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13. ABSTRACT (Maximum 200 Words) To examine men's perceptions of life transitions associated with prostate cancer through an analysis of their narratives, obtained in in-depth, qualitative interviews; compare men's narratives of perceived transitions with respect to quality of life outcome states, i.e., good vs. poor prostate cancer-related quality of life. Phase 1: interview participants in our quality of life survey of previously treated patients, stratified by quality of life. Phase 2: interview members of our prospective cohort who have completed 36-month follow-up, stratified by quality of life states and observed changes in urinary, bowel, and sexual function. Phase 3: prospectively interview patients with new diagnoses of early prostate cancer prior to treatment and 12 months later. Comparative analyses, with comparisons between strata and the three cohorts, will characterize the structure and content of patients' narratives of prostate cancer, including specific changes in identity and interpersonal relationships, that are linked to quality of life outcomes. Interviews conducted so far include: Phase 1, 24; Phase 2, 25; Phase 3, 38. Survey instrument to identify quality of life strata in prospective cohort was completed by 235 of 269 eligible patients (87%). Analysis of completed interviews is in progress; no reportable findings as yet.				
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INTRODUCTION

An estimated 190,000 American men, mostly aged 50 and older, will be told by their doctors that they have early prostate cancer this year. For many, if not all, this news will precipitate a crisis. They will be confronted with an ominous diagnosis and asked to make choices between a growing number of therapeutic alternatives (radical prostatectomy, external beam radiotherapy, brachytherapy, cryosurgery, observation/expectant management) in a context of uncertainty. While none of the active treatment alternatives has been shown to offer an efficacy advantage over observation, each is associated with long-term urinary, bowel, and sexual complications, which may have substantial effects on quality of life. Most of these men will survive for many years, some living with problematic treatment-related physical changes, psychosocial changes, and the possibility that treatment did not eliminate prostate cancer as a serious threat. The growing appreciation of the salience and magnitude of these effects, for both individual patients and an aging population, has resulted in advances in our knowledge of quality of life outcomes, informed by improved methods for measuring prostate cancer-related quality of life. Yet, our understanding of how men respond cognitively and emotionally to the diagnosis of prostate cancer and its treatment remains limited. In particular, we lack information about how men perceive the changes they go through, from their pre-treatment state to their health and quality of life state after treatment.

However, advances in social and behavioral science methods for studying how people perceive and make sense of their own lives through personal narratives offer a productive approach for research on the changes in quality of life that may be occasioned by the diagnosis and treatment for early prostate cancer. Narratives have clearly identifiable grammatical structures. They can be rigorously analyzed as meaningful social objects. Moreover, there is growing interest in patients' narratives of their illnesses within the medical community. Clinicians and researchers are regaining an appreciation for patients' stories, an interest as ancient as Hippocrates, since the stories individuals tell about themselves when ill reveal the ways in which they understand their illnesses and the impacts of illness on their lives.

Our study will extend a productive line of research on men's perceptions of the physical and psychosocial impacts of prostate cancer. We have developed questionnaires, research designs, and substantial databases for studying men's perceptions of the physical complications of treatment for early prostate cancer and the psychosocial impacts of these complications, as well as the emotional, symbolic effect of a cancer diagnosis. Much of this work has been strongly informed by what men say in open-ended discussions of their experiences, such as focus groups. Often, when asked to describe in their own words the impact of prostate cancer, men will begin by saying something like, "Well, it's a long story."

In this study, we will build on our previous research, particularly our well developed quantitative databases, to collect and analyze systematically men's narratives of prostate cancer, and examine their relationship with physical and psychosocial outcomes of care. We will proceed in three phases. First, we will identify men who have completed psychosocial questionnaires in our current survey of quality of life outcomes, and who fall into one of several contrasting outcome groups, that is, good or poor quality of life. We will interview these men, all of whom were diagnosed 12 to 48 months previously, elicit their narratives, and compare the stories associated with either good or poor quality of life. Second, we will verify the findings of

the first phase by replicating the analysis among men who have participated in a long-term follow-up study of physical complications of treatment. Thus, we will also examine the association between men's stories and carefully observed physical changes in urinary, bowel, and sexual function. Third, we will directly examine developing stories of the impact of prostate cancer by prospectively interviewing a small group of newly diagnosed men at two points in their prostate cancer "careers," shortly after diagnosis and 12 months later.

BODY

Task 1: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a sample of previously treated patients, Months 1-12.

- a. Identify subsample of 40 respondents to prostate cancer quality of life survey, defined by quality of life outcome status
- b. Conduct in-depth interviews with subsample of respondents.
- c. Analyze men's narratives of their lives with early prostate cancer.

A total of 24 patients who participated in the previous (1999) quality of life survey were successfully interviewed in accomplishing Task 1. Others who we attempted to contact and interview were either lost to follow-up (no longer at last known address; unable to locate) or declined our invitation to participate in an interview. Combined with 35 subjects interviewed from that survey panel prior to the initiation of this project, we have produced a very large database of 59 in-depth, qualitative interviews with patients previously treated for early prostate cancer.

