

Award Number: W81XWH-04-1-0117

TITLE: The Meaning of Incontinence and Impotence for Low Income African-American and Latino Men with Prostate Cancer.

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REPORT DATE: December 2005

TYPE OF REPORT: Annual

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*

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. **PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.**

<b>1. REPORT DATE</b> 01-12-2005		<b>2. REPORT TYPE</b> Annual		<b>3. DATES COVERED</b> 1 Dec 2004 – 30 Nov 2005	
<b>4. TITLE AND SUBTITLE</b>  The Meaning of Incontinence and Impotence for Low Income African-American and Latino Men with Prostate Cancer.				<b>5a. CONTRACT NUMBER</b>	
				<b>5b. GRANT NUMBER</b> W81XWH-04-1-0117	
				<b>5c. PROGRAM ELEMENT NUMBER</b>	
<b>6. AUTHOR(S)</b> Sally L. Maliski, R.N., Ph.D. Mark S. Litwin, M.D., MPH  Email: smaliski@sonnet.ucla.edu				<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>  University of California, Los Angeles Los Angeles, CA 90024				<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>  The purpose of this project is to describe the meaning of prostate cancer treatment-related incontinence and impotence for low income African American and Latino men. Preliminary common categories between the Latino and African American men included erectile dysfunction and incontinence were the price that had to be paid to cure cancer, trusting God as a means of coping, context of incontinence as determinant of its acceptability (e.g. if due to illness, acceptable; if due to drunkenness, not acceptable), and ambivalence toward role of erectile function in masculine identity and transitional masculinity.					
<b>15. SUBJECT TERMS</b> Prostate cancer, low income, uninsured, minority, African American, Latino, men, qualitative					
<b>16. SECURITY CLASSIFICATION OF:</b>			<b>17. LIMITATION OF ABSTRACT</b>	<b>18. NUMBER OF PAGES</b>	<b>19a. NAME OF RESPONSIBLE PERSON</b>
<b>a. REPORT</b>	<b>b. ABSTRACT</b>	<b>c. THIS PAGE</b>			USAMRMC
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## Table of Contents

Cover.....	1
SF 298.....	2
Table of Contents.....	3
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	7
Reportable Outcomes.....	8
Conclusions.....	9
References.....	
Appendices.....	10

## I. INTRODUCTION

Incontinence and impotence are potential side effects of the most common treatments for prostate cancer. Both incontinence and impotence can occur after surgery or radiation therapy, whereas impotence along with loss of libido can occur with hormone therapy; these outcomes can adversely affect men's quality of life. Discussing these outcomes is necessary to assist men with prostate cancer in making treatment decisions and coping with these symptoms when they occur. The primary purpose of this project is to describe the meaning of prostate cancer treatment related incontinence and impotence for low income African American and Latino men. This will begin the process of discovering influential variables that will support development of culturally appropriate educational material. The Principal Investigator (PI) hypothesizes that cultural, ethnic, religious, educational, and socioeconomic differences affect the viewpoint of these groups. In particular, cultural concepts such as machismo, stoicism, and fatalism may influence patients' perceptions. The research strategy being used is qualitative descriptive with applied ethnographic and phenomenological overtones.

## II. BODY

Task 1. To elicit African American and Latino men's perspectives on prostate cancer treatment- related incontinence and impotence. (Months 1-19)

- a. Identify and recruit potential participants (Months 1-15)
- b. Conduct initial interviews (Months 2-16)
- c. Conduct second interviews (Months 5-19)

Accomplishments: We have been able to enroll a total of 15 Latino men and 20 African American men. A total of 13 initial interviews and 1 follow-up interview have been completed with African American men and 9 initial interviews have been completed with Latino men. However, because of several unanticipated circumstances we were not able to enroll and interview the targeted number of men for this period, particularly African American men. There was an enrollment suspension of 8 months in the IMPACT program from which we were recruiting. Because IMPACT's enrollment is over 50% Latino, we were able to recruit enough Latino men despite the enrollment suspension, but because the number of African Americans is much smaller, we were not able to meet our goal for this group. To compensate, we obtained IRB approval to recruit African American participants at the West Los Angeles Veterans Administration Medical Center and through ethnic-specific newspapers allowing us to increase our recruitment pool. We are hopeful that this will allow us to approach of target recruitment goal.

