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TITLE: Incontinence Morbidity Following Radical Prostatectomy: Psychosocial Impact
on African American and White Men

PRINCIPAL INVESTIGATOR: Lorrie L. Powell, Ph.D.

CONTRACTING ORGANIZATION: Edith North Rogers Memorial Veterans Hospital
Center for Health Quality, Outcomes & Economic
Research
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14. ABSTRACT The purpose of this study was to characterize the impact of urinary incontinence following laparoscopic prostatectomy on psychosocial adaptation to prostate cancer and its treatment. A 90-minute telephone interview was completed with each of 6 men aged 50-60, and 61 to 75 years from a New England medical center. Data were analyzed using methods informed by grounded theory. Results indicated that men did not experience postoperative symptoms such as urinary incontinence and erectile dysfunction to the degree experienced by men who have undergone radical prostatectomy. Men found they were able to adapt well to their experience with prostate cancer and its treatment.					
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Introduction

Typically men who undergo radical prostatectomy as treatment for prostate cancer also deal with urinary incontinence. For many, incontinence improves within the first year of treatment, however some men face incontinence long after the fear of cancer has dissipated. In our society, stigma is attached to adult urinary incontinence. Its effects discredit societal ideals of masculine identity. Since individual identity is shaped by one's ethnic background, and one's cultural beliefs and practices, among other factors, the purpose of this study was to learn how men of different ethnic and cultural backgrounds construct the experience of postprostatectomy urinary incontinence. Accordingly, two objectives were identified: (1) Characterize the impact of postprostatectomy urinary incontinence qualitatively in African American and white men; and (2) Identify how individual identity, including ethnic background and age, effects one's perception of incontinence morbidity and its influence on psychosocial adaptation to illness. Both qualitative and quantitative methodologies were planned in two separate study phases. The qualitative portion of the study was to be based on 40 patient telephone interviews in Phase I, whereas quantitative methodology was to be utilized to analyze data from a mail survey of 200 men in Phase II. Two study sites were selected for the similarity of Center demographic characteristics to the study objectives. They included a Middle Atlantic Veterans Administration medical center at which a preponderance of African American patients were treated and a New England University-based medical center which treated predominately white men.

Dr. Jack A. Clark served as Dr. Powel's mentor on this project. Dr. Clark is a senior scientist at the Center for Health Quality, Outcomes, and Economic Research (CHQOER), Edith Nourse Rogers Memorial Veterans Hospital, and Associate Professor of Health Services at Boston University. He has been actively involved in research on quality of life outcomes of treatment for prostate cancer for ten years. He has developed a program of research in this area, sustained through collaborations with two other members of the CHQOER faculty, as well as long-standing collaborations with researchers in oncology and geriatrics at the Boston Medical Center, the Massachusetts General Hospital, and the Dana-Farber Cancer Institute, all in Boston, Massachusetts. His current work includes a large scale, prospective cohort study of treatment decisions and outcomes in the management of early prostate cancer, an investigation of age and race-related variation in psychosocial outcomes of early prostate cancer, and a qualitative study of men's treatment decision making and the role of their "trusted others," such as wives, partners, and friends. He has also recently completed a study of men's perceptions of the psychosocial outcomes of treatment through a careful analysis of their narratives of their experiences has recently been approved by the Department of Defense ("Living with Early Prostate Cancer: Decisions and Outcomes," (DAMD17-01-1-0026). That project, along with a companion study (NCI-RO3CA91737-01) funded to Drs. Barbara Bokhour and Clark provided the substantive context for Dr. Powel's training and professional development. Weekly meetings took place throughout the study time period to review study procedures and protocol, data, data analysis and other issues related to the conduct of this research.

Body

Table 1. Original Statement of Work

Year One	Year Two
Task 1: Develop interview protocol	Task 1: Phase II start-up
Task 2: Develop preliminary Phase I study plan	Task 2: Recruitment and mail survey
Task 3: Conduct participant interviews	Task 3: Analysis preparation
Task 4: Analysis of data	Task 4: Preliminary analyses
	Task 5: Final Analysis and preparation for findings dissemination

Year One

Task 1: Develop interview protocol. In order to facilitate the 90-minute telephone interview conducted in Phase I of the study, an interview protocol was developed. It defined the the practical aspects of completing the informed consent process, the structure and length of the interview, contingency plans if participants had not completed written consent forms prior to the scheduled interview or if participants were unable to conduct the interview, technical plans and equipment needs for audiotaping the interviews, a transcription protocol to be used with the professional transcription service, including maintenance of participant confidentiality and insuring the integrity of the data, developing a system for securing tapes and transcripts, and a plan for coding the data. To support these activities, office supplies, equipment, software, and books were purchased. An Access® (Microsoft Inc.) database was created to track completion of and adherence to the interview protocol for each participant.