All completed interviews have been transcribed and entered into the qualitative database. Analyses are underway. We are constructing a data dictionary that represents the major topics pertaining to the experiences of diagnosis, treatment decision making, and quality of life outcomes of treatment for early prostate cancer.

Task 2: Characterize men's retrospective perceptions of life transitions associated with early prostate cancer in a cohort of patients in which urinary, bowel, and sexual function have been monitored from pre-treatment baseline to 36 months post-treatment, Months 13-24

- a. Administer survey, using patient-centered quality of life measures, to members of prospective cohort.
- b. Identify subsample of 40 respondents to quality of life survey, defined by changes, from pre-treatment status, in urinary, bowel, and sexual function, and by quality of life status.
- c. Conduct in-depth interviews with subsample of respondents.
- d. Analyze men's narratives of their lives with early prostate cancer.

A survey instrument, based on the instrument developed in our previous survey of prostate cancer patients, was developed and sent to members of the cohort who had completed 36 months of follow-up in the Talcott/Clark prospective survey of urinary, bowel, and sexual function following treatment for early prostate cancer. A copy of this questionnaire is appended. Eligible patients had valid baseline and 36 month data. Interim data, collected at 3, 12, and 24 months after the initiation of treatment or indication of a choice to pursue a "watch and wait"

treatment approach, were also largely complete, but completion of interim data was not required for inclusion in Task 2. Of 338 names received from Talcott, 43 were excluded because of lack of valid baseline data; 19 were excluded because of lack of valid address; and 7 were deceased. The remaining 269 were sent questionnaires: ten actively refused and 24 declined to respond. Responses were obtained from 235 of 269: a response rate of 87.3%.

As planned, the survey data provided an opportunity to verify previous psychometric findings regarding psychosocial dimensions of prostate cancer-related quality of life. Psychometric analyses confirmed 11 previously defined quality of life scales, plus one new scale to assess the behavioral consequences of treatment-related bowel dysfunction.

Two of these scales were used to define four contrasting outcome groups for follow-up interviews: perceived cancer control and perceived quality of decision making. The former assesses confidence in cancer control and related distress about possible progression. The latter assesses perceptions of having made a well informed decision in choosing a course of treatment. Together, they represent perceptions of the overall effectiveness of cancer treatment. These two scales were relatively unrelated ($r=.28$). Groups were defined according to median splits on these two dimensions, allowing classification of 225 of 235 subjects with sufficient data on the two scales.

Quality of life characteristics of the four groups are summarized in Table 1. In order to provide optimum contrast groups for the qualitative analyses of Task 2, we have sampled patients in maximally different Groups 1 (poor (-) control, poor (-) decision) and 4 (good (+) control, good (+) decision). Interviews elicit narrative accounts leading to good and poor quality of life conclusions.

To date, we have interviewed 25 patients in Task 2.

Table 1: Characterization of Four Outcome Groups

	1 - control - decision	2 - control + decision	3 + control - decision	4 + control + decision	p
All values are means, unless noted as %					
Number of Subjects	66	47	48	64	
Age at Diagnosis	66	63	65	63	.035
PCS - 12	46	48	46	50	.044
MCS - 12	49	53	53	54	.005
MHI-5	74	79	81	83	.002
Vitality	56	61	59	68	.006
% Surgery	23	38	43	37	.001
% EBRT	65	36	39	29	
% Brachytherapy	11	22	7	29	
% Observation	2	4	11	5	
Urinary Incontinence	14	14	16	15	.901
Urinary Incontinence worse since pre-treatment	24	32	32	32	.727
Urinary Obstruction/Irritation	23	18	22	19	.190
EPIC Urinary Bother	17	11	15	12	.199
Bowel Dysfunction	11	7	8	5	.024
Bowel Dysfunction worse since pre-treatment	25	22	17	13	.431
EPIC Bowel Bother	14	8	10	5	.012

Table 1: Characterization of Four Outcome Groups

	1	2	3	4	p
	- control	- control	+ control	+ control	
All values are means, unless noted as %	- decision	+ decision	- decision	+ decision	
Number of Subjects	66	47	48	64	
Sexual Dysfunction	82	58	78	63	<.001
Sexual Dysfunction worse since pre-treatment	47	54	60	57	.518
EPIC Sexual Bother	55	43	54	42	.088
Urinary Control	90	95	92	95	.107
Bowel Control	89	91	92	96	.173
Sexual Intimacy	60	68	65	72	.093
Sexual Confidence	27	47	33	45	<.001
Masculine Self Esteem	80	87	86	89	.003
Health Worry	28	20	9	11	<.001
PSA Concern	62	75	68	65	.150
MOS Marital Function	74	86	82	84	.002
Spouse Affection	83	93	92	92	.008
% Regretful	14	4	10	0	.015
Outlook	39	47	46	48	.401
Stigma	6	2	3	2	.058
Somatic Awareness	70	65	73	73	.183
Most Recent PSA (%)					
≤ 0.1	20	38	52	44	.024
> 0.1 but ≤ 1	29	19	31	27	
> 1 but ≤ 4	23	26	8	16	
> 4	15	9	2	5	
don't know	12	9	6	8	
PSA ever rise (%)					
yes	36	34	11	19	<.001
no	48	66	85	78	
don't know	16	0	4	3	
PSA Trend (%)					
falling	19	11	13	25	<.001
staying the same	49	65	81	74	
rising	29	24	6	2	
don't know	3	0	0	0	
PSA Failure (≥ 1.0 or rose or rising) (%)	70	57	27	38	<.001
Social Support	60	84	66	83	<.001
Marital Status (%)					
married	76	89	74	91	.090
widowed	15	6	9	6	
divorced	5	4	13	3	
never married	5	0	4	0	

