

Award Number: W81XWH-07-1-0452

TITLE: Disparities in Prostate Cancer Treatment Modality and Quality of Life

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REPORT DATE: November 2010

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command  
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;  
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# REPORT DOCUMENTATION PAGE

Form Approved  
OMB No. 0704-0188

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<b>1. REPORT DATE</b> November 2010		<b>2. REPORT TYPE</b> Final	<b>3. DATES COVERED</b> 1 June 2007 - 1 October 2010		
<b>4. TITLE AND SUBTITLE</b>  Disparities in Prostate Cancer Treatment Modality and Quality of Life			<b>5a. CONTRACT NUMBER</b>		
			<b>5b. GRANT NUMBER</b> W81XWH-07-1-0452		
			<b>5c. PROGRAM ELEMENT NUMBER</b>		
<b>6. AUTHOR(S)</b>  Thomas A LaVeist  E-Mail: <a href="mailto:tlaveist@jhsph.edu">tlaveist@jhsph.edu</a>			<b>5d. PROJECT NUMBER</b>		
			<b>5e. TASK NUMBER</b>		
			<b>5f. WORK UNIT NUMBER</b>		
<b>7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)</b>  Johns Hopkins University Baltimore, MD 21205			<b>8. PERFORMING ORGANIZATION REPORT NUMBER</b>		
<b>9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)</b> U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			<b>10. SPONSOR/MONITOR'S ACRONYM(S)</b>		
			<b>11. SPONSOR/MONITOR'S REPORT NUMBER(S)</b>		
<b>12. DISTRIBUTION / AVAILABILITY STATEMENT</b> Approved for Public Release; Distribution Unlimited					
<b>13. SUPPLEMENTARY NOTES</b>					
<b>14. ABSTRACT</b>  On Page 2					
<b>15. SUBJECT TERMS</b> Prostate Cancer					
<b>16. SECURITY CLASSIFICATION OF:</b>			<b>17. LIMITATION OF ABSTRACT</b>  UU	<b>18. NUMBER OF PAGES</b>  6	<b>19a. NAME OF RESPONSIBLE PERSON</b> USAMRMC
<b>a. REPORT</b> U	<b>b. ABSTRACT</b> U	<b>c. THIS PAGE</b> U			<b>19b. TELEPHONE NUMBER</b> (include area code)

# Table of Contents

Table of Contents.....	1
Abstract.....	2
Introduction.....	3
Body.....	3
Key Research Accomplishments.....	8
Reportable Outcomes.....	8
Conclusions.....	13
Appendix	14

## **ABSTRACT**

Prostate cancer is a serious condition that has a substantial societal burden. In 2010, approximately 217,730 new cases of prostate cancer and 32,050 deaths were reported in the US. Between 2002 and 2006 race differences in age-adjusted prostate cancer incidence rates were substantial (155.5 and 25.6 per 100,000, respectively). A similar disparity exists in the age-adjusted prostate cancer death rates within the same period (23.6 deaths per 100,000 males for whites and 56.3 for African American men). Compared to whites, African Americans have higher prostate cancer incidence, are diagnosed at later stages of disease, and have lower five-year survival rates. Additionally, they are less likely to be enrolled in clinical trials and there are indications that supportive services may not be as readily available to them. Although African Americans have a substantially worst profile with regard to prostate cancer, there have been relatively few research investigations of race differences in prostate cancer screening, diagnosis and quality of life. We designed the Diagnosis and Decisions in Prostate Cancer Treatment Outcomes (DAD) Study to explore factors that influence race differences in prostate cancer screening, diagnosis, treatment and quality of life in 877 prostate cancer survivors. We observed that African Americans received fewer sources of information regarding prostate cancer treatment, appeared to be more self reliant in their decision making regarding prostate cancer treatment, and were more reliant on religious faith for coping with prostate cancer than whites. African Americans patients are less well-informed about their decision making related to prostate cancer. This may contribute to the well-documented disparities in patient outcomes.

## **INTRODUCTION**

The purpose of this project is to examine racial disparities in treatment decision-making and quality of life among white and African American prostate cancer patients. The long-term goals are (1) to establish a cohort of African American and white prostate cancer survivors in which to identify factors that influence the selection of prostate cancer treatment modality, and explore race differences in disease burden, quality of life and survival over a sustained period of time, (2) to establish a cohort of the adult sons of prostate cancer survivors in which to study prostate cancer knowledge, attitudes and screening practices with the goal of determining if they ultimately develop the disease, and (3) to develop interventions to reduce racial disparities in prostate cancer disease burden, quality of life, survival and disease stage at diagnosis. Under this award the first goal was completed.

The specific aims of the project are:

Specific aim 1: to develop data collection instruments to conduct a survey of factors that influence treatment decision making and quality of life among white and African American prostate cancer patients.

Specific aim 2: to establish a cohort of White and African American men in which to study factors that influence treatment decision making and quality of life among prostate cancer patients.

Specific aim 3: to administer a questionnaire designed to assess factors that affect prostate cancer treatment decision making and quality of life as the baseline data collection to the cohort of white and African American prostate cancer patients.

## **BODY**

The purpose of the study is to identify factors that influence the selection of prostate cancer treatment modality, and explore race differences in disease burden and quality of life. We will prospectively recruit 366 white and 366 African American men who enter the North Carolina Central Cancer Registry (NCCCR) using a rapid case ascertainment (RCA) procedure described below. According to North Carolina state law, all cancer diagnoses and treatment must be reported to the NCCCR and patient consent is not required to release data to the NCCCR. The RCA core was developed to support population-based epidemiology research and allow researchers to access new cancer patients within 1 month of NCCCR reporting.

### **Subject Identification**

On a monthly basis, Rapid Case Ascertainment (RCA) staff will contact the primary research network hospitals, and ask them to run a report identifying their patients meeting the eligibility criteria. The report will be sent to the study team and the investigators will confirm eligibility criteria. As a part of

standard NCCCR protocol, RCA core will mail these prospective study participants a pamphlet describing the NCCCR and informing them that they may be contacted in the future to participate in a study. Study investigators will begin contacting prospective study participants to ascertain their interest and obtain consent, per the following protocol. For individuals who are contacted but decline participation, all data will be immediately deleted by study investigators.

#### Procedures for Contacting and Recruiting Prospective Study Participants

Study staff will send to the physician of record in the NCCCR of each eligible study participant a notification of intent to contact the prospective participant about enrolling in the study. Although some state cancer registries require physician *permission* before patient contact (in which physician non-response is taken as passive refusal of patient contact), the NCCCR requires only that physicians be *notified* of an impending patient contact. Physician non-response is taken as passive permission of patient contact. Physicians will have three weeks to reply with a request that the patient not be contacted. If the physician does not refuse patient contact within three weeks, we will send the eligible study participant a brochure and cover letter describing the study and provide a phone number that he can call for questions or to decline. A week later, the interviewers will contact the eligible study participant by telephone, screen him for study eligibility, explain the study, answer questions, and seek his participation. If the eligible study participant expresses interest, the interviewer will obtain verbal consent and proceed with the survey questionnaire or schedule a time to administer the questionnaire if more convenient for the participant. For individuals who are contacted but decline participation, all personally identifying data in this table will be immediately deleted.

We will re-interview respondents to ascertain change in health status. The follow up interviews will occur between within two years of the baseline interview. The re-interview will consist of a brief (approximately 30 items) questionnaire which asks a set of questions designed to measure health status.

#### Population:

*Sample Size:* 877

*Power Calculations:* Power calculations were done using the POWER procedure in SAS/STAT. Sample size was calculated for power levels of 80%-95% at 5% intervals and alpha=0.05 to detect mean differences in quality of life indexes between blacks and whites. Mean differences of interest were 7 and 10. Standard deviations were obtained from a prior study by Lubeck et al (J Urol. 2001 Dec;166(6):2281-5).

Table 1. Sample size calculation for difference in **generic health related quality of life indexes:** Alpha=0.05, 2-sided test. Reference Lubeck et al "Health related quality of life differences between black and white men with prostate cancer: data from the cancer of the prostate strategic urologic research endeavor." J Urol. 2001 Dec;166(6):2281-5.