Task 2. To identify themes emerging from the interview data (Months 2-31)

- a. Verbatim transcription of interview tapes (Months 2-24)
- b. Translate Spanish transcripts (Months 2-26)
- c. Prepare transcripts for N Vivo entry (Months 3-28)
- d. Enter data into N Vivo (Months 3-28)
- e. Line-by-line coding of data and constant comparative technique (Months 3-28)
- f. Identify themes related to beliefs about urinary, sexual, and bowel function, and masculinity (Months 4-30)
- g. Verify themes with participants (Months 5-31)

Accomplishments: Transcription of 30 initial interviews and 0 second interviews has been completed. Translation of 23 of the initial Latino transcripts has been completed. NVivo has not proven to be as useful as anticipated with managing the data. Therefore, data management and analysis is being conducted using Word documents of the transcripts. Line-by-line coding is being accomplished with color-coding and highlighting for the documents. From this codes are copied and pasted in category documents and the PI is maintaining a log of all analysis decisions. Working with the study team and a doctoral student in nursing, initial themes related to urinary and sexual issues and masculinity have been identified. Emergent themes and categories

are being verified and modified where needed with 6 participants in the second interviews.

Task 3. To describe concepts of meaning and their underlying structure  
(Months 20-36)

- a. Cluster themes into conceptual categories (Months 20-34)
- b. Compare categories across interview transcripts (Months 20-34)
- c. Identify clusters related to incontinence and impotence (Months 20-34)
- d. Develop narratives describing the meanings of incontinence and impotence as it has emerged from the data along with the underlying cultural beliefs (Months 30-36)

Accomplishments: Analysis of the data is ongoing using close and multiple readings, line-by-line coding, development of categories and constant comparison within and between transcripts. Initial themes and categories related to incontinence and erectile dysfunction can be found in Appendix 1 which provides posters and abstracts of presentation of findings and a manuscript that was nominated for the Oncology Nursing Society's 2005 Excellence in Cancer Nursing Award. Currently we are working on deepening the analysis of two prominent themes that have emerged from the data. One is on masculine identity shifts and the other is related to the functions of spirituality in living with prostate cancer treatment-related symptoms among low-income Latino men. We will continue this in-depth analysis to fully describe the processes by which the men participating in this study make meaning of their treatment-related symptoms within the context of their social and cultural backgrounds.

### III. KEY RESEARCH ACCOMPLISHMENTS

#### Findings

Preliminary common categories between the Latino and African American men included:

- erectile dysfunction and incontinence were the price that had to be paid to cure cancer,
- context of incontinence as determinant of its acceptability (e.g. if due to illness, acceptable; if due to drunkenness, not acceptable), and
- ambivalence toward role of erectile function in masculine identity

Both Latino and African American remain hopeful that erectile function will return, captured under the code of “hopeful waiting”, men also talk about ambivalence relative to important components of masculinity, sexual function vs. caring for family. Contextual masculinity is seen in the transcripts when men tell about conversing with other men about women and sex as a man able to have intercourse and then when talking about the things that are important for a man to do as taking care of one’s family and providing support. We are continuing to explore how age and occupation may influence perception of masculinity within the context for prostate cancer treatment-related erectile dysfunction and for the African American men, how social movements such as the Million Man March may provide an additional influence for this group.

#### IV. REPORTABLE OUTCOMES:

- Abstracts, manuscripts, and presentations: Please see Appendix 1.
- Based on work from this project we have applied for and received intramural funding to investigate symptom clusters related to prostate cancer treatment among low-income Latino men and the impact of prostate cancer treatment-related symptoms on low-income Latino couples.



## V. CONCLUSION:

Little is known about the impact of incontinence and impotence from prostate cancer treatment on the lives of low-income men from other cultural backgrounds nor how cultural beliefs surrounding urinary, and sexual function and the definitions of masculinity influence how these symptoms are perceived. Understanding what incontinence and erectile dysfunction mean as they relate to beliefs and attitudes toward urinary and sexual function is critical to understanding how prostate cancer treatment decisions may be influenced and how best to discuss these symptoms and intervene with low-income African American and Latino men. The results of this study are laying the foundation for the development of culturally appropriate educational and will lay a foundation from culturally appropriate symptom management interventions for this population.