Task 3: Characterize men's prospective perceptions of life transitions associated with early prostate cancer in a cohort of patients observed prior to treatment and 12 months following the initiation of treatment, Months 10-27.

- a. Identify and recruit cohort of 40 patients with newly diagnosed early prostate cancer at two sites: VAMC's at Buffalo, NY and Washington, DC.
- b. Conduct baseline, in-depth interviews
- c. Conduct 12-month follow-up interviews.
- d. Analyze men's narratives of their lives with early prostate cancer.

We have completed baseline interviews with 33 patients with newly diagnosed early prostate cancer, and 12 month follow up interviews with eight. Completed interviews have been transcribed and entered into the qualitative database. Analysis is in progress as data collection continues.

Task 4: Complete comparative analysis of narratives elicited in three cohorts, Months 28-34

Preliminary analyses of the interviews conducted in accomplishing Tasks 1, 2, and 3 are leading to the development of a generic codebook for analyzing these accounts of living with prostate cancer. The codes are being developed through grounded theory methods, as described in the study protocol. The codes represent and organize the content of the accounts.

At present, six major domains of content have been identified.

1. Disease, including men's depictions of the prostate cancer itself, their discovery of their cancer (including but not limited to the medical diagnostic process), and other health conditions that define a context for the prostate cancer.
2. Management, including treatment decision making, retrospective appraisals of the decisions that were made (e.g., regret), and the activities of undergoing treatment for prostate cancer.
3. Physical (Dys-)Function, including perceptions of and problems with urinary control, sexuality, bowel control, hot flashes, and other physical dysfunction attributed to the prostate cancer or its treatment.
4. Social Relationships/Context, including intimate partners and their roles in dealing with prostate cancer, family members, friends, medical settings and providers (i.e., interactions with doctors), and other social relationships (e.g. support groups, public/media discourse, and spiritual practice settings).
5. Life, including characterizations of life notwithstanding prostate cancer (e.g., accounts of living well in spite of cancer) and, conversely, consciousness of one's mortality.
6. Identity, including representations of oneself and feelings as a man living with prostate cancer, with subdomains focusing on masculinity, personal responsibility, occupational identity.

Task 5: Complete final report, Months 35-36.

Pending completion of analyses.

KEY RESEARCH ACCOMPLISHMENTS

none to date, as data collection is in progress

REPORTABLE OUTCOMES

There are not reportable findings from this study as yet, as data collection is in progress. However, interim findings provide verification of psychosocial dimensions of prostate cancer-related quality of life, as reported in recently published findings from our previous research.¹ Preliminary analyses of interviews suggest that we will be able to explore and explicate life changes, suggested in recent analyses of cross-sectional survey data, through planned analyses of men's narratives.²

The research team has been expanded by the addition of Dr. Lorrie Powel. Her study of quality of life outcomes associated with post-prostatectomy urinary incontinence has been supported by DoD as a post-doctoral training grant, under the supervision of Dr. Jack A. Clark (DAMD17-02-1-0236). Dr. Powel brings extensive clinical experience in nursing to the project. While Dr. Powel's project is a separate undertaking, her training will include participation in the analysis of data collected in the present study. In addition, Dr. Barbara G. Bokhour, co-investigator, has recently completed the first year of a two-year study, funded by the National Cancer Institute (RO3 CA 91737001), to explore the clinical utility of the qualitative findings derived from the present study. As a result, the overall project has been strengthened by clinical expertise and an direct examination of the clinical utility of the findings, as they emerge.

CONCLUSIONS

Subject accrual was accomplished as expected at the Buffalo site in completing Task 3. However, subject accrual was not successfully initiated at the Washington DC site because of substantial delays in the granting of final approval by the local IRB. The IRB was audited by the VA in the Fall and Winter of 2001/2002, resulting in significant delays in the processing of protocols. While we had anticipated that this problem would be resolved, our expectations were not met. We explored and secured the participation of an additional site in order to meet subject accrual goals: the urology clinic at Boston Medical Center. The investigators have a relationship with this clinic, developed in previous studies. The clinic also serves a racially and economically diverse population, thus it would be suitable to the goals of the study, including analyses of quality of life changes associated with treatment for early prostate cancer in a diverse population.