Index	Time (months)	Mean Difference	Sample Weights: 2.5 White: 1 African American				Sample Weights: 1 White: 1 African American			
			Power				Power			
			80%	85%	90%	95%	80%	85%	90%	95%
Bodily pain	0-3	7	504	576	673	831	397	454	531	656
	0-3	10	249	284	332	410	196	224	261	323
	9-12	7	654	747	873	1,079	491	561	657	811
	9-12	10	323	368	430	531	242	276	323	399
Family interference	0-3	7	465	532	621	767	367	419	490	605
	0-3	10	230	263	307	378	181	207	241	298
	9-12	7	601	687	803	993	453	517	605	748
	9-12	10	297	339	396	489	223	255	298	368
General health	0-3	7	458	524	612	756	363	414	485	599
	0-3	10	227	259	302	373	179	204	239	295
	9-12	7	542	619	724	894	416	475	556	687
	9-12	10	268	306	357	441	205	234	274	338
Health distress	0-3	7	409	467	546	674	321	367	429	530
	0-3	10	203	231	270	333	159	181	212	261
	9-12	7	489	558	653	806	372	425	497	614
	9-12	10	242	276	322	397	183	210	245	302
Mental health	0-3	7	285	326	380	469	225	257	300	371
	0-3	10	142	162	189	232	111	127	148	183
	9-12	7	347	396	462	571	262	299	350	432
	9-12	10	172	196	229	282	130	148	173	213

Physical function	0-3	7	597	682	798	985	471	538	630	778
	0-3	10	295	337	393	485	232	265	310	382
	9-12	7	727	831	972	1,200	555	634	742	917
	9-12	10	359	410	478	591	273	312	365	450
Prostate Ca interference	0-3	7	368	420	491	607	291	332	388	479
	0-3	10	183	208	243	300	144	164	191	236
	9-12	7	483	552	645	796	363	415	485	600
	9-12	10	239	273	318	393	179	205	239	295
Role emotional	0-3	7	1,357	1,552	1,816	2,244	1,077	1,232	1,441	1,782
	0-3	10	667	763	892	1,102	529	605	707	874
	9-12	7	1,780	2,036	2,382	2,944	1,338	1,530	1,790	2,213
	9-12	10	875	1,000	1,170	1,445	657	751	879	1,086
Role physical	0-3	7	1,779	2,035	2,381	2,943	1,409	1,612	1,886	2,332
	0-3	10	874	999	1,169	1,444	692	791	925	1,144
	9-12	7	2,337	2,673	3,127	3,866	1,761	2,014	2,356	2,913
	9-12	10	1,148	1,312	1,535	1,897	864	988	1,156	1,429
Self-esteem	0-3	7	338	387	452	557	266	304	356	439
	0-3	10	168	192	224	275	132	150	176	217
	9-12	7	401	458	535	661	307	351	410	506
	9-12	10	199	227	265	326	152	173	202	249
Social function	0-3	7	555	634	741	916	438	500	585	723
	0-3	10	274	313	366	451	216	246	288	356
	9-12	7	738	843	986	1,218	554	634	741	916
	9-12	10	364	416	486	599	273	312	365	450



Vitality fatigue	0-3	7	425	486	567	701	336	384	448	554
	0-3	10	211	240	280	346	166	189	221	273
	9-12	7	521	595	696	860	396	452	529	653
	9-12	10	258	294	343	424	195	223	260	321
Largest Sample										
Size:	0-3	7	1,779	2,035	2,381	2,943	1,409	1,612	1,886	2,332
	0-3	10	874	999	1169	1444	692	791	925	1144
	9-12	7	2,337	2,673	3,127	3,866	1,761	2,014	2,356	2,913
	9-12	10	1,148	1,312	1,535	1,897	864	988	1,156	1,429

For follow up interviews, we anticipate approximately 10% of respondents will be deceased and about 10% lost to follow up. This will result in an estimated sample size of 701 at follow up.

*Inclusion/Exclusion Criteria:* White and African American men, age 35 and over, diagnosed with localized prostate cancer who entered the North Carolina Central Cancer Registry during the year 2007-2008 will be recruited into this study. The large majority of prostate cancer patients, even among African Americans, have been diagnosed with localized prostate cancer. Therefore, stage at diagnosis will not be used to exclude participants. The age to begin prostate cancer screening for men who have a father or brother diagnosed with prostate cancer has been suggested as early as 34.

*Gender, Age and Locale:* Males 35 and over who are registered in the North Carolina Central Cancer Registry and have met the inclusion/exclusion criteria.

Procedures:

*Recruitment Process:* We will recruit 877 men (462 white and 415 African American) who entered the North Carolina Central Cancer Registry during the years 2007-2008. On a monthly basis, RCA staff will contact the primary research network hospitals, and ask them to run a report identifying their patients meeting the eligibility criteria. After the study team confirms the eligibility of the patients, the RCA core will mail these prospective study participants a pamphlet describing the NCCCR and informing them that they may be contacted in the future to participate in a study. Study staff will send to the physician of record in the NCCCR of each eligible study participant a notification of intent to contact the prospective participant about enrolling in the study. Physicians will have three weeks to reply with a request that the patient not be contacted. If the physician does not refuse patient contact within three weeks, we will send the eligible study participant a packet containing a recruitment letter describing the study and a copy of the consent form. In the letter, we will provide a phone number that he can call for questions or to decline. A week later, the interviewers will contact the eligible study participant by telephone, screen him for study eligibility, explain the study, answer questions, and seek his participation. If the

eligible study participant expresses interest, the interview will review the consent form and obtain verbal consent. The consent form will explain the purpose, procedures, risks/discomfort, benefits, and confidentiality associated with the study and a copy will be provided to keep for their records. For individuals who are contacted but decline participation, all personally identifying data in this table will be immediately deleted. Approximately every two years post baseline interview we will re-interview respondents to ascertain change in health status.

**KEY RESEARCH ACCOMPLISHMENTS**

This section lists each task outline in the approved Statement of Work and provided detailed summary of each of the activities for the funding period.

Task 1

- The goal for Black males was 366; as of 7/23/11 we’ve completed 371 Blacks.
- The goal for White males was 366; as of 7/23/11 we’ve completed 478 Whites.

**REPORTABLE OUTCOMES**

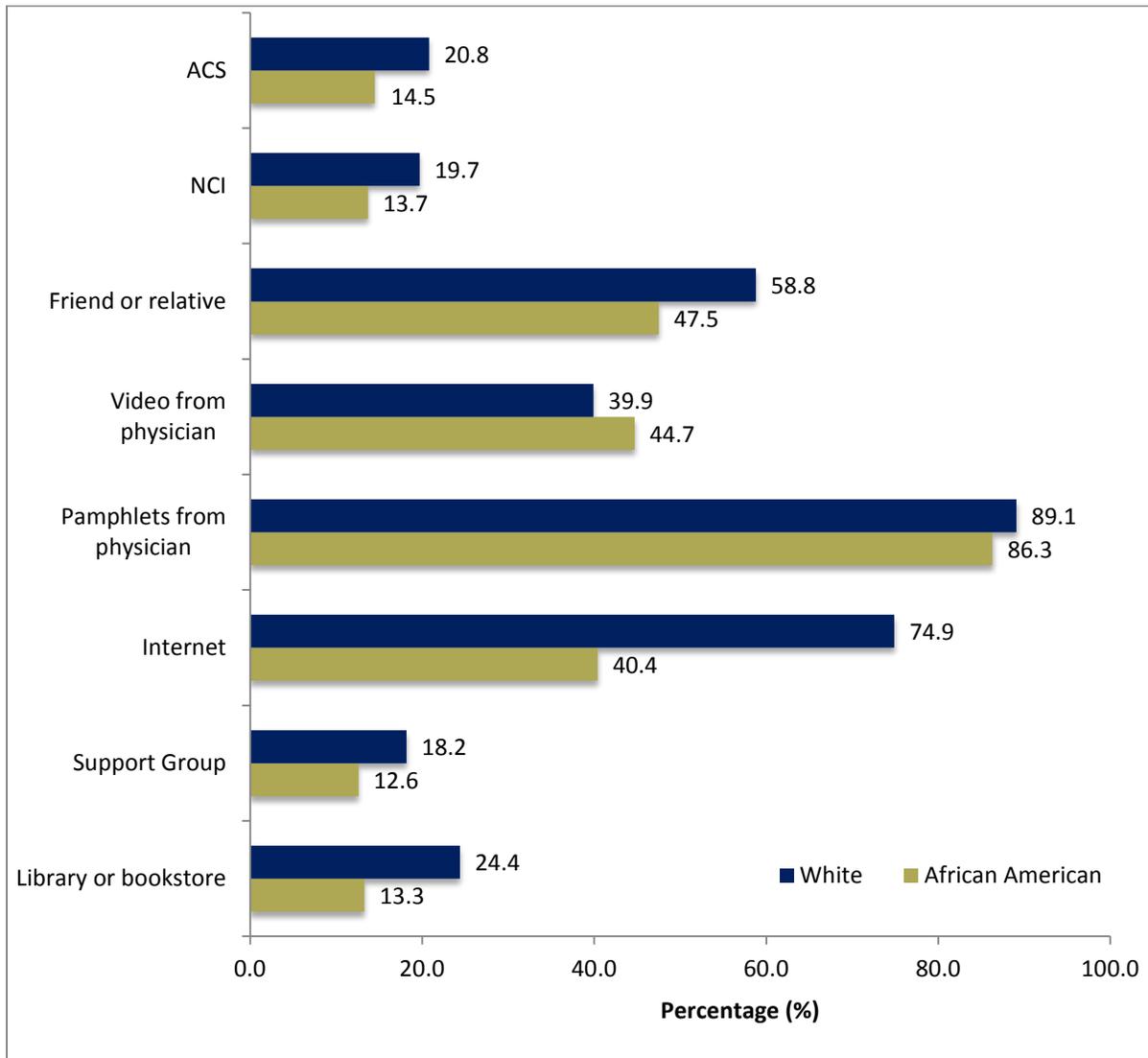
African American men had a lower income, were less likely to be a high school graduate, be married, have private insurance, or have a full time job.