## Appendices

1. Professional Presentations
  - a. 2005 Biennial Cancer Nursing Research Conference Poster Presentation
  - b. Oncology Nursing Society's Excellence in Cancer Nursing Award nominated manuscript



# The Meaning of Prostate Cancer Treatment-Related Incontinence and Impotence for Low-Income Latino Men

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## Preliminary Results from 6 Initial Interviews with Latino Men

### Introduction

- Prostate cancer most common new cancer diagnosis in men
- Incontinence and impotence common with most treatments
- Latino & low-income men experience more negative outcomes than white men
- Little known about how cultural beliefs influence perception of incontinence and impotence
- IMPACT (Improving Access, Counseling, and Treatment for Californians with prostate cancer) experience
- Objective
  - To describe the meaning of prostate cancer treatment-related incontinence and impotence for low-income Latino men

### Methods

- Ethnomethodology
- Semi-structured interviews
- Bilingual male interviewer
- Sample drawn from a public assistance program, IMPACT:
- Income < 200% of Federal Poverty Level
- Uninsured
- Biopsy proven prostate cancer
- Institutional Review Board approval obtained
- Line-by-line coding
- Constant comparative process

CODE	QUOTE EXAMPLE
Putting pre-diagnosis events in order/ Creating closure	"And that's the way it was"
Getting cancer out as overriding priority	"I wanted it out so the problem wouldn't come back."
Impotence as the price paid to get cancer out	"It is more important to be alive than to have sex."
Acceptance	"You just have to accept what comes your way."
Faith in God	"If you're well with God, everything else will be resolved somehow over time."
Faith in the doctor	"I had the surgery because that was how my doctor said he could get it all out."
Impotence threatens sense of masculine identity	"You don't feel as much of a man as you were before." "It feels bad not being able to fulfill your wife as a man."
Being a man	"Being a man means taking care of your kids and setting a good example."
Incontinence as temporary/Impotence more meaningful problem	"Don't give much importance to incontinence 'cause it goes away, but the impotence stays."

### Conclusions

- Work in progress
- Incontinence and impotence may be price paid for getting rid of the cancer
- Being able to trust and have faith in God and/or doctor may be a means of coping
- Impotence is more meaningful issue
- Ambivalence in role of erectile function in masculine identity
- Process of reframing meaning of masculinity and being a man may be emerging

### Limitations

- Still preliminary phase
- All data not collected and analyzed

### Next Steps

- Complete analysis process
- Verify with participants
- Identify structure of meaning
- Compare with low-income African American men
- Create narrative describing meanings of prostate cancer treatment-related incontinence and impotence for low-income Latino men

**The Meaning of Prostate Cancer Treatment-Related Incontinence and Impotence Among  
Low-Income African American Men**

(Nominated for Oncology Nursing Society Excellence in Cancer Nursing Research Award)

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## **Abstract**

*Purpose/Objectives:* To describe the meaning ascribed to prostate cancer treatment-related incontinence and impotence among low-income African American men.

*Design/Research Approach:* Ethnomethodology that combines ethnographic perspective (cultural) with phenomenologic techniques (meaning) to develop an in-depth understanding of incontinence and impotence.

*Setting:* Public assistance program providing free prostate cancer treatment to low-income uninsured and underinsured men within their home communities throughout California and the Greater Los Angeles Veterans Affairs Medical Center.

*Participants:* Six low-income African American men who have experienced prostate cancer treatment-related incontinence and/or impotence.

*Methods/Methodologic Approach:* Two personal interviews by a trained African American male interviewer using a semi-structured interview guide.

*Main Research Variables:* The meaning attributed to prostate cancer treatment-related incontinence and impotence

*Findings:* Diagnosis of cancer viewed as death and choice was between treatment and life and sex and life. They minimized the importance of sex, stating that it was not necessary to be a man, yet saw erectile dysfunction as a loss of a natural part of being a man.

*Conclusions:* The elements of the meaning for these men emerged as impotence and incontinence were the price for continuance of life, a reframing of masculinity, and continuing hopefulness.