The results of this study will be useful in several ways. They will guide the design of future, large scale studies of the processes and outcomes of care for early prostate cancer. Yet, they will have more immediate utility. They will provide informative materials for health care providers about the significant changes men see themselves as undergoing. They will also provide information to men who face the ominous diagnosis and those who continue to live with the outcomes of their treatment. Moreover, we will provide information about the changes men experience in the understandable form of men's stories.

REFERENCES

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APPENDICES

Survey Questionnaire Used in Accomplishing Task 2

Section One: Treatment for Your Prostate Cancer

The questions in this section ask about the treatment you have received for prostate cancer. First, we ask about treatment during the first 6 months after getting the diagnosis. Since your situation may have changed, we will then ask about your treatment in the years after the first 6 months following your diagnosis.

1. What treatments did you receive during the first 6 months after your prostate cancer was diagnosed?
Please answer every question, 1a through 1h below, since every man's case is unique and sometimes more than one treatment appears necessary.

	Yes	No
a. Did you decide not to do anything for the time being (watch and wait)?	1	2
b. Did you have an operation to remove your prostate (a radical prostatectomy)?	1	2
c. Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)?	1	2
d. Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy).	1	2
e. Did you have a procedure in which your prostate was frozen (cryotherapy)?	1	2
f. Did you receive a <i>brief course</i> (less than 1 year) of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds?	1	2
g. Did you start a long-term course of hormone treatment (injections, pills or both) for more than 12 months or that you continue to receive?	1	2
h. Did you have an operation in which your testicles were removed (an orchiectomy)?	1	2

2. During the first 6 months, how many doctors did you talk to about how your prostate cancer should be treated?

Write in number of doctors

Yes	No
1	2

3. During the first 6 months, did any doctor you talked to offer you a choice between two or more types of treatment for your prostate cancer?

4. During the first 6 months, did you get different recommendations about the best treatment from different doctors you talked to?
Yes, I got different recommendations

No, all doctors recommended the same treatment	I talked to only one doctor
1	2
2	3

5. Each man and his doctor may reach the decision on which treatment a man should get for early prostate cancer in a different way. Which statement best describes how the treatment you received during the first 6 months was chosen?

1 The choice was mostly my doctor's; my doctor made the decision or made a strong recommendation	2 My doctor and I came to the decision together	3 The choice was mostly mine; my doctor left the decision entirely or mostly up to me
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Treatment for your prostate cancer since the first 6 months.

6. After your first treatment for prostate cancer, did your PSA ever start to go up again?

Yes 1	No 2	Don't Know 3
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7. The last time you heard from your doctor, what was your PSA doing?

Falling 1	Staying the same 2	Rising 3	Don't Know 4
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8. What was your most recent PSA result?

	Write in the approximate number
	Don't know; check here

Treatment for your prostate cancer since the first 6 months.

9. In the years following the first 6 months after diagnosis, what treatments have you received?

Since every man's case is unique and more than one treatment may be necessary at different times, be sure to mark an answer for each of these questions, 8a through 8h.

	Yes	No
a. Did you decide not to do anything for the time being (continue to watch and wait)?	1	2
b. Did you have an operation to remove your prostate (a radical prostatectomy)?	1	2
c. Did you have a procedure in which radioactive seeds were implanted in your prostate (brachytherapy)?	1	2
d. Did you receive a course of daily radiation treatment (external beam radiation)? This may be done by itself or added after surgery or radioactive seeds (brachytherapy).	1	2
e. Did you have a procedure in which your prostate was frozen (cryotherapy)?	1	2
f. Did you receive a <i>brief course (less than 1 year)</i> of hormone treatment (injections, pills or both) around the time you were diagnosed, or along with another treatment, such as surgery, radiation or seeds?	1	2
g. Did you start a long-term course of hormone treatment (injections or pills) for more than 12 months or that you continue to receive?	1	2
h. Did you have an operation in which your testicles were removed (an orchiectomy)?	1	2

Section Two: Urinary Problems

1. In the past week, how easy has your urine flow been?

Very easy	Fairly easy	Slow, but I don't have to strain or bear down	Slow, and I do have to strain or bear down	Very slow, and I have to strain or bear down hard
1	2	3	4	5

2. In the past week, how often did you urinate at night?

Seldom or never	Once a night	2 to 3 times a night	More than three times a night
1	2	3	4

3. In the past week, how often did you urinate?

4 or fewer times a day	5 to 8 times a day	9 to 12 times a day	More than 12 times a day
1	2	3	4

4. In the past week, how often have you felt pain or burning during urination?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

5. In the past week, how often have you urinated blood?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

6. In the past week, how often did you have the feeling that it is urgent that you pass your urine?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

7. In the past week, how much control did you have over your urine?

Had complete control (no leaking)	Leaked urine, but only at certain times	Leaked urine most of the time	Little or no control
1	2	3	4

8. In the past week, how often did you leak urine?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

9. IF YOU LEAKED URINE IN THE PAST WEEK, how much usually comes out?

Had complete control (no leaking)	A few drops	Less than a tablespoon	More than a tablespoon	Can't tell how much
1	2	3	4	5

Yes	No
1	2

10. In the past week, did you wear a pad to absorb urine in your underwear?

10a. In the past week, if you wore a pad in your underwear, how often during the day did you change it?