Table 2. Demographic Characteristics of Men in the DAD Study by Race		
	African American n=255	White n=451
Age (mean±SD)	63.4±0.56	64.8±0.43
Income (mean±SD)	\$47110±2610	\$100,847±45369
Education(%)		
Less than high school	17.3	5.9*
High school grad/GED	34.9	15.7
Some college	16.1	14.9
Associate	7.1	8.2
Bachelor’s	13.7	28.6
Master’s	7.5	16.9
Doctoral	3.5	9.5
Marital Status (%)		

Married/Living as married	69.4	86.5*
Divorced/Separated	16.9	6.7
Widowed	5.1	3.1
Never married	7.5	3.3
Insurance Type (%)		
Private	32.1	46.7
Medicare	34.5	43.2
Medicaid	17.6	3.5
CHAMPUS/CHAMPVA	4.3	2.8
Employment Status (%)		
Full time	32.5	40.3
Part time	5.1	6.8
Retired	40.3	42.5
Unemployed	9.8	3.5
Disabled	10.5	2.2
*p<0.05		

African American men were less likely to obtain information about prostate cancer information from the Internet, American Cancer Society, National Cancer Institute, friends or relatives, or the library or bookstore compared to white men.

**Figure 1. Sources of Prostate Cancer Information by Race**



- African American men were less likely to seek advice about prostate cancer treatment from a wife or partner, someone who has been treated for prostate cancer, friends or neighbors, or a second physician relative to white men.
- African American men were more likely to seek advice about prostate cancer treatment from another female relative than white men.
- African American men were equally likely to seek advice about prostate cancer treatment from their family, a religious counselor or a social worker or other professional counselor than White men.

Individual	African American	White
	n=255	n=451
Wife or partner	39.2	58.8*
Children	17.3	13.8
Parents	6.7	4.4
Brother	14.5	11.1
Sister	7.1	6.0
Other male relative	12.9	10.4
Other female relative	5.9	2.7*
Your friends or neighbors	25.1	36.8*
A religious counselor	8.2	6.7
Someone who had been treated for prostate cancer	32.9	55.0*
A second medical doctor	21.2	30.4*
A counselor, social worker, or other professional	2.8	2.4
*p<0.05		

- African American men were more likely to believe in God or a higher power than white men.
- African American men were more likely to have stronger beliefs about their faith in God and the prognosis of their prostate cancer than white men.

Belief	African American	White
I believe in God or a higher power or force	97.7	90.5*
Getting prostate cancer was punishment from God	2.5	1.9
Getting prostate cancer was a way to test my faith in God	30.6	14.2*
Since being diagnosed with prostate cancer, my faith in God has gotten stronger	68.1	46.8*
My faith in God has helped me cope with my disease	91.1	83.9*

Whether or not I am cured will be decided by God only	70.5	41.8*
If I pray enough, I will be cured	56.6	21.8*
Since being diagnosed with prostate cancer, my faith in God has weakened	2.0	1.2
*p<0.05		

## OTHER REPORTABLE OUTCOMES

Presentation on preliminary findings on race disparities in prostate cancer treatment and quality at the 2011 Howard-Hopkins Symposium by co-investigator Roland J. Thorpe, Jr. on March 24, 2011 in Washington, DC.

Abstract submission and acceptance of a symposium on the topic of race, psychosocial correlates and prostate cancer treatment decisions at the 2011 American Public Health Association (APHA) meeting in Washington, DC on October 31, 2011.

Presentation on prostate cancer health knowledge, attitudes, and behaviors among prostate cancer survivors by co-investigator Mimi Kim at the 2011 Academy Health Annual Research meeting in Seattle, WA.

Presentation on disparities in prostate cancer patient information-seeking by Thomas LaVeist at the Sidney Kimmel Comprehensive Cancer Center at the Johns Hopkins University, School of Medicine, July 28, 2011.

In addition to the presentations, we have four manuscripts in progress that are the presentations in the 2011 APHA symposium listed above. Below, we briefly describe each paper and the preliminary findings.

Paper 1. "Race Disparities in Prostate Cancer Treatment Experiences and Quality of Life: An Overview of the Diagnosis and Decisions in Prostate Cancer Treatment Outcomes (DAD) Study". Members of the writing group are: Drs. Janice Bowie, Daniel Howard, Thomas LaVeist, and Roland J. Thorpe, Jr. (lead author). In this paper we will provide an overview of the study that focuses on the motivation for conducting the study to include the recruitment strategy, study design, and key dependent and independent variables. Preliminary findings indicate that the African American men had a lower income, were more likely to be a high school graduate, and less likely to be married, have private insurance, or have a full time job. There were no race differences in age. African American men were less likely to seek advice about prostate cancer treatment from a wife or partner, someone who has been treated for prostate cancer, friends or neighbors, or a second physician relative to white men. African American men were more likely to seek advice about prostate cancer treatment from another female relative than white men. African American men were equally likely to seek advice about prostate cancer treatment from their family, a religious counselor or a social worker or other professional counselor than White men.

Paper 2. “Assessing Sources of Information That Contribute to Treatment Decisions for Adult Men with Prostate Cancer “. Members of the writing group are: Drs. Janice Bowie, Keon Gilbert, Daniel Howard, Mimi Kim (lead author), Thomas LaVeist, Louie Ross, and Roland J. Thorpe, Jr. In this paper we will explore sources of information that contribute to the decision making processes for treatment among men with or at risk for prostate cancer. Preliminary findings indicate that those men who did not speak to an oncologist are more likely to make a treatment decision with influence from others. These same individuals also were more likely to receive information from printed materials than from the doctor. Additionally, these individuals received advice from a friend, cancer survivor, or healthcare professional and received input and emotional support from family. These results highlight the importance of printed materials and broad social networks of family, friends, and professionals to educate patients and inform them throughout the treatment decision making process.

Paper 3. “Differences and Satisfaction with Prostate Cancer Treatment Choice among Black and White Men.” Members of the writing group are: Drs. Janice Bowie, Keon Gilbert, Daniel Howard, Mimi Kim, Thomas LaVeist, Louie Ross (lead author), and Roland J. Thorpe, Jr. In this paper we will examine the differences in initial prostate cancer treatment choice among a group of Black and White men. Preliminary findings indicate that the majority of men reported that surgery was the most frequent treatment chosen and was the best for them. Few men reported any form of decisional regret or feeling that they did not have the best treatment. Individual level variables play an important role in men’s satisfaction with their initial treatment for prostate cancer.