*Implications for Nursing/Interpretation:* Oncology nurses can be aware that low-income African American men may not feel empowered to participate in treatment decision-making. By being cognizant of this and the possibility that incontinence and impotence are viewed as the price they need to pay for treatment, nurses can not only provide information on prostate cancer and its treatment, but also coach men on how to participate more actively in their own care. Oncology nurses can contribute by facilitating men's reframing of their masculine identity.

**Key Points:**

1. Incontinence and impotence may be viewed as the price paid to treat prostate cancer.
2. Cancer is equated with death and treatment with living.
3. Men may need to reframe masculinity when experiencing prostate cancer treatment-related impotence.

## **The Meaning of Prostate Cancer Treatment-Related Incontinence and Impotence Among Low-Income African American Men**

Prostate cancer is the most common new cancer diagnosis in men and is second only to lung cancer in cause of cancer deaths among men (Arai, Okubo et al. 1999; ACS 2004). An estimated 220,900 new cases of prostate cancer will be diagnosed in 2003. African American men still bear a disproportionate burden, with significantly higher incidence rates for prostate cancer (ACS, 2004 #50) and death rates than among other ethnicities (MMWR 2002), even though a recent study suggested that distributions of stage, grade, and prostate specific antigen (PSA) have become more favorable for African Americans (Ashesh, Vaida et al. 2001).

Incontinence and impotence are potential side effects of the most common treatments for prostate cancer. Both incontinence and impotence can occur after surgery or radiation therapy, while impotence along with loss of libido can occur with hormone therapy; all of which can have effects on men's quality of life (Bokhour, Clark et al. 2001; Litwin, Lubeck et al. 2001) (Lubeck, 2001 #2). Thus, discussing incontinence and impotence is necessary in order to assist men with prostate cancer in becoming informed participants in making treatment decisions and managing and coping with these symptoms when they occur. How best to do this is not clear.

Additionally, incontinence and impotence are sensitive topics. Consideration of the surrounding issues touches at the core of masculine identity for many men (Bokhour, 2001 #4). Previous studies have considered the impact that impotence and/or incontinence may have on quality of life (Litwin 1995; Yarbrow and Ferrans 1998; Clark, Rieker et al. 1999; McCammon, Kolm et al. 1999; Kao, Cruess et al. 2000; Eton, Lepore et al. 2001; Litwin, Lubeck et al. 2001; Lubeck, Grossfeld et al. 2001). In general, findings indicate the general quality of life as measured was not significantly diminished, even in the presence of these symptoms. Some

investigators have speculated that men adapt to these symptoms because of good overall function or because of a determination to live with the symptoms (Fowler, 1995 #14). Bacon and colleagues (Bacon, Giovannucci et al. 2001; Bacon and Giovannucci 2002) compared the impact of various localized prostate cancer treatment on general, cancer specific and prostate cancer specific quality of life domains. Their findings indicated that there were significant differences in all quality of life measures by treatment modality with the largest differences occurring in sexual, urinary, and bowel symptoms (Bacon, 2001 #24) highlighting the importance of these issues for men with prostate cancer. Jenkins and colleagues concluded that African American men may be more at risk for distress when treatment causes sexual dysfunction (Jenkins, Schover et al. 2004). A few studies have qualitatively explored the impact of postprostatectomy incontinence and/or impotence on couples (Heyman and Rosner 1996; Pickett, Cooley et al. 1996; Maliski, Heilemann et al. 2001). These studies reveal strategies used to deal with the symptoms such as using incontinence aids to control urine leakage, reframing the symptoms within the context of having had their prostate cancer removed, and minimizing the impact of impotence in light of their current stage in life. However, participants in these studies were predominantly white, middle to upper income, well-educated men. Little is known about the impact of incontinence and impotence from prostate cancer treatment on the lives of low-income men from other cultural backgrounds nor how cultural beliefs surrounding urinary, bowel, and sexual function and the definitions of masculinity influence how these symptoms are perceived. Even less known is how religious beliefs and spirituality as part of the cultural milieu may play a role in the meaning of these symptoms. Understanding what incontinence and impotence mean as they relate to beliefs and attitudes toward urinary, sexual, and bowel function is critical to



understanding how prostate cancer treatment decisions may be influenced and how best to discuss these symptoms with low-income African American men.