Not at all	Once or twice a day	Three or more times a day	Did not wear a pad
1	2	3	4

11. How big a problem, if any, has each of the following been for you during the past 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
a. Dripping or leaking urine	1	2	3	4	5
b. Pain or burning on urination	1	2	3	4	5
c. Bleeding with urination	1	2	3	4	5
d. Weak urine stream or incomplete emptying	1	2	3	4	5
e. Waking up to urinate	1	2	3	4	5
f. Need to urinate frequently during the day	1	2	3	4	5

12. Overall, how big a problem has your urinary function been for you during the past 4 weeks?

	No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5	

Questions 13a – 13q ask about how you may feel about urinary problems and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I worry about wetting myself.	1	2	3	4	5
b. I worry about coughing or sneezing making me lose control.	1	2	3	4	5
c. I worry about others smelling urine on me.	1	2	3	4	5
d. I am careful to watch for any signal that I need to urinate.	1	2	3	4	5
e. I am careful not to laugh, for fear of losing control.	1	2	3	4	5
f. Leaking urine makes me feel dirty.	1	2	3	4	5
g. I am sometimes embarrassed or humiliated because of my urinary problems.	1	2	3	4	5
h. I'm often afraid of having an accident and making a mess.	1	2	3	4	5
i. My urinary problems make me feel helpless.	1	2	3	4	5
j. I feel nervous when I don't know where the bathrooms are.	1	2	3	4	5
k. The need to urinate is never far from my mind.	1	2	3	4	5
l. I can rely on my body to warn me that I need to urinate soon enough.	1	2	3	4	5
m. My urinary problems complicate everything I do.	1	2	3	4	5
n. The things I have to do to just to urinate are embarrassing.	1	2	3	4	5
o. I avoid situations in which I might not be able to get to a bathroom in time.	1	2	3	4	5
p. My urinary problems have affected my enjoyment of life.	1	2	3	4	5
q. Urination makes me miserable.	1	2	3	4	5

Section Three: Bowel Problems

The questions in this section ask about bowel problems that may be caused by various physical conditions.

1. In the past week, how often did you have diarrhea, or loose, watery stools?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

2. In the past week, how often did you have a sense of urgency that you move your bowels?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

3. In the past week, how often did you have tenderness or pain when you move your bowels?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

4. In the past week, how often did you have bleeding with your bowel movements?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

5. In the past week, how often did you have abdominal cramping or pain?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

6. In the past week, how often have you passed mucus from your rectum?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

7. In the past week, how often did you have the feeling that you have an urge to move your bowels, but have nothing to pass?

Not at all	Occasionally	Fairly frequently	Frequently	Very frequently
1	2	3	4	5

8. How big a problem, if any, has each of the following been for you during the past 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
a. Urgency to have a bowel movement	1	2	3	4	5
b. Increased frequency of bowel movements	1	2	3	4	5
c. Watery bowel movements	1	2	3	4	5
d. Losing control of your stools	1	2	3	4	5
e. Bloody stools	1	2	3	4	5
f. Abdominal/pelvic/rectal pain	1	2	3	4	5

9. Overall, how big a problem have your bowel habits been for you during the past 4 weeks?

No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5

Questions 10a - 10h ask about how you may feel about bowel problems and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

13. How true has each of the following statements been for you during the past 4 weeks?

	NOT AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	VERY MUCH
a. I worry about soiling myself.	1	2	3	4	5
b. I am careful to watch for any signal that I need to have a bowel movement.	1	2	3	4	5
c. My bowel problems make me feel helpless.	1	2	3	4	5
d. I feel nervous when I don't know where the bathrooms are.	1	2	3	4	5
e. The need to move my bowels is never far from my mind.	1	2	3	4	5
f. I can rely on my body to warn me that I need to have a bowel movement soon enough.	1	2	3	4	5
g. My bowel problems complicate everything I do.	1	2	3	4	5
h. My bowel problems have affected my enjoyment of life.	1	2	3	4	5

Section Four: Sexual Functioning

1. In the past 4 weeks, how interested in sex have you been?

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

2. In the past 4 weeks, how often have you felt sexual desire?

Almost never/never	A few times (less than half the time)	Sometimes (about half the time)	Most times (more than half the time)	Almost always/always
1	2	3	4	5

3. In the past 4 weeks, how would you rate your level of sexual desire?

Very low/none at all	Low	Moderate	High	Very high
1	2	3	4	5

4. In the past 4 weeks, have you had any erections at all (including morning erections)?

Yes	No
1	3

5. In the past 4 weeks, what is the most erect (or hard) your penis has become at any time?

Full erection	Nearly full erection - sufficient for penetration without manual assistance	Partial erection - capable of penetration with manual assistance	Partial erection - not capable of penetration even with manual assistance	No erection at all
1	2	3	4	5

6. In the past 4 weeks, what is the most erect (or hard) your penis has become at any time without the use of Viagra, Erec-Aid or any other type of erection aid?