Task 2: Develop preliminary Phase I study plan. Originally anticipated to be completed in the first few months of the grant, Institutional Review Board approval for this study was delayed. Final approval from the DoD's Office of Regulatory Compliance and Quality, CHQOER, and both clinical sites was completed in August 2003. In the interim period prior to study approval, activities revolved around development of the study infrastructure. Due to the multi-site nature of the study, and the geographic proximity from the PI's institution, that required recruiting master's prepared nurse practitioners specializing in oncologic urology as study site investigators at the 2 study sites. Both site investigators managed large caseloads of patients who underwent radical prostatectomy as treatment for prostate cancer and therefore had access to patient databases. Once IRB approval was obtained, their responsibility was to identify potentially eligible participants at their institutions, send a prewritten invitational letter to those men, remove names of men who returned opt-out postcards, and send that list of potentially eligible men to the PI who would continue with the study protocol. Both site investigators as well as ancillary staff underwent training in human subjects and best clinical practice. In addition written role descriptions were developed and discussed with the site coordinators. Training related to recruitment, patient confidentiality, and study integrity was also implemented. During

this time, the PI visited both study sites and had extensive telephone and email correspondence with both site investigators, as well as ancillary personnel who supported the site investigators at both institutions. In addition, this work and the selection of the site investigators were undertaken with the support of the Director of Nursing Research and the Chief of Urology at the respective institutions.

Task 3: Conduct Participant Interviews. Once the study site investigators from the New England site sent the list of potentially eligible men (N=60) to the PI, the interview protocol was initiated. It included calling the men to reestablish their eligibility and interest in participating in the study, scheduling a telephone interview at some later date convenient to the participant, and sending a consent form to those men who agreed to participate. Signed consent forms were then returned to the PI. No interviews took place prior to receipt of the signed consent form. Thus the time lapse from the original screening telephone call until the actual study interview ranged from 2 to 4 weeks, depending on when the consent form was returned and the availability of the subject for the interview. In one instance, the interview had to be rescheduled because the signed consent form was not received pending the designated interview date. During the period October through December 2003, 6 men returned signed consent forms and completed the audio-taped 90-minute interviews. Adherence to this protocol was monitored in an Access® (Microsoft, Inc.) database.

Recruitment at the Middle-Atlantic Veterans medical center proceeded according to the same protocol used at the New England-based medical center. Names of men who met the study eligibility criteria and did not opt-out (N=31) were sent to the PI in December 2003. Over the next several months the PI attempted to contact men by telephone to reestablish their eligibility and interest in participating in the study, however of eleven men contacted, no one was reached directly. That is, telephone calls were placed and messages were left by the PI, however messages were not returned. In those homes in which the telephone was answered, some men no longer lived at the telephone number given and the answering party had no forwarding number. Others who were reached agreed to consider the study but did not call back. Follow-up calls were made by the PI however no calls were returned. One man was finally contacted, and did agree to participate, however even after two reminder phone calls to return the consent form, when the scheduled interview came about, he was not at home and did not return subsequent telephone calls to reschedule the interview.

Following these unsuccessful telephone calls, several conference calls were set up with the site study coordinator and the Center's Director of Nursing Research to brainstorm strategies that might be more successful in reaching potential participants. One concern was that the PI was not known to the men even though her name was identified in the original invitational letter and secondly, that the PI is white and most of the men were African American, and third, that the PI was calling from a number in Massachusetts that was unknown to the potential participant. The strategy that was agreed on included having the study site investigator, an African American woman with whom the men were acquainted, call identified men on the eligible list, reiterate the purpose of the study, and explain that the PI would be calling within twenty-four hours.