Our involvement with the IMPACT (Improving Access, Counseling and Treatment for Californians with prostate cancer) program, a California state-funded program providing prostate cancer treatment to uninsured men below 200% of the federal poverty level, has made clear the need to understand what incontinence and impotence mean for these men in order to create culturally sensitive education approaches, provide relevant counseling, and assist men in managing and adapting to these symptoms in ways that are consistent with their beliefs. Therefore the purpose of this study was to describe the meanings attributed to prostate cancer treatment-related incontinence and impotence by low-income African American men who have experienced these symptoms.

## **METHODS**

For areas about which little is known, qualitative techniques are ideal to explore the phenomena of interest in detail, laying the foundation for future studies (Creswell 1998). Ethnographic approaches illuminate cultural influence (Denzin and Lincoln 2000) and phenomenology focuses on meaning (Denzin and Lincoln 2000). Thus, the combination of these two approaches, sometimes referred to as ethnomethodology (Creswell 1998), was used to yield both meanings and cultural underpinnings. Within this overall methodology, a psychological phenomenological approach will guide the development of the interview scripts, the approach to analysis, and the interpretation of the data. This approach directs the investigator to focus on the meaning an experience has for those who have had it and who can provide a comprehensive description of it (Moustakis 1994). In drawing on ethnography, there is a recognition that meaning is made within the context of culture and is influenced by it (Creswell 1998).

## *Participants*

After receiving IRB approval, participants for this study were recruited from enrollees in the IMPACT program. We report here the findings from the African American men. Criterion-based sampling (Creswell 1998) was used to enroll men who were African American or Latino and had experienced incontinence and/or impotence related to their prostate cancer treatment. Treatment and clinical symptoms were determined from the IMPACT electronic record. For men with early stage disease, IMPACT provides radical prostatectomy, radiation therapy, and watchful waiting. We did not include men being followed under watchful waiting, because they would not have treat-related incontinence and impotence. When there is biochemical recurrence and/or metastasis, men are likely to receive hormone therapy as primary treatment, alone or in combination with radiation therapy. IMPACT also provides hormone therapy. Participants were low-income (below 200% of the federal poverty level) and uninsured, both eligibility requirements of the IMPACT program. Potential participants were identified as African American as indicated in the IMPACT record. Also, because IMPACT covers the entire state of California, participants were from different regions of the state.

Inclusion criteria were being 9-12 months postprostatectomy, 9-12 months post-radiation therapy, or 4-6 months after 1<sup>st</sup> hormone therapy injection; having experienced incontinence and/or impotence; self-identified African American ethnicity ; and willingness to articulate experiences. The timeframes were chosen to encompass a period during which men are most likely to have developed the treatment-related symptoms. Based on previous experience interviewing men about prostate cancer treatment-related incontinence and impotence (Maliski, Heilemann et al. 2001; Maliski, Heilemann et al. 2002), men have been willing to articulate their experience with these symptoms. Also, based on results of our preliminary work, we chose to

use male interviewers who were ethnicity- and language-matched because this was acceptable to all men responding to the questionnaire

### *Sample Size*

Five to twenty-five participants are generally considered an adequate sample size for phenomenological investigations because of the extensiveness of the interview process (Creswell 1998). We interviewed 6 African American men for this analysis.

### *Procedure*

After potential participants were identified, IMPACT clinical staff requested permission for the investigator to contact the patient. The study coordinator then contacted those giving permission, explained the study, and requested verbal consent. If consent was given, ethnicity was verified and a written consent form was mailed with an addressed, postage-paid return envelope. During this call, a time and place for the first interview was arranged. Participants were given a choice of being interviewed at IMPACT offices, at their home, or by telephone. An appointment card was mailed to the participant listing the appointment date and time and providing directions to the interview site. The study coordinator called the participant the day before the scheduled interview to confirm the appointment. If a participant's consent had not been received by the first interview date, the interviewer brought the form, answered questions, and obtained written, informed consent before proceeding with the interview.