Paper 4. “The Effect of Cancer-Related Religious Beliefs and Cancer Treatment Behaviors”. Members of the writing group are: Drs. Janice Bowie (lead author), Keon Gilbert, Daniel Howard, Mimi Kim, Thomas LaVeist, Louie Ross, Roland J. Thorpe, Jr., and Ms. Caryn Bell. In this paper we examine the role of religiosity and religious coping to understand if men in this study found religion a help or a hindrance during their illness and in the face of uncertainty, and the extent to which religious coping was used and varied by demographic factors. Preliminary findings indicate the African American men are more reliant on religious faith for coping with prostate cancer than white men.

## **CONCLUSIONS**

There are three key conclusions from our preliminary findings. They are:

- African American men utilized fewer sources of information regarding prostate cancer treatment than white men.
- African American men appear to be more self reliant in their decision making regarding treatment for prostate cancer than white men.
- African American men are more reliant on religious faith for coping with prostate cancer than white men.

**APPENDIX 1:**  
**STUDY QUESTIONNAIRE**



**PROSTATE CANCER  
QUALITY OF LIFE ASSESSMENT**

Hello, I'm (INTERVIEWER NAME) calling on behalf of a study being conducted by the Johns Hopkins Bloomberg School of Public Health and Shaw University.

Recently we mailed you an information packet about a study we are conducting of men with prostate cancer. The long-term goal of this study is to develop programs and procedures to improve the quality of life of men who have this disease. We are interested in finding out about your experience since being diagnosed with prostate cancer. Did you receive our information packet? **REVIEW CONSENT FORM AND OBTAIN CONSENT. IF RESPONDENT DOES NOT GIVE CONSENT, THANK RESPONDENT AND END INTERVIEW. Now that we have reviewed the consent form, would you like to give us your verbal consent to continue?**

Would this be good time to complete the interview? IF "NO", SCHEDULE APPOINTMENT TIME.

CONTINUE AT TIME OF THE INTERVIEW. Of course, this interview is completely voluntary. If we come to any question you don't want to answer, please tell me and we will go to the next question. All information you give us is confidential.

I think you'll find the questions interesting, and you'll want to give them careful thought.

**INITIAL SCREENER**

I am going to ask a few questions to make sure that you qualify for participation in this study.

A1. Have you been diagnosed with prostate cancer?

1 Yes      0 No **(If no, end interview)**

A2. Are you over the age of 34?

1 Yes      0 No **(If no, end interview)**

A3. Which category best describes your race?

- 1 White
  - 2 Black/African-American
- (If other, end interview)**

**B. TREATMENT DECISION MAKING**

We will start with some questions about your decision making process regarding your prostate cancer treatment.

Please tell us about how you came to be diagnosed with prostate cancer.

B1. Have you previously diagnosed with another cancer before you were told that you had prostate cancer?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B1a. If so, what type of cancer were you first diagnosed with?

---

B2. Before your prostate cancer diagnosis, did you have any symptoms that made you think you should be checked by a doctor?

- 1 Yes
- 2 No (**If no, skip to question B3**)
- 3 Don't Know
- 4 Refused

B3. What were the symptoms? (**check all that apply**)

- 1 Pain
- 2 Urinary problems
- 3 Sexual functioning problems
- 4 Other, please specify \_\_\_\_\_
- 5 Don't Know
- 6 Refused

B4. How many months were there between when you thought you should get a prostate exam and when you actually got one? (In months)

---

B5. In what month and year were you diagnosed with prostate cancer? (MM/YYYY)

\_\_\_\_\_

B6. When you were first told you have prostate cancer, did your doctor discuss your choices for treatment?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B7. Which doctors and health care professionals did you talk with when deciding how your prostate cancer would be treated? (**check all that apply**)

- 1 Urologist who performed the biopsy
- 2 Other urologists
- 3 Radiation Oncologist
- 4 Medical Oncologist
- 5 Internist
- 6 Nurse
- 7 Psychologist, therapist, counselor
- 8 Other, please specify \_\_\_\_\_
- 9 Don't Know
- 10 General/Family Practitioner
- 11 Refused

B8. Which of the following were you offered as treatment when you were first told that you had prostate cancer? (**check all that apply**)

	Yes	No	DK	RF
B8a. Prostatectomy (surgery to remove your prostate)	1	0	10	11
B8b. External beam radiation (radiation to your prostate)	1	0	10	11
B8c. Radioactive seeds or beads (radioactive seeds implanted into your prostate)	1	0	10	11
B8d. Orchiectomy (surgery to remove your testicles)	1	0	10	11
B8e. Hormone therapy (injections to keep your testicles from producing hormones)	1	0	10	11
B8f. Watchful waiting (no treatment, wait and see if your prostate cancer grows)	1	0	10	11
B8g. Cryotherapy (process to freeze and destroy prostate tissue)	1	0	10	11
B8h. Chemotherapy (use of anti-cancer drugs)	1	0	10	11
B8i. Any other treatments (If yes, explain)_____	1	0	10	11

B9. Did your doctor tell you that he/she preferred one of the treatment choices to the others?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B9a. If so, what was the treatment that your doctor preferred?

\_\_\_\_\_

B10. How much time were you given to choose a treatment?

- 1 Less than a day
- 2 1 day
- 3 2-3 days
- 4 4-7 days
- 5 More than a week
- 6 Don't Know
- 7 Refused

B11. Did you feel this was enough time to decide on a treatment?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B12. What treatment(s) did you get? (check all that apply)

- 1 Prostatectomy (surgery to remove your prostate)
- 2 External beam radiation (radiation to your prostate)
- 3 Radioactive seeds or beads (radioactive seeds implanted into your prostate)
- 4 Orchiectomy (surgery to remove your testicles)
- 5 Hormone therapy (injections to keep your testicles from producing hormones)
- 6 Watchful waiting (no treatment, wait and see if your prostate cancer grows)
- 7 Cryotherapy (process to freeze and destroy prostate tissue)
- 8 Chemotherapy (use of anti-cancer drugs)
- 9 Any other treatments (If yes, explain)\_\_\_\_\_
- 10 Don't Know
- 11 Refused

B13. In what month and year did you receive your first treatment? (MM/YYYY)

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B14. Was that the treatment that you wanted at that time?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B15. Did you feel you had a choice about which treatment you would get for your prostate cancer?

- 1 Yes
- 2 No (**Go to question B15**)
- 3 Don't Know
- 4 Refused

B15a. **If Yes**, did you get the treatment your doctor preferred?

- 1 Yes
- 2 No
- 3 Does not apply
- 4 Refused

B16. Do you now believe that the treatment you got was the one that was best for you?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

B17. I am going to read a list of factors you may have considered in deciding which treatment to get for your prostate cancer. Please indicate how important each of the factors was to you. READ STATEMENT. Would you say this factor was not important, somewhat important, or very important?

	Not Important	Somewhat Important	Important	Very Important	DK	RF
B17a. Getting the cancer completely out of your body	1	2	3	4	5	6
B17b. The number of visits you would have to make to the hospital/clinic for treatment	1	2	3	4	5	6
B17c. The length of time you would be getting treatment	1	2	3	4	5	6
B17d. The amount of pain associated with the treatment	1	2	3	4	5	6
B17e. Your view of yourself as a man	1	2	3	4	5	6
B17f. Being able to get a good enough erection to have sexual intercourse after treatment	1	2	3	4	5	6
B17g. Being able to control your urine after treatment	1	2	3	4	5	6
B17h. Being able to control your bowels after treatment	1	2	3	4	5	6
B17i. Your doctor's opinion about which was the best treatment	1	2	3	4	5	6
B17j. Your wife or partner's opinion about which was the best treatment	1	2	3	4	5	6
B17k. The possibility of having your cancer cured	1	2	3	4	5	6
B17l. Lowering the chance that your cancer will come back	1	2	3	4	5	6
B17m. The type of insurance you have	1	2	3	4	5	6
B17n. Concern about the amount of money the treatment would cost you	1	2	3	4	5	6

B18. Did you get information about prostate cancer treatment from any of the following sources? **(check all that apply)**

	Yes	No	DK	RF
B18a. The library/bookstore	1	0	9	10
B18b. A prostate cancer support group	1	0	9	10
B18c. The Internet	1	0	9	10
B18d. Books or pamphlets your doctor gave you	1	0	9	10
B18e. A video you saw at home or doctor's office	1	0	9	10
B18f. Friend or relative	1	0	9	10
B18g. National Cancer Institute	1	0	9	10
B18h. American Cancer Society	1	0	9	10

B19. Did you seek advice about which treatment you should get for your prostate cancer from any of the following people? **(check all that apply)**

	Yes	No	DK	RF
B19a. Your wife or partner	1	0	14	15
B19b. Your children	1	0	14	15
B19c. Your parents	1	0	14	15
B19d. Your brother	1	0	14	15
B19e. Your sister	1	0	14	15
B19f. Other male relative	1	0	14	15
B19g. Other female relative	1	0	14	15
B19h. Your friends or neighbors	1	0	14	15
B19i. A religious counselor	1	0	14	15
B19j. Someone who had been treated for prostate cancer	1	0	14	15
B19k. A second medical doctor	1	0	14	15
B19l. A counselor, social worker, or other professional	1	0	14	15
B19m. Other, please specify _____	1	0	14	15

B20. Was the final decision about your treatment your decision or one made with someone else?