Task 4: Analysis of data. Beginning in January 2004 tape recordings of the interviews were sent to a transcription service and all tapes were fully transcribed verbatim according to the protocol. Transcripts were received in late February and analysis began in March. One of the unexpected events that occurred was that the New England-based medical center changed their procedure for prostatectomy from radical prostatectomy to exclusive use of laparoscopic prostatectomy. Therefore all of the men who were interviewed had undergone laparoscopic

prostatectomy instead of a radical prostatectomy as was previously done at the Center. A decision was made to analyze the data from the 6 patient interviews to determine if the procedure had an impact on the incidence of reported urinary incontinence and thus the objectives of the study. Preliminary data analysis of these transcripts took place from March through May 2004.

Year 2, tasks 1-5. As reported in the 2004 Annual Report, in June 2004, the New England-based medical center reported that they no longer had the capacity to support the study due to increasing clinical demands in the urology clinic. In addition, clinical demands at the Middle-Atlantic Veterans medical center also made it difficult for that study site coordinator to continue study-related activities. Therefore, it was recommended that plans for Phase II be dropped. In addition, because of the administrative issues that delayed study start-up, at the end of the 2 year postdoctoral fellowship, only the first year study tasks had been addressed. Thus the study endpoint was extended to allow completion of the study. Although the PI left CHQOER to take a faculty position at another institution, she maintained a contract with CHQOER in order to complete Phase I of the study. However, despite several conference calls over a number of months in Fall 2004 and Spring 2005 with the Middle Atlantic Veterans medical center study site coordinator and the Director of Nursing Research regarding recruitment strategies, accrual efforts were beleaguered by the same issues that prevented accrual in the first year resulting in no patient accruals from the Middle Atlantic Veterans Medical Center. In addition, no further accrual was attempted in those men originally recruited from the New England-based medical center because the 6 men who underwent laparoscopic prostatectomy reported less urinary incontinence than typically reported in men who undergo radical prostatectomy and therefore their narrative accounts did not include substantive concerns regarding urinary incontinence. In addition, by the second year, the time from surgery in those men originally recruited had exceeded the 12 months stipulated in the original study design as the time telephone interviews would be conducted. Since this study site was no longer able to provide support to the study, no additional men were recruited.

Other experience/training supported by this award. In addition to the study activities described above, Dr. Powel participated in weekly meetings throughout the 2-year fellowship with Drs. Clark and Bokhour for the purposes of analyzing data generated from their previously identified studies that focused on examining the meaning of men's experiences with the complications of prostate cancer and its treatment, such as urinary incontinence, erectile dysfunction, bowel dysfunction, and other issues of survivorship such as worry of cancer recurrence. The objectives of the study were to: (1) examine personal transitions associated with the diagnosis and treatment of early prostate cancer; (2) determine how men integrated the physical changes they experience into their daily lives; and (3) examine the impact of prostate cancer on how men see themselves as men. Thus, the objectives of this work were congruent with the original aims of the work described in this report.

We examined the narrative accounts of 32 men diagnosed with early stage prostate cancer who were randomly selected from 349 respondents to Clark's original study recruited from the Washington D.C. VA Medical Center, the Buffalo VA Medical Center, and the Harvard Vanguard Plan in Boston. The sample included 47% African American men and 53% Caucasian men of which nearly half (47%) were 50-69 years and half (53%) were 70-80 years old. They were treated with radical prostatectomy (29%), external beam radiotherapy (50%), brachytherapy (12%), watchful waiting (6%), concomitant hormone ablation therapy (6%), and both external beam and brachytherapy (3%). Some 38% and 25% respectively had intermittent and poor urinary control, 23% and 8% respectively had intermittent and poor bowel function, and 38% and 52% respectively had intermittent and poor sexual function.

The interviews were based on an unstructured question asked by either Dr. Clark or Bokhour, "Tell me what it's been like for you since you were first diagnosed with prostate cancer". Participants discussed issues most pertinent to them and then responded to probes by the interviewers regarding issues of cancer control, urinary, sexual, and bowel problems. These interviews were fully transcribed verbatim. We examined the interviews 4-5 transcripts at a time. They were coded for symptom specific concerns, life and personal identity discussions, discussions about decisions making and their interactions with their doctors and the medical world. A grounded thematic analysis, informed by grounded theory was conducted to derive the themes specific to each of the content areas. Further narrative analysis was conducted with selected transcripts to examine ways in which individual experiences fit into the extended narrative. Men provided their accounts of their experiences with prostate cancer and treatment within the context of their families, personal lives, and personal histories. Thus, they provided accounts of their lives with prostate cancer. We divided the accounts into five general segments: 1) disease; 2) disease acts; 3) physical dysfunction; 4) social context; and 5) identity. Each of these segments were further categorized, e.g., physical dysfunction included urinary, bowel, and sexual components. All of the investigators participated in all aspects of the coding and analysis however each investigator took the lead on particular aspects of the analysis, for example Dr. Powel took the lead on all urinary-related coding and analysis. Two manuscripts based on these data are in preparation and several more are anticipated.