Full erection	Nearly full erection - sufficient for penetration without manual assistance	Partial erection - capable of penetration with manual assistance	Partial erection - not capable of penetration even with manual assistance	No erection at all
1	2	3	4	5

7. In the past 4 weeks, how much difficulty have you had getting an erection during sexual activity?

A lot	Some	A little	No difficulty	Have not had sexual activity
1	2	3	4	5

8. In the past 4 weeks, how much difficulty have you had keeping an erection during sexual activity?

A lot	Some	A little	No difficulty	Have not had sexual activity
1	2	3	4	5

9. In the past 4 weeks, have you been able to reach orgasm (sensation of climax)?

Yes, all the time	Yes, some of the time	No, not at all	Have not engaged in sexual activity in the past 4 weeks
1	2	3	4

10. In the past 4 weeks, have you been able to ejaculate?

Yes, all the time	Yes, some of the time	No, not at all	Have not engaged in sexual activity in the past 4 weeks
1	2	3	4

11. In the past 4 weeks, how satisfied have you been with your sex life?

Extremely satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Extremely dissatisfied
1	2	3	4	5

12. In the past 4 weeks, how much have you cared about having an active sex life?			
Not at all	A little	Some	A lot
1	2	3	4

13. How big a problem, if any, has each of the following been for you during the past four weeks?						
	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem	
a.	Your level of sexual desire	1	2	3	4	5
b.	Your ability to relax and enjoy sex	1	2	3	4	5
c.	Your ability to become sexually aroused	1	2	3	4	5
d.	Your ability to have an erection	1	2	3	4	5
e.	Your ability to reach orgasm	1	2	3	4	5

13. Overall, how big a problem has your sexual function or lack of sexual function been for you during the past 4 weeks?				
No problem	Very small problem	Small problem	Moderate problem	Big problem
1	2	3	4	5

14. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
b. I'm confident in my sexual ability.	1	2	3	4	5
c. Trying to have sex is too complicated.	1	2	3	4	5
d. My sex life feels unnatural to me.	1	2	3	4	5
e. I am able to enjoy physical intimacy.	1	2	3	4	5
f. I feel helpless to act on my sexual urges.	1	2	3	4	5
g. When it comes to getting close physically, I have to be careful not to start something I can't finish.	1	2	3	4	5
h. I am worried that I might embarrass myself if I try to have sex.	1	2	3	4	5
i. I feel good about my sexuality.	1	2	3	4	5
j. Thinking about my sex life leaves me with an uneasy feeling.	1	2	3	4	5
k. When I hear talk about sex I feel like the odd man out.	1	2	3	4	5
l. I feel good about the way I deal with my own sexual needs and desires.	1	2	3	4	5
m. It feels good to think about sex.	1	2	3	4	5
n. I would feel ill at ease if someone flirted with me.	1	2	3	4	5

New treatments have become available for problems with sexual function. Questions 15a—15f ask about your experience with these treatments.

15. Which statement best describes your experience with each of these sexual function treatments in the past 12 months?

	Have not used this in the past 12 months	Have used this and plan to use it again	Have used this, but do not plan to use it again
a. Viagra	1	2	3
b. Yohimbe	1	2	3
c. Medicine inserted into the tip of the penis (MUSE)	1	2	3
d. Erec-Aid or other vacuum device	1	2	3
e. Injection therapy (medicine injected into a vein in the penis)	1	2	3
f. Penile prosthesis	1	2	3

Section Five: Social Relationships

1. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I avoid other people.	1	2	3	4	5
b. I feel that other people are avoiding me.	1	2	3	4	5
c. I feel odd and different from other people.	1	2	3	4	5
d. I feel self-conscious and embarrassed.	1	2	3	4	5
e. I am able to take care of the people who depend on me.	1	2	3	4	5

2. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?
Write in the number of close friends and relatives

3. People sometimes look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
b. Someone to get together with for relaxation.	1	2	3	4	5
c. Someone to help with daily chores if you were sick.	1	2	3	4	5
d. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
e. Someone to love and make you feel wanted.	1	2	3	4	5

The following statements are about your relationship with your spouse or partner.

Yes	No
1	2

→ If NO, go to Section Seven.