- 1 100% my decision
- 2 75% my decision and 25% someone else
- 3 50% my decision and 50% someone else
- 4 25% my decision and 75% someone else
- 5 100% someone else
- 6 Don't Know
- 7 Refused

B21. Who helped you to make your treatment decision? (**check all that apply**)

	Yes	No	DK	RF
B21a. Your wife or partner	1	0	14	15
B21b. Your children	1	0	14	15
B21c. Your parents	1	0	14	15
B21d. Your brother	1	0	14	15
B21e. Your sister	1	0	14	15
B21f. Other male relative	1	0	14	15
B21g. Other female relative	1	0	14	15
B21h. Your friends or neighbors	1	0	14	15
B21i. A religious counselor	1	0	14	15
B21j. Someone who had been treated for prostate cancer	1	0	14	15
B21k. A second medical doctor	1	0	14	15
B21l. A counselor, social worker, or other professional	1	0	14	15
B21m. Other, please specify _____	1	0	14	15

### C. FAMILY HISTORY

I am now going to ask you about you family history of cancer.

C1. Were you adopted?

- 1 Yes, and I know my family history
- 2 Yes, and I don't know my family history (**Skip to Section D**)
- 3 **Don't Know** (**Skip to Section D**)
- 4 **Refused**



C2. Have any of the following blood relatives ever had prostate cancer? (**check all that apply**)

- 1 Father
- 2 Brother - full
- 3 Brother - half
- 4 Son
- 5 Grandfather – maternal
- 6 Grandfather – paternal
- 7 Uncle – maternal
- 8 Uncle – paternal
- 9 First cousin – maternal
- 10 First cousin – paternal
- 11 Nephew – sister’s side
- 12 Nephew – brother’s side
- 13 Grandson
- 14 Other
- 15 Don’t know
- 16 Refused

C2a. If you have a blood relative that has been diagnosed with prostate cancer, have you discussed his (their) treatment with him (them)?

- 1 Yes
- 2 No (**Skip to Section D**)
- 3 Don’t Know
- 4 Refused

C3. The next statements concern the effect of your blood relatives’ treatment decisions on your own treatment decisions. **READ STATEMENT.** Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
C3a. Talking to my relative helped my decision making process.	1	2	3	4	5	6	7
C3b. I wanted to seek treatment for my prostate cancer because my relative(s) had a good experience with his treatment.	1	2	3	4	5	6	7
C3c. I wanted to seek treatment for my prostate cancer because my relative had a bad experience with his treatment.	1	2	3	4	5	6	7
C3d. I wanted to seek treatment for my prostate cancer because my relative had a bad experience when he did not seek treatment.	1	2	3	4	5	6	7
C3e. I did not want to seek treatment for my prostate cancer because my relative(s) had a bad experience with their treatment.	1	2	3	4	5	6	7

**D. GENERAL QUALITY OF LIFE**

This next set of questions deal with your quality of life.

**(FACT-P Version 3)** The following is a list of statements that people with your illness have said are important. Please indicate how true these statements have been for you during the past 7 days. **READ STATEMENT.** Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

PHYSICAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D1. I have a lack of energy	1	2	3	4	5	6	7
D2. I have nausea	1	2	3	4	5	6	7
D3. Because of my physical condition, I have trouble meeting the needs of my family	1	2	3	4	5	6	7
D4. I have pain	1	2	3	4	5	6	7
D5. I am bothered by side effects of treatment	1	2	3	4	5	6	7
D6. I feel sick	1	2	3	4	5	6	7
D7. I am forced to spend time in bed	1	2	3	4	5	6	7

I am now going to read statements about your social and family well-being. **READ STATEMENT.** Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D8. I feel distant from my friends	1	2	3	4	5	6	7
D9. I get emotional support from my family	1	2	3	4	5	6	7
D10. I get support from my friends and neighbors	1	2	3	4	5	6	7
D11. My family has accepted my illness	1	2	3	4	5	6	7
D12. Family communication about my illness is poor	1	2	3	4	5	6	7
D13. I feel close to my partner (or the person who is my main support)	1	2	3	4	5	6	7
D14. Have you been sexually active in the past year?	Yes=1		No=2			3	4
D14a. If yes: I am satisfied with my sex life	1	2	3	4	5	6	7

The next statements concern your relationship with your doctor(s). READ STATEMENT. Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

RELATIONSHIP WITH DOCTOR	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D15. I have confidence in my doctor(s)	1	2	3	4	5	6	7
D16. My doctor(s) is(are) available to answer my questions	1	2	3	4	5	6	7

The next statements concern your emotional well-being. READ STATEMENT. Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

EMOTIONAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D17. I feel sad	1	2	3	4	5	6	7
D18. I am proud of how I'm coping with my illness	1	2	3	4	5	6	7
D19. I am losing hope in the fight against my illness	1	2	3	4	5	6	7
D20. I feel nervous	1	2	3	4	5	6	7
D21. I worry about dying	1	2	3	4	5	6	7
D22. I worry that my condition will get worse	1	2	3	4	5	6	7

**(Center for Epidemiologic Studies Depression Scale (CES-D), NIMH)** Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week. During the past week (READ OPTION).

	Rarely or none of the time (less than 1 day )	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)	DK	RF
D23. I was bothered by things that usually don't bother me.	1	2	3	4	5	6
D24. I did not feel like eating; my appetite was poor.	1	2	3	4	5	6
D25. I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4	5	6
D26. I felt I was just as good as other people.	1	2	3	4	5	6
D27. I had trouble keeping my mind on what I was doing.	1	2	3	4	5	6
D28. I felt depressed.	1	2	3	4	5	6
D29. I felt that everything I did was an effort.	1	2	3	4	5	6
D30. I felt hopeful about the future.	1	2	3	4	5	6
D31. I thought my life had been a failure.	1	2	3	4	5	6
D32. I felt fearful.	1	2	3	4	5	6
D33. My sleep was restless.	1	2	3	4	5	6
D34. I was happy.	1	2	3	4	5	6
D35. I talked less than usual.	1	2	3	4	5	6
D36. I felt lonely.	1	2	3	4	5	6
D37. People were unfriendly.	1	2	3	4	5	6
D38. I enjoyed life.	1	2	3	4	5	6
D39. I had crying spells.	1	2	3	4	5	6
D40. I felt sad.	1	2	3	4	5	6
D41. I felt that people dislike me.	1	2	3	4	5	6
D42. I could not get "going."	1	2	3	4	5	6

I am now going to read statements that deal with your functional well-being. READ STATEMENT. Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

FUNCTIONAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D43. I am able to work (include work in home)	1	2	3	4	5	6	7
D44. My work (include work in home) is fulfilling	1	2	3	4	5	6	7
D45. I am able to enjoy life	1	2	3	4	5	6	7
D46. I have accepted my illness	1	2	3	4	5	6	7
D47. I am sleeping well	1	2	3	4	5	6	7
D48. I am enjoying the things I usually do for fun	1	2	3	4	5	6	7
D49. I am content with the quality of my life right now	1	2	3	4	5	6	7

The next statements deal with additional concerns about your quality of life. READ STATEMENT. Would you say that this is not at all true, a little bit true, somewhat true, quite a bit true, or very much true?