In addition to these training activities, Dr. Powel also conducted two secondary analyses of data of prostate cancer interviews: one based on her own previous study and one based on a comparison of Black and white men in Dr. Clark's DoD study (see reportable outcomes section for manuscript and presentations). Dr. Powel participated in bimonthly meetings for postdoctoral fellows and junior faculty at CHQOER. These included seminars on various methodological concerns, statistical analyses, writing for publication, preparing papers for dissemination at meetings, applying for faculty positions, and tenure. In addition, all faculty and fellows at CHQOER participated in weekly research meetings in which research proposals or presentations were critiqued.

Laparoscopic analyses. The indepth analyses described above also provided the backdrop from which to code and analyze the narratives of men who underwent laparoscopic prostatectomies. These men, aged 50-68 and Caucasian, portrayed themselves as survivors of prostate cancer. All participants strongly believed that they had knowingly chosen "life" over the possibility of symptoms and did not regret their choice. All wanted to "cut the cancer out"... "get rid of the cancer". Interestingly, because the laparoscopic procedure was new at the New England-based medical center, they had a team specifically focused on that procedure and protocols for teaching, medical, nursing, psychosocial, and follow-up care. Thus, in contrast to many of the men in the larger cohort, they believed they were informed about their treatment decision and spoke very highly of the caring, professional, medical and nursing care they received. Two men who underwent the procedure early in the surgeon's technical experience with laparoscopic prostatectomy, struggled to adapt to their experience with erectile dysfunction, an expected outcome. While all experienced changes in sexual function, most had erectile function sufficient for intercourse. Urinary incontinence one month postop was rare and report loss was negligible. No participant described it as problematic. Men's stories about prostate cancer and its treatment extended beyond the physical dimensions. They spoke of it within the context of their retirement, other stressful experiences in life, and within the context of their family life. In the Clark, Bokhour, and Powel analysis described above, we examined segments in which men discussed issues of masculinity, of their identities within the other roles they played (e.g., professional, breadwinner, protector, etc.). Many spoke of how their identity had changed given

the lack of control they felt with urinary incontinence or the lack of ability to engage in sexual activity. Men in the laparoscopic group did not discuss changes in identity or affronts to masculinity. Most constructed the experience as a blip on the road that they had managed in a educated, directed fashion. Overall, they felt good about their treatment choice, the outcome, and prospects for the future.

Key Research Accomplishments

- Completion of Year Tasks 1-4 with modifications to the study interviews and analysis
- Met original study objectives through analysis of Clark & Bokhour data, as well as secondary analyses

Reportable Outcomes

Manuscripts

Powel, L. & Clark, J.A. (2005). The value of the marginalia as an adjunct to structured questionnaires: Men's experiences after prostate cancer surgery. *Quality of Life Research*, 14 (3), 827-835. *This paper resulted from a secondary analysis conducted during the postdoctoral fellowship.*

Bokhour, B.G., Powel, L. & Jack, J.A. (In preparation). No less a man: Reconstructing identity after prostate cancer. For special issue of *Communication and Medicine: Constructing Identities in Medical Discourses*.

Powel, L. Clark, J.A. & Bokhour, B.G. (In preparation). The symptom experience of men with urinary incontinence after prostatectomy.

Refereed Presentations

Powel, L. (2004) Research Paper Presentation. Cognitive Representations and Emotional Responses to Postprostatectomy Urinary Incontinence in Men of Diverse Backgrounds. The Society for Behavioral Medicine's 25th Annual Meeting & Scientific Sessions, Baltimore, MD.

Powel, L. (2003). Research Paper Presentation. It's Not Just Black and White: Examining Perceptions of Urinary Incontinence Postprostatectomy in Men of Diverse Ethnic Backgrounds. The Gerontological Society of America Meeting, San Diego, CA.

Powel, L. (2003). Research Paper Presentation. Anything else you'd like to tell me regarding... - Men's characterizations of Treatment for Prostate Cancer. The Veterans Administration Health Services Research & Development Service National Meeting, Washington, D.C.