4. Do you have a spouse or a partner who is like a spouse to you?

5. In the past 4 weeks, how TRUE or FALSE has each of the following statements been for you and your spouse or partner?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. We said anything we wanted to say to each other.	1	2	3	4	5
b. We often had trouble sharing our personal feelings.	1	2	3	4	5
c. It was hard to blow off steam with each other.	1	2	3	4	5
d. I felt close to my spouse or partner.	1	2	3	4	5
e. My spouse or partner was supportive of me.	1	2	3	4	5
f. We tended to rely on other people for help rather than on each other.	1	2	3	4	5
g. My spouse or partner is satisfied with our sex life.	1	2	3	4	5

6. How true has each of the following statements been for you during the past 4 weeks?

	NOT AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	VERY MUCH
a. I feel uncomfortable when my spouse or partner acts very affectionate.	1	2	3	4	5
b. My spouse or partner seems cool and distant from me.	1	2	3	4	5
c. My partner avoids embracing, kissing or caressing me.	1	2	3	4	5
e. I feel that my spouse or partner may want to turn to others for affection.	1	2	3	4	5
g. I do a good job taking care of my spouse or partner.	1	2	3	4	5
h. My spouse or partner understands completely what I've gone through with prostate cancer.	1	2	3	4	5

7. How would you rate your spouse's health in general?

	Very Good	Good	Fair	Poor
1 Excellent	2	3	4	5

Section Six: How You Feel About Yourself

1. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I have negative feelings about the way my body looks.	1	2	3	4	5
b. I avoid being seen without a shirt on.	1	2	3	4	5
c. I have been concerned about loss of muscle tone.	1	2	3	4	5
d. I feel that my body is getting soft and flabby.	1	2	3	4	5
e. I worry about becoming dependent on others.	1	2	3	4	5
f. I am embarrassed about my physical condition.	1	2	3	4	5
g. I worry about being compared unfavorably to other men.	1	2	3	4	5
h. I feel I have been too emotional.	1	2	3	4	5
i. It's hard to think things through coolly and logically.	1	2	3	4	5
o. I feel as if I am no longer a whole man.	1	2	3	4	5
p. I feel like I've lost part of my manhood.	1	2	3	4	5
q. I'm not the man I used to be.	1	2	3	4	5
r. I feel that others think that I'm not the man I used to be.	1	2	3	4	5
s. I feel weak and small.	1	2	3	4	5

Section Seven: Living With Prostate Cancer

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I am confident that my cancer is under control.	1	2	3	4	5
b. I worry that my cancer might come back.	1	2	3	4	5
c. I worry about my cancer spreading.	1	2	3	4	5
d. I feel that my cancer has given me a better outlook on life.	1	2	3	4	5
e. I worry keep my thoughts about prostate cancer to myself.	1	2	3	4	5
f. I feel that coping with cancer has made me a stronger person.	1	2	3	4	5
g. I wonder whether the treatment I got for prostate cancer really worked.	1	2	3	4	5
h. It worries me that I can't tell what is going on with my prostate cancer.	1	2	3	4	5
i. Finding the prostate cancer saved my life.	1	2	3	4	5
j. I wonder if I would have been better off with a different treatment.	1	2	3	4	5
k. I sometimes wonder whether it was really worthwhile being treated at all.	1	2	3	4	5
l. I sometimes feel the treatment I had was the wrong one for me.	1	2	3	4	5
m. I had all the information I needed when a treatment was chosen for my prostate cancer.	1	2	3	4	5

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
n. My doctors told me the whole story about the effects of the treatments.	1	2	3	4	5
o. I wish I had chosen a more aggressive treatment for my prostate cancer.	1	2	3	4	5
p. I knew the right questions to ask my doctor.	1	2	3	4	5
q. I had enough time to make a decision about my treatment.	1	2	3	4	5
r. If I had it to do over, I would choose some other treatment.	1	2	3	4	5
s. I am satisfied with the choices I made in treating my prostate cancer.	1	2	3	4	5
t. I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer.	1	2	3	4	5
u. People in my life don't understand what it's like to have prostate cancer.	1	2	3	4	5
v. People in my life have been very supportive since I was diagnosed with prostate cancer.	1	2	3	4	5

2. Overall, how satisfied are you with the care you have received for your prostate cancer?

Not at all	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

3. Overall, how satisfied are you with the way things have turned out since you found out you had prostate cancer?

Not at all	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

Section Eight: General Attitudes

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. When a man is feeling a little pain he should try not to let it show very much.	1	2	3	4	5
b. A man always deserves the respect of his wife and children.	1	2	3	4	5
c. It is essential for a man to have the respect and admiration of everyone who knows him.	1	2	3	4	5
d. It bothers me when a man does something that I consider feminine.	1	2	3	4	5
e. In an emergency a man should be able to take charge.	1	2	3	4	5
f. Lack of erection will always spoil sex for a man.	1	2	3	4	5
g. A man should never back down in the face of trouble.	1	2	3	4	5
h. I think a man should try to become physically tough, even if he's not big.	1	2	3	4	5
i. I admire a man who is totally sure of himself.	1	2	3	4	5
j. A man should always think everything out coolly and logically, and have rational reasons for everything he	1	2	3	4	5

1. How true is each of the following statements for you?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
does.					
k. A man should never go to other people for help if he can manage things himself.	1	2	3	4	5
l. A man will lose respect if he talks about his problems.	1	2	3	4	5
m. Men are always ready for sex.	1	2	3	4	5