ADDITIONAL CONCERNS	Not at all	A little bit	Somewhat	Quite a bit	Very much	DK	RF
D50. I am losing weight	1	2	3	4	5	6	7
D51. I have a good appetite	1	2	3	4	5	6	7
D52. I have aches and pains that bother me	1	2	3	4	5	6	7
D53. I have certain areas of my body where I experience significant pain	1	2	3	4	5	6	7
D54. My pain keeps me from doing things I want to do	1	2	3	4	5	6	7
D55. I am satisfied with my present comfort level	1	2	3	4	5	6	7
D56. I am able to feel like a man	1	2	3	4	5	6	7
D57. I have trouble moving my bowels	1	2	3	4	5	6	7
D58. I have difficulty urinating	1	2	3	4	5	6	7
D59. I urinate more frequently than usual	1	2	3	4	5	6	7
D60. My problems with urinating limit activities	1	2	3	4	5	6	7
D61. I am able to have and keep an erection	1	2	3	4	5	6	7

**(Health ABC Study)** Now, I'd like to ask you about your ability to do physical activities. (READ STATEMENTS)

D62. Because of any health or physical problems, do you have any difficulty walking a quarter of a mile (about 2-3 blocks)?

- 1 Yes
- 2 No **(If no, go to question D62b)**
- 3 Does not do **(Go to question D64)**
- 4 **Refused**

D62a. How much difficulty do you have walking a quarter of a mile (2-3 blocks)?

- 1 Little **(Go to question D64)**
- 2 Some **(Go to question D64)**
- 3 A lot **(Go to question D64)**
- 4 Unable **(Go to question D64)**
- 5 Not applicable
- 6 **Refused**

D62b. How easy is it for you to walk a quarter of a mile (2-3 blocks)?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D63. Because of any health or physical problems, do you have any difficulty walking one mile (about 8-12 blocks)?

- 1 Yes **(If yes, go to question D66)**
- 2 No
- 3 Don't do **(Go to question D66)**
- 4 **Refused**

D63a. How easy is it for you to walk one mile (8-12 blocks)?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D64. Because of any health or physical problems, do you have any difficulty walking up 10 stairs (about 1 flight) without resting?

- 1 Yes
- 2 No (**If no, go to question D64b**)
- 3 Don't do (**Go to question D66**)
- 4
- 9 **Refused**

D64a. How much difficulty do you have walking up 10 stairs without resting?

- 1 Little (**Go to question D66**)
- 2 Some (**Go to question D66**)
- 3 A lot (**Go to question D66**)
- 4 Unable (**Go to question D66**)
- 5 Not applicable
- 6 **Refused**

D64b. How easy is it for you to walk up 10 stairs without resting?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D65. Because of any health or physical problems, do you have any difficulty walking up 20 stairs (about 2 flights)?

- 1 Yes (**If yes, go to question D66**)
- 2 No
- 3 Don't do (**Go to question D66**)
- 4 **Refused**

D65a. How easy is it for you to walk up 20 stairs without resting?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D66. Because of any health or physical problems, do you have any difficulty standing up from a chair without using your arms?

- 1 Yes
- 2 No (**If no, go to question D66b**)
- 3 Don't do (**Go to question D67**)
- 4 **Refused**

D66a. How much difficulty do you have standing up from a chair without using your arms?

- 1 Little (**Go to question D67**)
- 2 Some (**Go to question D67**)
- 3 A lot (**Go to question D67**)
- 4 Unable (**Go to question D67**)
- 5 Not applicable
- 6 **Refused**

D66b. How easy is it for you to stand up from a chair without using your arms?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 9 **Refused**

D67. Because of any health or physical problems, do you have any difficulty lifting or carrying something that weighs about 10 pounds (e.g., a small bag of groceries or an infant)?

- 1 Yes
- 2 No (**If no, go to question D67b**)
- 3 Don't do (**Go to question D69**)
- 4 **Refused**

D67a. How much difficulty do you have lifting or carrying something that weighs about 10 pounds?

- 1 Little (**Go to question D68**)
- 2 Some (**Go to question D68**)
- 3 A lot (**Go to question D68**)
- 4 Unable (**Go to question D68**)
- 5 Not applicable
- 6 **Refused**



D67b. How easy is it for you to lift or carry something that weighs around 10 pounds?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D68. Because of any health or physical problems, do you have any difficulty lifting or carrying something that weighs about 20 pounds (e.g., infant large bag of groceries)?

- 1 Yes (**If no, go to question D69**)
- 2 No
- 3 Don't do (**Go to question D69**)
- 4 **Refused**

D68a. How easy is it for you to lift or carry something that weighs about 20 pounds?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D69. Because of any health or physical problems, do you have any difficulty stooping, crouching, or kneeling (difficulty means problems getting down or getting up)?

- 1 Yes
- 2 No (**If no, go to question D69b**)
- 3 Don't do (**Go to question D70**)
- 4 **Refused**

D69a. How much difficulty do you have stooping, crouching, or kneeling?

- 1 Little (**Go to question D70**)
- 2 Some (**Go to question D70**)
- 3 A lot (**Go to question D70**)
- 4 Unable (**Go to question D70**)
- 5 Not applicable
- 6 **Refused**

D69b. How easy is it for you to stoop, crouch, or kneel?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D70. Because of any health or physical problems, do you have any difficulty pulling or pushing large objects like a living room chair?

- 1 Yes
- 2 No **(If no, go to question D70b)**
- 3 Don't do **(Go to question D71)**
- 4 **Refused**

D70a. How much difficulty do you have pulling or pushing large objects?

- 1 Little **(Go to question D71)**
- 2 Some **(Go to question D71)**
- 3 A lot **(Go to question D71)**
- 4 Unable **(Go to question D71)**
- 5 Not applicable
- 6 **Refused**

D70b. How easy is it for you to pull or push large objects like a living room chair?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D71. Because of any health or physical problems, do you have any difficulty doing heavy work around the house like vacuuming, shoveling snow, mowing or raking the lawn, gardening, or scrubbing windows, walls, or floors?

- 1 Yes
- 2 No **(If no, go to question D71b)**
- 3 Don't do **(Go to question D72)**
- 9 **Refused**

D71a. How much difficulty do you have doing heavy work around the house?

- 1 Little (**Go to question D72**)
- 2 Some (**Go to question D72**)
- 3 A lot (**Go to question D72**)
- 4 Unable (**Go to question D72**)
- 5 Not applicable
- 6 **Refused**

D71b. How easy is it for you to do heavy work around the house?

- 1 Very easy
- 2 Somewhat easy
- 3 Not easy
- 4 Not applicable
- 5 **Refused**

D72. Do you have any difficulty using your fingers to grasp or handle?

- 1 Yes
- 2 No (**If no, go to question D73**)
- 3 Don't do (**Go to question D73**)
- 4 **Refused**

D72a. How much difficulty do you have using your fingers to grasp or handle?

- 1 Little
- 2 Some
- 3 A lot
- 4 Unable
- 5 Not applicable
- 6 **Refused**

D73. Do you have any difficulty raising your hands over your head?

- 1 Yes
- 2 No (**End of section**)
- 3 Don't do (**End of section**)
- 4 **Refused**

D73a. How much difficulty do you have raising your hands over your head?

- 1 Little
- 2 Some
- 3 A lot
- 4 Unable
- 5 Not applicable
- 6 **Refused**

**E. RELIGIOSITY**

The next set of questions deal with your religious beliefs or practices as they relate to your prostate cancer diagnosis.

E1. Do you believe in God or a higher power or force?

- 1 Yes
- 2 No (skip to F)
- 3 **Don't Know**
- 4 **Refused**

E2. What religious faith do you belong to? **(If respondent says “Christian” or “Protestant”, probe for denomination.)**

1	Apostolic
2	Baptist
3	Catholic
4	Episcopalian
5	Holiness
6	Islamic
7	Jehovah's Witness
8	Jewish
9	Lutheran
10	Methodist
11	Muslim
12	Pentecostal
13	Presbyterian
14	Seventh Day Adventist
15	Other – specify _____
16	None
17	<b>Don't Know</b>
18	<b>Refused</b>

E3. Before your prostate cancer, how many times in an average month did you attend your place of worship (not counting weddings and funerals)? \_\_\_\_\_

E4. Since your diagnosis, how many times in an average month have you attended your place of worship (not counting weddings and funerals)? \_\_\_\_\_

E5. **(Janice Bowie)** Please indicate your level of agreement with each of the following statements. READ STATEMENT. Would you say that you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	DK	RF
E5a. Getting prostate cancer was punishment from God	1	2	3	4	5	6	7
E5b. Getting prostate cancer was a way to test my faith in God	1	2	3	4	5	6	7
E5c. Since being diagnosed with prostate cancer, my faith in God has gotten stronger	1	2	3	4	5	6	7
E5d. My faith in God has helped me cope with my disease	1	2	3	4	5	6	7
E5e. Whether or not I am cured will be decided by God only	1	2	3	4	5	6	7
E5f. If I pray enough, I will be cured	1	2	3	4	5	6	7
E5g. Since being diagnosed with prostate cancer, my faith in God has weakened	1	2	3	4	5	6	7

**(Brief RCOPE Items)** Think about how you try to understand and deal with major problems in your life. To what extent is each involved in the way you cope?