Powel, L. (2003). Research Poster Presentation. Men's Characterizations of Psychosocial Effects of Radical Prostatectomy. The 7th National Conference on Cancer Nursing Research, San Diego, CA.

Powel, L. (2003). Research Paper Presentation. Diverse Methods of Evaluating Health Care Disparities: Thinking Outside of the Box. The Primary Care Research Methods & Statistics Conference, The University of Texas Health Sciences Center, San Antonio, TX.

Based on training completed during this fellowship, Dr. Powel has recently obtained intramural funding at the University of Central Florida to study fatigue in men with recurrent prostate cancer – an issue identified in the Clark, Bokhour, & Powel analysis, and submitted an intervention study proposal to the Lance Armstrong Foundation (7/05) for men with persistent postprostatectomy urinary incontinence.

Conclusions

This ambitious project was beset from the start by a number of issues that challenged its completion as originally proposed. Given the number of potential problems that are inherent in any clinical research study, in retrospect, it seems apparent that a study of this magnitude was beyond the scope of a two-year structured postdoctoral fellowship. Although the research project itself was not completed as planned, the objectives of the study were met through analysis of data based on patient interviews that mirrored the original proposal with respect to time since treatment, ethnic distribution, and the nature of the open-ended research question. Moreover, it offered information on the nature of men's experience following laparoscopic prostatectomy. Future work should further explore men's experience after laparoscopic prostatectomy and focus on interventions that will address many of the issues identified by Clark, Bokhour, & Powel.

STATEMENT OF WORK

Incontinence Morbidity Following Radical Prostatectomy: Psychosocial Impact on African American and White Men

Year One

- Task 1.* Develop interview protocol, Month 1
- a. Dissect interview process and specify protocol for individual interviews.
 - b. Set up equipment needs and software requirements.
 - c. Develop coding plan
- Task 2.* Develop Preliminary Phase One Study Plan, Months 2-4
- a. Define study sample and recruitment efforts and define eligible sites.
 - b. Obtain Institutional Review Board approval from all sites.
 - c. Review patient databases and narrow sample based on eligibility criteria.
 - d. Begin recruitment.
- Task 3.* Participant Interviews, Months 5-7
- a. Conduct interviews.
 - b. Begin immediate ongoing analysis.
- Task 4.* Analysis, Months 8-12
- a. Continuation of grounded theory analysis.
 - b. Follow-up interviews/phone calls with participants.
 - c. Identification of items to be used for instruments.

Year Two

- Task 1.* Phase Two study start-up, Months 13-16
- a. Prepare and submit manuscript from phase one.
 - b. Conduct reliability and validity testing on any items generated from phase one.
 - c. Review patient data files and generate subject recruitment plan.
- Task 2.* Recruitment and survey mailing, Month 17-18
- a. Send out letters of invitation to potential subjects.
 - b. Send study questionnaire to respondents.
- Task 3.* Analysis Preparation, Months, 19
- a. Set up secure files for subject data collection.
 - b. Develop SAS program files and quality control measures in anticipation of data entry.
 - c. Develop coding book and decision log.

- Task 4.* Preliminary analyses, Months, 20
- a. Interim analyses will be performed on a periodic basis.
 - b. Tracking of missing data will be maintained and modification to procedures will be made.
- Task 5.* Final Analysis and Preparation for Dissemination of Findings, Months, 21-24
- a. Final analyses will be performed.
 - b. Abstracts for scientific meetings will be prepared.
 - c. Manuscript preparation.

Curriculum Vitae

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I. EDUCATION

Year	Degree	Institution	Clinical Major	Role Preparation
2002-2004	Postdoctoral Fellowship	Boston University School of Public Health and Center for Health Quality, Outcomes, & Outcomes Research, Edith Nourse Rogers Memorial Veterans Hospital, Bedford, MA	Health Services & Outcomes Research	Researcher
1997-2001	PhD	University of Maryland School of Nursing, Baltimore, MD	N/A	Researcher
1982-1984	MS	Boston University School of Nursing, Boston, MA	Rehabilitation Oncology	Clinical Nurse Specialist
1974-1980	BS	Salve Regina College, Newport, RI	Nursing	Clinical practice

II. LICENSURE/CERTIFICATION

Pending	Registered Nurse, Florida
2002-present	Registered Nurse, Massachusetts, 152633
1992-2003	Registered Nurse, California
1980-1991	Registered Nurse, Massachusetts
1984-1987	Registered Nurse, Connecticut
1994-1997	Oncology Certified Nurse (OCN), Oncology Nursing Society