Two interviews were conducted with each participant and audiotaped. The first was an intensive, topic-guided, open-ended discussion of the participant's experience with incontinence and impotence related to his prostate cancer treatment and what this meant to him. Interviews lasted from 1-2 hours and were conducted in-person or by telephone, based on the participant's

preference. The second interview was confirmatory and followed-up on questions arising from the previous interview. These interviews were conducted by telephone and lasted 30-60 minutes.

All interviewers were trained in qualitative interviewing techniques and timeline procedure and were supervised by the principal investigator. After this, the principal investigator and study coordinator listened to all audiotapes and had monthly contact with the interviewers to ensure that interviews were conducted according to the guide. Interviewers maintained a log recording their observations of the interview environment, participant's appearance and body language, the interviewer's level of comfort with the interview, reflections on the interview, and the interviewer's thoughts and feelings after each interview.

Before starting the interview, the interviewer reviewed the study and provided an opportunity for questions. The interviewer then let the participant know that the audiotape was being started and asked the man to talk about his experience with prostate cancer. A timeline procedure in which the interviewer provides the participant with a graphic that shows a line with points marked for diagnosis, treatment, now and future, was used to facilitate this discussion. This gave the participant and the interviewer a point of reference during the interview and also allowed the participant to focus on the paper if he is uncomfortable making eye contact during some of the discussion at in-person interviews. The interviewer oriented the participant to a point on the timeline, such the time of the diagnosis. The man was asked to talk about his experiences surrounding this time including what he knew about prostate cancer, what he was told, and his reactions and expectations. He was asked to expand on his thoughts and feelings about hearing of the possibility of incontinence and impotence, what that meant to him at that time, and how that did or did not influence his treatment choice. The interviewer asked about pre-treatment continence and erectile function. Next on the timeline was the initiation of

treatment. The participant asked to elaborate on his thoughts and feelings and how or if incontinence and/or impotence were in his thoughts at this time. The next point was the present. The interviewer asked the participant to fill in the events between treatment and the present. He was asked to talk about his experiences with incontinence and/or impotence and what that has meant to him, how it has made him feel, and how he as dealt with it. The interviewer asked the participant to explain what being a man means to him while probing to elicit cultural underpinnings of those meanings. The participant was asked to talk about what he has been taught and believes about urinary function/dysfunction, bowel function/dysfunction and sexual function/dysfunction, again with probes to elicit any cultural underpinnings. Finally, the participant was asked to talk about what he saw happening next, relative to his prostate cancer in general and his incontinence and/or impotence in specific. The interview ended by giving the participant an opportunity to talk about anything else that he felt was important for us to know. The interviewer reminded the participant that he would be called to schedule a second interview to be conducted by telephone. The participant was mailed a financial incentive following the first interview.

During the second interview, the interviewer asked if emerging themes were consistent with the subject's experience and to expand on how they were or were not. Questions that developed from the concurrent data analysis were asked as they related to understanding the meaning of incontinence and impotence for the participants. The participant was mailed a small financial incentive after this interview.

All interviews were audiotaped with the participant's permission and then transcribed verbatim. Transcripts were reviewed by the interviewer and study coordinator with the audiotapes for accuracy of transcription.

## *Analysis*

Data analysis began with the first interview and continued concurrently with data collection. This will allowed confirmation of emerging themes by participants in second interviews as well as more in-depth exploration of emerging concepts. A constant comparative process was used throughout the analysis. The principal investigator maintained a log throughout the analysis recording thoughts, ideas, actions, and interpretive decisions to provide auditability of the process.

Initially, the principal investigator read all transcripts in their entirety to obtain an overall sense of what is being conveyed by each participant. Next, transcripts were broken down by sentence as the unit of analysis. Unit-by-unit coding was accomplished, identifying the major thought conveyed in each unit. For each transcript, themes were identified in the codes, and coded passages were grouped together under the identified themes. Emerging codes and themes were constantly compared to previous ones. More abstract concepts were then identified from the categories under which these themes were then clustered across transcripts. These concepts were dimensionalized to show the range of themes supporting the concepts and the surrounding variations of the themes within the codes.

Themes and concepts were re-examined for expressions of culture-influenced beliefs upon which the themes and concepts used to create meaning were built. Finally, as themes and concepts were identified and interpretations of meanings made from them, they were checked with the participants during the second interviews to confirm accuracy and relevance. We used available demographic data to describe each group in terms of age, type of treatment, and length of time since treatment.