	A great deal	Quite a bit	Somewhat	Not at All	DK	RF
E6. I think about how my life is part of a larger spiritual force.	1	2	3	4	5	6
E7. I work together with God as partners to get through the hard times.	1	2	3	4	5	6
E8. I look to God for strength, support, and guidance in crises.	1	2	3	4	5	6
E9. I try to find the lesson from God in crises.	1	2	3	4	5	6
E10. I confess my sins and ask for God's forgiveness.	1	2	3	4	5	6
E11. I feel that stressful situations are God's way of punishing me for my sins or lack of spirituality.	1	2	3	4	5	6
E12. I wonder whether God has abandoned me.	1	2	3	4	5	6
E13. I try to make sense of the situation and decide what to do without relying on God.	1	2	3	4	5	6
E14. I question whether God really exists.	1	2	3	4	5	6
E15. I express anger at God for letting terrible things happen.	1	2	3	4	5	6

## F. SOCIAL SUPPORT

**(Rand Social Health)** The next few questions are about friends and social activities.

F1. About how many families in your neighborhood are you well enough acquainted with that you visit each other in your homes? \_\_\_\_\_

F2. About how many close friends do you have – people you feel at ease with and can talk with about what is on your mind? You may include relatives. \_\_\_\_\_

F3. Over a year's time, about how often do you get together with friends or relatives, like going out together or visiting in each other's homes?

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times a month
- 5 About once a month
- 6 5 to 10 times a year
- 7 Less than 5 times a year
- 8 Don't Know
- 9 Refused

F4. During the past month, about how often have you had friends over to your home? Do not count relatives.

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times in the past month
- 5 Once in the past month
- 6 Not at all in the past month
- 7 Don't Know
- 8 Refused

F5. About how often have you visited with friends at their homes in the past month?

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times in the past month
- 5 Once in the past month
- 6 Not at all in the past month
- 7 Don't Know
- 8 Refused

F6. About how often were you on the telephone with close friends or relatives during the past month?

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times in the past month
- 5 Once in the past month
- 6 Not at all in the past month
- 7 Don't Know
- 8 Refused

F7. About how often did you write a letter or send an email to a friend or relative during the past month?

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times in the past month
- 5 Once in the past month
- 6 Not at all in the past month
- 7 Don't Know
- 8 Refused

F8. In general, how well are you getting along with other people these days?

- 1 Better than usual
- 2 About the same
- 3 Not as well as usual
- 4 Don't Know
- 5 Refused

F9. How often have you attended a religious service during the past month?

- 1 Every day
- 2 More than once a week
- 3 Once a week
- 4 2 or 3 times in the past month
- 5 Once in the past month
- 6 Not at all in the past month
- 7 Don't Know
- 8 Refused



F10. About how many voluntary groups or organizations do you belong to – like church groups, clubs or lodges, parent groups, etc.? (“Voluntary” means because you want to.)

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F11. How active are you in the affairs of these groups or clubs you belong to?

- 1 Very active, attend most meetings
- 2 Fairly active, attend fairly often
- 3 Not very active, belong but hardly ever go
- 4 Varies, depends on club
- 5 Don't Know
- 6 Refused

F12. Are you currently in a committed relationship?

- 1 Yes
- 2 No (End of Section)
- 3 Don't Know
- 4 Refused



F13k. Do you and your mate engage in outside interests together?

- 1 All of them
- 2 Some of them
- 3 Very few of them
- 4 None of them
- 5 Don't Know
- 6 Refused

F13L\_1. In leisure time, do you generally prefer: to be “on the go” \_\_\_\_, to stay home \_\_\_\_?

- 1 On the go
- 2 To stay home
- 3 Don't Know
- 4 Refused

F13L\_2. Does your mate generally prefer: to be “on the go” \_\_\_\_, to stay home \_\_\_\_?

- 1 On the go
- 2 To stay home
- 3 Don't Know
- 4 Refused

Does your mate generally prefer: to be “on the go” \_\_\_\_, to stay home \_\_\_\_?

- 1 Both responses are ‘stay home’
- 2 Both responses are ‘on the go’
- 3 Responses are in disagreement
- 4 Don't Know
- 5 Refused

F13m. Do you ever wish you had not gotten involved in this relationship?

- 1 Frequently
- 2 Occasionally
- 3 Rarely
- 4 Never
- 5 Don't Know
- 6 Refused

F13n. If you had your life to live over, do you think that you would:

- 1 Be in a committed relationship with the same person
- 2 Not be in a committed relationship at all
- 3 Be in a committed relationship with a different person
- 4 Don't Know
- 5 Refused

F13o. Do you confide in your mate?

- 1 Almost never
- 2 Rarely
- 3 In most things
- 4 In everything
- 5 Don't Know
- 6 Refused

## G. SATISFACTION WITH CARE/ATTITUDES TOWARD CARE

Now I have a few questions about your satisfaction with your health care.

G1. (**Commonwealth Survey**) How would you rate the doctor you saw most often for treatment of your prostate cancer on the job he or she did (READ OPTION)? Would you say the doctor did an excellent, good, fair, or poor job?

	Excellent	Good	Fair	Poor	DK	RF
G1a. Providing you with good healthcare overall	1	2	3	4	5	6
G1b. Treating you with dignity and respect	1	2	3	4	5	6
G1c. Making sure you understood what you'd been told about your medical problems and medication	1	2	3	4	5	6
G1d. Listening to your health concerns and taking them seriously	1	2	3	4	5	6
G1e. Being available either by phone or in person	1	2	3	4	5	6

**G2. (LaVeist and Nickerson – Medical Mistrust Inventory)** I am going to read some statements about various beliefs and attitudes that some people hold about hospitals and other healthcare facilities. Please tell me how much you agree or disagree with each statement based on your beliefs about hospitals in general and not about any specific hospital, doctor, nurse, or other staff with whom you've had contact. READ STATEMENT. Would you say you strongly disagree, disagree, agree, or strongly agree?

	Strongly Disagree	Disagree	Agree	Strongly Agree	DK	RF
G2a. Patients have sometimes been deceived or misled at hospitals.	1	2	3	4	5	6
G2b. Hospitals have sometimes done harmful experiments on patients without their knowledge.	1	2	3	4	5	6
G2c. Mistakes are common in healthcare organizations.	1	2	3	4	5	6
G2d. When dealing with hospitals, one better be cautious.	1	2	3	4	5	6
G2e. Hospitals don't always keep your information totally private.	1	2	3	4	5	6
G2f. Sometimes I wonder if hospital's staffs really know what they are doing.	1	2	3	4	5	6
G2g. When hospitals make mistakes they usually cover it up.	1	2	3	4	5	6

**G3. (Nickerson and LaVeist – Discriminatory Care Index – Short Form)** I am going to read you some statements. Please tell me how much you agree or disagree with each statement. READ STATEMENT. Would you say you strongly disagree, disagree, agree, or strongly agree?

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree	DK	RF
G3a. Doctors treat African-Americans and white people the same	1	2	3	4	5	6	7
G3b. Racial discrimination in a doctor's office is common	1	2	3	4	5	6	7
G3c. In most hospitals, African-Americans and whites receive the same kind of care	1	2	3	4	5	6	7
G3d. African-Americans can receive the care they want as equally as white people can	1	2	3	4	5	6	7

## H. DEMOGRAPHICS

Now I have some questions about your background.

H1. What is your date of birth?    \_\_\_ / \_\_\_ / \_\_\_

H2. In what state were you were born? \_\_\_\_\_

H3. Have you changed your name at any point in your life?