III. EMPLOYMENT

ACADEMIC APPOINTMENTS:

Aug 2004 to present	Associate Professor, University of Central Florida School of Nursing, Orlando, FL
July to Aug 2004	Visiting Research Associate, University of Central Florida School of Nursing, Orlando, FL
1998 to 2001	Predoctoral Research Assistant, University of Maryland School of Nursing, Orlando, FL
1996 to 1997	Assistant Clinical Professor, University of California School of Nursing, San Francisco CA
1987 to 1991	Adjunct Assistant Professor, MGH Institute of Health Professions, Boston, MA
1985 to 1987	Assistant Clinical Professor, University of Connecticut School of Nursing, Storrs, CT
1985 to 1987	Associate Faculty, St. Joseph College School of Nursing, West Hartford, CT

CLINICAL APPOINTMENTS:

1993 to 1997 Oncology Clinical Nurse Specialist, California Pacific Medical Center, San Francisco, CA
1991 to 1993 Coordinator, CALGB Research Pgm./Staff Nurse, Bone Marrow Transplant, University of California, San Francisco, CA

1991 to 1993 Oncology Nursing Consultant, Private Practice, San Francisco, CA
1987 to 1991 Oncology Clinical Nurse Specialist, Massachusetts General Hospital, Boston, MA
1984 to 1987 Oncology Clinical Nurse Specialist, Mount Sinai Hospital, Hartford, CT
1983 to 1984 Staff Nurse, Dana Farber Cancer Institute, Boston, MA
1980 to 1983 Staff Nurse, Brigham & Women's Hospital, Boston, MA

IV. FUNDED RESEARCH

Year	Grant, Amount, Funding Agency
2004-2005	<u>Principal Investigator</u> , Fatigue in Men with Recurrent Prostate Cancer: The Patient's Perspective. Dean's New Faculty Start-Up Scholarship, College of Health and Public Affairs, University of Central Florida, Orlando, FL. (\$3000)
2002-2005	<u>Principal Investigator</u> , Incontinence Morbidity Following Radical Prostatectomy: Psychosocial Impact on African American and White Men. Postdoctoral Award, United States Department of Defense, (\$147,000).
2002-2004	<u>Coinvestigator</u> , Living with Early Prostate Cancer: Decisions and Outcomes, Dr. Jack A. Clark, (PI). United States Department of Defense.
2002-2004	<u>Coinvestigator</u> , Prostate Cancer Survivors' Narratives and Doctor's Responses, Dr. Barbara G. Bokour, (PI), National Institutes of Health, National Cancer Institute.
2001	<u>Principal Investigator</u> , Incontinence Morbidity, Adjustment to Illness, and Quality of Life One Year After Prostatectomy, Dissertation Award, United States Department of Health & Human Services, Health Care Finance Administration (\$30,000)
2001	<u>Graduate Research Award</u> , Graduate Student Association, University of Maryland, (\$1000)
2001	<u>Research Award</u> , Sigma Theta Tau International Nursing Honor Society, Alpha Eta Chapter (\$1000)
2000-2001	<u>Graduate Research Assistant</u> , Anger, Salivary Cortisol, and Blood Pressure in Black Female Caregivers and Noncaregivers, Dr. Sandra J. Picot, (PI) University of Maryland
1998-1999	<u>Project Director</u> , Coping with Incontinence After Prostate Surgery Drs. Mary H. Palmer, Mark Somerfield, Co-PIs) Oncology Nursing Foundation (\$7500)
1998	<u>Graduate Research Assistant</u> , The Meaning of Breast Cancer for African American Women. Dr. Janice M. Phillips, (PI), Oncology Nursing Society
1998	<u>Sara Whitehurst Scholarship</u> , University of Maryland, School of Nursing (\$500)
1997-2001	<u>Doctoral scholarship in nursing</u> , American Cancer Society, (\$32,000)
1997	<u>Doctoral Scholarship</u> , Oncology Nursing Foundation (\$3000)
1997	<u>Graduate Merit Award</u> , University of Maryland, School of Nursing (\$2000)
1997	<u>Public Health Service Professional Nurse Traineeship</u> , University of Maryland, School of Nursing, (\$2000)
1996-1997	<u>Principal Investigator</u> , A Pilot Study Describing the Domains of Illness for Women with Ovarian Cancer, SmithKline Beecham Pharmaceuticals, Inc. (\$5000)
1992-1996	<u>Research Assistant, Study Site Coordinator</u> , Self-Care Intervention to Decrease Mucositis Morbidity Dr. Marilyn Dodd, (PI). National Institutes of Health, National Institute of Nursing Research (\$1,543,876)
1989-1991	<u>Coinvestigator, Study Site Coordinator</u> , A Nursing Rehabilitation Program for Breast Cancer Patients Receiving Cytotoxic Chemotherapy, Dr. Victoria Mock, (PI), American Cancer Society, the American Nurses Foundation, the Massachusetts Nurses Foundation, and Boston College.