## FINDINGS

Of the 8 men approached, 6 agreed to participate and completed the interviews. One non-participant felt that he did not have time to participate and the other gave no reason. All the participants were experiencing erectile dysfunction at the time of the first interview and 2 were still experiencing incontinence requiring the use of pads. All had an intimate partner at the time of the interview. Ages ranged from 53-61. Three of the men had had a radical prostatectomy, 2 had had radiation and hormone therapy and 1 was on hormone therapy only. Time since treatment ranged from about 2 years to currently on treatment. Details are displayed in Table 1. Two initial interviews were in- person at the study office and four were conducted by telephone.

Results are presented as a narrative of the essential elements of incontinence and erectile dysfunction as described by the low-income African American men interviewed. For these men, the initial feelings engendered by the diagnosis of cancer were shock, death, and powerlessness. The men reported that having cancer meant that they were going to die. They talked about notions of not being able to change fate and of having no choice relative to getting cancer or treating it. The lack of choice was described as having to put things in God's hands existentially and having to put things in the physician's hands medically, especially the choice of treatment. This was exemplified by statements like "You have to do what the doctor says and just accept what happens." Men stated that at this point in time erectile dysfunction and incontinence did not enter their thoughts or decision-making. The focus was on treating the cancer regardless of the side effects. Erectile dysfunction and incontinence were less important than treating the cancer and as all of men expressed, "treating the cancer meant living". From this men then said that "you could live with prostate cancer" and would "get well if you do the right thing". Doing the right thing was defined as doing what the doctor instructed.

Men then described their treatment-related erectile dysfunction in a number of ways. Most (5) of the men downplayed the importance of sex in various ways. One way was to express that sex was no longer important when you are older, have already had your children, and/or have had an active sex life. Several men stated that they chose life over sex in having their prostate cancer treated. All were hoping for improvement in their sexual function in the future but recognized the possibility that function might not return.

In describing current sexual function, men stated that it was “not like it used to be”. Several men stated that “being able to respond sexually was necessary to be a complete man” and that sex and sexual functioning are a “natural” part of being a man. On the other hand, one man said that loss of sex is loss of the “natural,” but that this “didn’t take away the man part.” Another man, who was receiving hormone therapy, talked about having hot flashes as “something women have” in addition to his erectile dysfunction and decreased libido.

Being a man was described as taking care of your family. As one man put it, “being a man is taking good care of your kids.” This was learned from older men such as fathers and uncles while growing up. These men also talked about where men talk with each other and topics about which men talk. The contexts cited by these men included playing dominoes, a bar, or a small group of friends “hanging out somewhere.” The men indicated that the topics discussed included women, sex, and work. One man stated, “you can talk about it (sex), even if you can’t do it.” The “talk” was important. Health issues were generally agreed not to be a topic of conversation for men. Several of these men stated that they had talked to other men who had had prostate cancer, but that this was not within the context of these “man talk” sessions. Also, several of the men stated that sexual issues were not topics to be discussed with women. There are things “you talk about with men but not with ladies,” referring to sexual functioning.



However, one man, who stated his wife was a nurse, said that they talked about everything related to his prostate cancer, including erectile dysfunction. He expressed that her understanding and support were extremely helpful to him.

Incontinence was discussed less than erectile dysfunction by these men. There were beliefs expressed such as “peeing a lot is a sign of drinking” or that incontinence is a sign of problems with the kidneys or prostate. As long as incontinence was managed so that it was not visible, it was not discussed as a major problem. However, “if a man walked around with wet pants in the front, it would be disgusting.” These men felt that if incontinence did occur, it should be “taken care of right away.” One man stated that his incontinence interfered with his ability to be intimate with his partner. The men who were no longer incontinent talked about it as having been manageable as a temporary side effect.