- 1 Yes
- 2 No (**Go to H4**)
- 3 **Don't Know**
- 4 **Refused**

H3a. **If yes**, what was your name at birth? \_\_\_\_\_

H4. What is your current marital status?

- 1 Never married
- 2 Married
- 3 Living together but, not married
- 4 Divorced/Separated
- 5 Widowed
- 6 **Don't Know**
- 7 **Refused**

H5. What is the **highest** educational level that you have completed?

- 1 Less than 8<sup>th</sup> grade
- 2 Between 8<sup>th</sup> and 11<sup>th</sup> grade
- 3 High school graduate/GED
- 4 Some college
- 5 Associates degree
- 6 Bachelors degree
- 7 Masters degree
- 8 Doctoral degree
- 9 **Don't Know**
- 10 **Refused**

H6. Do you have any sons over the age of 34?

- 1 Yes
- 2 No (**Skip to question H12**)
- 3 **Don't Know**
- 4 **Refused**

H6a. **If Yes**, how many? \_\_\_\_\_

H7. Have any of them been diagnosed with cancer?

- 1 Yes
- 2 No
- 3 **Don't Know**
- 4 **Refused**

H7a **If Yes**, who? \_\_\_\_\_

**Note to interviewer: If respondent has sons aged 35 or over who has not been diagnosed with cancer, read the following. We would like to collect the information on the oldest biological son who has not been diagnosed with prostate cancer.**

We would like your permission to contact your sons at some future point in this study to ask about their screening behaviors for prostate cancer. We will not divulge the nature of your condition to your son when we contact them. Please provide your son's name, address, and phone number. We are interested in your oldest biological son age 35 or above that has NOT been diagnosed with prostate cancer.

H8a. Name \_\_\_\_\_

H8b. Address \_\_\_\_\_

H8c. City \_\_\_\_\_

H8d. State \_\_\_\_\_

H8e. Zip \_\_\_\_\_

H8f. Phone Number (\_\_\_\_) \_\_\_\_\_

H9. How would you rate your relationship with this son?

- 1 Not close
- 2 Somewhat close
- 3 Close
- 4 Very Close
- 5 Don't Know
- 6 Refused

H10. About how often do you speak to this son in person or on the telephone in a typical month?

- 1 Every day
- 2 Several days a week
- 3 About once a week
- 4 2 or 3 times a month
- 5 Once a month
- 6 Not at all
- 7 Don't Know
- 8 Refused

H11. Have you told this son that you have been diagnosed with prostate cancer?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

We will not inform your son the nature of your condition when we contact them. We will simply state that we are conducting a study about men's knowledge, beliefs, and attitudes concerning prostate cancer and preventative measures.



Now, I have a question about different kinds of health insurance, including those provided by the government. As I read each of the following health plans, please tell me whether or not you are covered by any of them. Are you covered by (READ OPTIONS)?

	No	Yes	DK	RF
H12a. private health insurance (such as through a job)	1	2	3	4
H12b. Medicare, a government plan that pays health care bills for people over age 65 and people who are disabled	1	2	3	4
H12c. Medicaid or public aid (also called medical assistance)	1	2	3	4
H12d. CHAMPUS/CHAMPVA	1	2	3	4

H13. Was there any time in the past two years when you were completely without any health plan or insurance coverage?

- 1 Yes
- 2 No
- 3 Don't Know
- 4 Refused

H14. How would you describe your current employment status?

- 1 Working full time
- 2 Working part time
- 3 Retired
- 4 Attending school
- 5 Maintaining the home
- 6 Unemployed
- 7 Disabled
- 8 Other – specify \_\_\_\_\_
- 9 Don't Know
- 10 Refused

H15. To get a picture of people’s financial situation, we need to know the general range of income of all people we interview. Now, think about your household’s total income from all sources, before taxes, including wages, salaries, and any other income. About how much did your household receive in the last 12 months?

\$ \_\_\_\_\_

**If the answer is “don’t know” or respondent refuses to answer, continue with the following. If the above question is answered, go to H17.**

H16. Maybe if I give you some income ranges it would help. When I say the income range that matches your total household income for last year, please tell me.

- 1 Less than \$10,000
- 2 \$10,000 - \$19,999
- 3 \$20,000 - \$34,999
- 4 \$35,000 - \$49,999
- 5 \$50,000 - \$64,999
- 6 \$65,000 - \$79,999
- 7 \$80,000 - \$99,999
- 8 \$100,000 or more
- 9 Don’t Know
- 10 Refused

**If H16 is answered, go to question H17. If not, continue with the following.**

H16a. Can you tell me if your household income was more or less than \$10,000 in the past 12 months?

- 1 Less than \$10,000 (**go to H17**)
- 2 More than \$10,000
- 3 Don’t Know
- 4 Refused

H16b. Can you tell me if your household income was more or less than \$35,000 in the past 12 months?

- 1 Less than \$35,000 (**go to H17**)
- 2 More than \$35,000
- 3 Don’t Know
- 4 Refused

H16c. Can you tell me if your household income was more or less than \$60,000 in the past 12 months?

- 1 Less than \$60,000
- 2 More than \$60,000
- 3 Don't Know
- 4 Refused

H17. How much of that income did you yourself bring in?

\$ \_\_\_\_\_

**The next set of questions deal with your resources.**

H18. Does anyone in the family own a car, truck, recreational vehicle, motorcycle, or boat?

- 1 Yes
- 2 No (Go to H20)
- 3 Don't Know
- 4 Refused

H19. Altogether, how much are all the cars or trucks in the family worth?

- 1 Less than \$2,000
- 2 \$2,000-\$4,999
- 3 \$5,000-\$9,999
- 4 \$10,000-\$19,999
- 5 \$20,000-\$49,999
- 6 \$50,000-\$99,999
- 7 \$100,000 or more
- 8 Don't Know
- 9 Refused

H20. Is the house in which you live owned or being bought by you or someone in the household?

- 1 Yes
- 2 No (Go to H23)
- 3 Don't Know
- 4 Refused

H21. Is the house in which you live fully paid for or do you still owe something?

- 1 Paid off
- 2 Still owe something
- 3 Don't Know
- 4 Refused

H22. If you were to sell the house and pay off any mortgage that still exists, about how much money would you or your family get?

- 1 Less than \$25,000
- 2 \$25,000-\$49,999
- 3 \$50,000-\$99,999
- 4 \$100,000-\$199,999
- 5 \$200,000-\$499,999
- 6 \$500,000 or more
- 7 Don't Know
- 8 Refused

H23. Do you or does anyone in your family own other property, such as another home, rental property or land?

- 1 Yes
- 2 No (**Go to H25**)
- 3 Don't Know
- 4 Refused

H24. If you or your family sold this other property now and paid off any debts on it, about how much would you or your family get?

- 1 Less than \$25,000
- 2 \$25,000-\$49,999
- 3 \$50,000-\$99,999
- 4 \$100,000-\$199,999
- 5 \$200,000-\$499,999
- 6 \$500,000 or more
- 7 Don't Know
- 8 Refused

H25. Do you or does your family own part or all of a business, farm, or professional practice?

- 1 Yes
- 2 No (**Go to H27**)
- 3 Don't Know
- 4 Refused

H26. If you or your family sold this business, farm, or professional practice now and paid off any debts on it, about how much would you or your family get?

- 1 Less than \$25,000
- 2 \$25,000-\$49,999
- 3 \$50,000-\$99,999
- 4 \$100,000-\$199,999
- 5 \$200,000-\$499,999
- 6 \$500,000 or more
- 7 Don't Know
- 8 Refused

H27. Do you or does your family have any other savings, assets, or property including stocks, bonds, and certificates of deposit (CDs)?

- 1 Yes
- 2 No (**Go to next section**)
- 3 Don't Know
- 4 Refused

H28. Altogether, what is the present value of these other savings, assets or property?

- 1 Less than \$25,000
- 2 \$25,000-\$49,999
- 3 \$50,000-\$99,999
- 4 \$100,000-\$199,999
- 5 \$200,000-\$499,999
- 6 \$500,000 or more
- 7 Don't Know
- 8 Refused



Thank you for participating in this study. We appreciate the time you gave us for this interview and your willingness to answer our questions.

The long-term goal of this study is to develop programs and procedures to improve the quality of life of men who have prostate cancer, and we may need to develop future studies that will help us to learn more about this disease. May we contact you to tell you about future studies you may want to participate in?

1      Yes                      0      No