V. PUBLICATIONS

REFEREED NATIONAL/INTERNATIONAL JOURNALS:

1. **Powel, L.** & Clark, J.A. (2005). The value of the marginalia as an adjunct to structured questionnaires: Men's experiences after prostate cancer surgery. Quality of Life Research, 14 (3), 827-835.
2. Palmer, M.H., Fogarty, L., Somerfield, M., & **Powel, L.** (2003). Incontinence after Prostatectomy: Coping with incontinence after prostate cancer surgery. Oncology Nursing Forum, 30 (2), 229-238.
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8. Gallagher, J., Spross, J., & **Powel, L.** (1992) A report from the second national invitational conference on the role of the oncology clinical nurse specialist. Oncology Nursing Forum, (suppl) 19 (1), 7-10.
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NON-REFEREED NATIONAL/INTERNATIONAL:

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12. Rivers, R. & **Powel, L.** (2000). Practice tips from the Shands Cancer Center at the University of Florida, Gainesville. *Oncology Nursing Forum*, 27 (5), 775-7.
13. **Powel, L.** (2000). Guest editorial. The nurse's role in prostate cancer treatment: challenge or opportunity? *Journal of Wound Ostomy and Continence Nursing*, 27 (3), 127-8.
14. Freitas, B & **Powel, L.** (2000). Practice tips from the Queen's Medical Center in Honolulu, HI. *Oncology Nursing Forum*, 27 (3), 441-2.
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26. Powel, L. & Whedon, M. (Eds.) (1998). *Quality of Life – A Nursing Challenge: Ovarian Cancer*. Philadelphia PA: Meniscus Educational Institute.
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33. Powel, L. (1991). Cancer nursing research: Accepting the challenge. BONS Bulletin (Newsletter of the Boston Chapter of the Oncology Nursing Society). (Winter)
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TEXTBOOKS:

35. M. Wallace & L. Powel. (Eds.) (2002). *Prostate Cancer: Nursing Assessment, Management & Care*, New York: Springer Publishing Company. (*American Journal of Nursing, 2002 Book of the Year Award*).

BOOK CHAPTERS:

36. Wallace, M. & Powel, L. (2002). Prostate cancer: the nature of the problem. In: M. Wallace & L. Powel (Eds.) *Prostate Cancer: Nursing Assessment, Management & Care*, New York: Springer Publishing Company.
37. Powel, L. & Wallace, M. (2002). Quality of life with prostate cancer. In: M. Wallace & L. Powel (Eds.) *Prostate Cancer: Nursing Assessment, Management & Care*, New York: Springer Publishing Company.
38. Picot, S. & Powel, L. (2000). Caregiver burden and burnout. In: J. Fitzpatrick & T. Fulmer (Eds.) *Encyclopedia of Geriatric Nursing*, New York: Springer Publishing Company.
39. Palmer, MH. & Powel, L. (2000). Prostate cancer. In: J. Fitzpatrick & T. Fulmer (Eds.) *Geriatric Nursing Research Digest*, New York: Springer Publishing Company, 301-305.