Coping with these side effects included a number of strategies. Men talked about managing their incontinence successfully with “diapers.” They talked of needing to plan for pad changes and to know bathroom locations, but overall described it as manageable. One exception was the man who was floridly incontinent. He expressed a great deal of frustration at the disruption that his incontinence was causing him. He indicated that he had not expected his degree of incontinence for the length of time that he was experiencing it. In dealing with erectile dysfunction, men talked about using Viagra, the vacuum pump, and “shots.” Men described varying degrees of success and satisfaction with these treatments. One man described alternate means of sexual activity not requiring intercourse. All indicated that their sexual life “was not like it used to be” with one man expressing that it was no longer “natural.” Another man indicated that he used prayer to cope while still another talked about comparing his progress with others who had had prostate cancer to gauge his progress. All remained hopeful that sexual

and urinary function would return to normal. However, they expressed that given the choice between “life and sex” they would chose life.

## CONCLUSIONS

Based on these findings, the key elements of the meaning of prostate cancer treatment-related incontinence and erectile dysfunction for these men emerged as the price for continuance of life, a reframing of masculinity, and continuing hopefulness.

Throughout all of these men’s stories, there was the sense that side effects, specifically incontinence and erectile dysfunction were less of a concern than treating the cancer. Treating the cancer meant they would live. As we have previously found, (Maliski, Heilemann et al. 2002), a diagnosis of cancer is initially associated with death. However, unlike the men in our prior study who came to see prostate cancer as a good cancer after much research and soul searching, these African American men felt that they could live with cancer only if they did the right thing. This meant accepting fate and putting it in God’s hands and the physician’s hands perhaps representing undertones of cultural fatalism. Alternatively, the sense of powerlessness may be related to being of lower socioeconomic status and the sense of powerlessness that that engenders. Studies have shown that those without insurance and or economic resources have less access to health care (Lantz, House et al. 1998; Penson, Stoddard et al. 2001). Fate, treating the cancer, was seen to be much less in their own hands by these men than it was for the more affluent men who have been the subjects of previous studies. These men expressed that they did not have a choice. There was a sense from these men that incontinence and erectile dysfunction were the price they had to pay to be treated for prostate cancer which meant they would live.

While these men downplayed the importance of sex and incontinence within the context of having been treated for prostate cancer, they conveyed ambivalence relative to erectile

dysfunction and their masculine identity. This was seen in that being a man meant taking care of your family, but that “man talk” often involved women and sex. Erectile dysfunction did not remove the masculine role of caring for your family, but it did alter how the men perceived their sexuality, sometimes covering the loss with other men by continuing to engage in the sexual aspects of “man talk.” Subjects saw the loss of erectile function as the loss of a “naturalness” of being a man. Even when erectile aids were used, they were seen as “unnatural.” This experience of erectile dysfunction lead to a reframing of masculine identity in which relational aspects were more important than sexual-performance aspects of manhood. This redefinition may be supported by social movements such as the Million Man movement that emphasizes the importance of African American men within the context of the family. This provides an alternative to masculine identity being primarily tied to sexual performance. However, as seen in the narratives from these men, erectile function was important to them and their sense of masculinity, creating ambivalence as they reframed what it meant to be a man.

Continuing hopefulness tempered perceiving the side effects as permanent. For the men whose incontinence had resolved or who had had some success with erection aids, they interpreted this as indications that they would eventually return to “natural function.” Their stated expectations of treatment were that they would get rid of the cancer, have incontinence and erectile dysfunction for a while, but would return to normal. The man who was experiencing heavy incontinence was not having his expectations met and expressed much less hopefulness about his erectile as well as his urinary function. In his case, his urinary incontinence was interfering with his sexual function.

## IMPLICATIONS

While these conclusions necessarily relate to this group of men, they also provide insights to consider when providing nursing care for low-income African American men with prostate cancer and certainly suggest that further research is much needed in this population. Oncology nurses can be aware that low-income African American men may not feel empowered to participate in treatment decision-making. They may feel more comfortable deferring their physician's advice. By being cognizant of this and also the possibility that incontinence and erectile dysfunction are viewed as the price that they need to pay for treatment, nurses can use an approach that not only provides information on prostate cancer and its treatment, but also coaches them on how to be a participant in their care. Also, facilitation of reframing of masculine identity can be another beneficial role played by oncology nurses.

More research is needed in low-income populations to elucidate further the meaning of symptoms, the impact of meaning on symptom management, the health care system response, and to develop and test interventions based on the particular needs of disadvantaged men with cancer.