Section Nine: Health Behaviors

1. How often do you...

	Never / Rarely	Sometimes	Regularly
a. Read articles or buy literature in order to learn more about ways to protect your health?	1	2	3
b. Watch or listen to programs on the TV or radio to learn more about protecting your health?	1	2	3
c. Visit web sites on the internet to learn more about your health?	1	2	3
c. Exchange information with your friends about ways to keep your health at its best?	1	2	3
d. Perform self-examinations or check over parts of your body in order to check for physical changes that might require medical attention?	1	2	3
e. Attend prostate cancer support groups?	1	2	3

2. During the past 4 weeks, how much of the time did you....

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	None of the Time
a. Think about how your body feels?	1	2	3	4	5
b. Try to figure out how your body works?	1	2	3	4	5
c. Notice changes in how your body feels?	1	2	3	4	5
d. Wonder why your body feels the way it does?	1	2	3	4	5

Section Ten: Your General Health

The questions in this section pertain to your health in general, and how any health issues you may have affect your daily life.

1. In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

The following items are about activities you might do during a typical day.

2. Does your health now limit you in these activities? If so, how much?

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
b. Climbing several flights of stairs	1	2	3

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
a. Accomplished less than you would like	1	2
b. Were limited in the kind of work or other activities	1	2
c. Cut down the amount of time you spent on work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	Yes	No
a. Accomplished less than you would like	1	2
b. Didn't do work or other activities as carefully as usual	1	2
c. Cut down the amount of time you spent on work or other activities	1	2

5. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

	A little bit	Somewhat	Quite a bit	Very much
1	2	3	4	5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one best answer that comes closest to the way you have been feeling.

6. During the past 4 weeks, how much of the time...

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Have you felt calm and peaceful?	1	2	3	4	5	6
b. Did you have a lot of energy?	1	2	3	4	5	6
c. Have you felt downhearted and blue?	1	2	3	4	5	6
d. Did you feel full of pep?	1	2	3	4	5	6
e. Have you been a very nervous person?	1	2	3	4	5	6
f. Have you felt so down in the dumps nothing could cheer you up?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you ever feel tired?	1	2	3	4	5	6

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

8. Compared to one year ago, how would you rate your health in general now?

Much better now	About the same	Somewhat worse now	Much worse now
1	2	3	4
			5

12. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I think my health will be worse in the future than it is now.	1	2	3	4	5
b. In the future, I expect to have better health than other people I know.	1	2	3	4	5
c. I expect to have a very healthy life.	1	2	3	4	5
d. I expect my health to get worse.	1	2	3	4	5
e. My future will be unhealthy.	1	2	3	4	5
j. Good health is in my future.	1	2	3	4	5

14. During the past 4 weeks, how much have you felt...

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. My health could take a turn for the worse at any time.	1	2	3	4	5
b. I doubt that cancer will ever be a big problem for me.	1	2	3	4	5
c. I sometimes worry about dying before my time.	1	2	3	4	5
d. I worry about what my doctor will find next.	1	2	3	4	5
e. I worry that changes in my medical condition will not be detected early.	1	2	3	4	5
f. I am uneasy about the present state of my health.	1	2	3	4	5
g. It is hard to make sense of what I am told about my health.	1	2	3	4	5

15. How true has each of the following statements been for you during the past 4 weeks?

	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
a. I keep close track of my PSA.	1	2	3	4	5
b. I live in fear that my PSA will rise.	1	2	3	4	5
c. I am confused by what PSA really means.	1	2	3	4	5
d. Knowing my PSA level is comforting to me.	1	2	3	4	5

Section Eleven: Personal Background Information

1. Which category best describes your race / ethnic background?

White	Black / African-American	Hispanic / Latino	Asian / Pacific Islander	Aleutian, Eskimo, or American Indian	Other
1	2	3	4	5	Specify: _____ 6

2. What is your current marital status? (Circle one number.)

Married	Widowed	Separated	Divorced	Never married
1	2	3	4	5

3. How would you describe your current work or retirement situation? (Circle one number.)

Working at a paying job full or part time	Retired, not working at all	Retired, but working part or full time	Laid off or unemployed	Other
1	2	3	4	Specify: _____ 5

The following list includes events that may occur in anyone's life from time to time. Each one may have a good effect, a bad effect or no effect on a person's life. Think back over the **past 12 months** of your life.

4. Over the **past 12 months**, have any of the following events occurred in your life?

	Yes	No
a. Someone close to you had a serious illness or injury.	1	2
b. You had a financial crisis.	1	2
c. Someone close to you died.	1	2
d. You resigned or retired from work.	1	2

Thank you for completing The Prostate Cancer Quality of Life Questionnaire.

Have you...

- Reviewed and circled all the answers?
- Signed the informed consent form on the second page?

Enclose both the survey AND the informed consent form in the self-addressed stamped envelope we have provided for you and drop in any mailbox.

If you should have any questions, please call Kristen Solemina at (781) 687-3255.