry DL. Detection and diagnosis experiences of employed persons with urologic cancer. *Urol Nurs* 1994;14:52–6.
- [7] Llewellyn-Thomas HA. Patients' health-care decision making: a framework for descriptive and experimental investigations. *Med Decis making* 1995;15:101–6.
- [8] Deber RB. Shared decision making in the real world. *J Gen Intern Med* 1996;11:377–8.
- [9] Brock DW, Wartman SA. When competent patients make irrational choices. *N Engl J Med* 1990;322:1595–9.
- [10] O'Rourke ME. Narrowing the options: the process of deciding on prostate cancer treatment. *Cancer Invest* 1999;17:349–59.
- [11] Catanzaro M. Nursing research: theory and practice. St. Louis: CV Mosby, 1998.
- [12] Krueger RA. Analyzing & reporting focus group results. Thousand Oaks: SAGE Publications, Inc., 1998.
- [13] Strauss A, Corbin J. Basics of qualitative research: grounded theory procedures and techniques. Newbury Park, California: Sage Publications, Inc., 1990.
- [14] Polit D, Hungler B. Nursing research: principles and methods. Philadelphia: Lippincott, 1995.
- [15] Glaser B, Strauss A. The discovery of grounded theory. New York: Aldine Publishing, 1967.
- [16] Lincoln Y, Guba E. Naturalistic inquiry. Beverly Hills: Sage Publications Inc., 1985.
- [17] Holmboe E, Concato J. Treatment decisions for localized prostate cancer. *J Gen Intern Med* 2000;15:694–701.

- [18] Chelf JH, Agre P, Axelrod A., et al. Cancer-related patient education: an overview of the last decade of evaluation and research. *Oncol Nurs Forum*. 2001;28:1139–47.
- [19] Sutherland HJ, Llewellyn-Thomas MA, Lockwood GA. Cancer patients: their desire for information and participation in treatment decisions. *J R Soc Med* 1989;82:260–3.
- [20] Davison J, Gleave M, Goldenberg S, et al. Provision of individualized information to men with prostate cancer and their partners. (in preparation).
- [21] Powe BD. Cancer fatalism among elderly Caucasians and African American. *Oncol Nurs Forum* 1995;22:1355–9.
- [22] O'Rourke ME, Germino BB. Prostate cancer treatment decisions: a focus group exploration. *Oncol Nurs Forum* 1998;25:97–104.
- [23] Kiebert GM, Stiggelbout AM, Kievit J, et al. Choices in oncology factors that influence patients' treatment preference. *Qual Life Res* 1994;3:175–82.
- [24] Feldman-Stewart D, Brundage MD, Nickel JC, et al. The information required by patients with early-stage prostate cancer in choosing their treatment. *BJU Int* 2001;87:218–32.
- [25] Kunkel EJ, Myers RE, Lartey PL, et al. Communicating effectively with the patient and family about treatment options for prostate cancer. *Semin Urol Oncol* 2000;18:233–40.
- [26] Nexcura (2002). Prostate cancer profiler. Retrieved from <http://cancerfacts.com>.
- [27] Moul JW, Esther TA, Bauer JJ. Implementation of a web-based prostate cancer decision site. *Semin Urol Oncol* 2000;18:241–4.