PROFESSIONAL REVIEWS:

40. Powel, L. (2000). Patient-reported symptoms after primary therapy for early prostate cancer: Results of a prospective cohort study. (Review) Journal of Wound, Ostomy, & Continence, 27 (1), 14A-15A.
41. Powel, L. (1996). A comparison of morphine, pethidine and fentanyl in the post surgical patient-controlled analgesia environment. (Review) ONS Nursing Scan in Oncology.
42. Powel, L. (1995). Cancer patterns among women in the United States. (Review) ONS Nursing Scan in Oncology.
43. Powel, L. (1995). A review of late effects of cancer in women. (Review) ONS Nursing Scan in Oncology.
44. Powel, L. (1995). Prevention and early detection of cancer in women. (Review) *ONS Nursing Scan in Oncology*, 4 (6), 10.
45. Powel, L. (1995). When is cancer pain mild, moderate or severe? Grading pain severity by its interference with functions. (Review) *ONS Nursing Scan in Oncology*, 4 (6), 6.
46. Powel, L. (1995). The meaning of cancer and oncology nursing: Link to effective care. (Review) *ONS Nursing Scan in Oncology*, 4 (4), 19.
47. Powel, L. (1995). The meaning of cancer pain. (Review) *ONS Nursing Scan in Oncology*, 4 (4), 5.
48. Powel, L. (1995). Physician's attitudes and practices regarding the long-term prescribing of opioids for non-cancer pain. (Review) *ONS Nursing Scan in Oncology* 4 (3), 9.
49. Powel Schwager, L. (1995). Productivity and workload measurement in ambulatory oncology. (Review) *ONS Nursing Scan in Oncology*, 4(3), 19.
50. Powel Schwager, L. (1995). Patient-related barriers to management of cancer pain in Puerto Rico. (Review) *ONS Nursing Scan in Oncology*. 4 (2).

51. **Powel Schwager, L.** (1995). Pain characteristics of advanced lung cancer patients referred to a palliative care service. (Review) *ONS Nursing Scan in Oncology*, 4 (2), 6.
52. **Powel Schwager, L.** (1995). Creating critical care oncology beds. (Review) *ONS Nursing Scan in Oncology* 4 (1), 11.
53. **Powel Schwager, L.** (1994). Strategies to meet the needs of the rural poor. (Review) *ONS Nursing Scan in Oncology*, 3 (6), 11.
54. **Powel Schwager, L.** (1994). Treatment of Cancer Pain in Norway: A questionnaire study. *ONS Nursing Scan in Oncology*, 3 (6), 9.
55. **Powel Schwager, L.** (1994). Pain Measurement in cancer patients: A comparison of six methods. (Review) *ONS Nursing Scan in Oncology*, 3 (6), 7.
56. **Powel Schwager, L.** (1994). The dilemma of conversion from systemic to epidural morphine: A proposed treatment of cancer pain. (Review) *ONS Nursing Scan in Oncology*, 3 (5), 6.
57. **Powel Schwager, L.** (1994). Quality of life in adult bone marrow transplant patients: Beyond the first year. (Review) *ONS Nursing Scan in Oncology*, 3 (5), 9.
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59. **Powel Schwager, L.** (1993). Management of terminal cancer pain in Sweden: A nationwide survey. (Review) *ONS Nursing Scan in Oncology*.
60. **Powel Schwager, L.** (1993). Cancer and the family: Strategies to assist spouses. (Review) *ONS Nursing Scan in Oncology*.
61. **Powel Schwager, L.** (1993). Comparison of hydromorphone continuous subcutaneous infusion and basal rate subcutaneous infusion plus PCA in cancer pain: a pilot study. (Review) *ONS Nursing Scan in Oncology*, 2 (6), 10.
62. **Powel Schwager, L.** (1993). Comparison of Prostate Cancer Patients With and Without Pain. (Review) *ONS Nursing Scan in Oncology*, 2 (5).
63. **Powel Schwager, L.** (1993). Survival Work: The Experience of the Patient and the Spouse Involved in Experimental Treatment for Cancer. (Review) *ONS Nursing Scan in Oncology*, 2 (5), 12.
64. **Powel Schwager, L.** (1993). The Challenge of Cancer Care Marketing. (Review) *ONS Nursing Scan in Oncology*, 2 (5), 21.
65. **Powel Schwager, L.** (1993). TENS for Children's Procedural Pain" (Review) *ONS Nursing Scan in Oncology*, 2 (4), 6.
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67. **Powel, L.** (1993). Transdermal Fentanyl and Initial Dose-Finding with Patient-Controlled Analgesia in Cancer Pain: A Pilot Study with 20 Terminally Ill Cancer Patients. (Review) *ONS Nursing Scan in Oncology*, 2 (1), 7.
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69. Powel, L (1993). Response of Intractable Pain to Continuous Intrathecal Morphine: A Retrospective Study. (Review) *ONS Scan in Oncology* 2 (1), 5.
70. Powel, L (1992). Drug Interactions in the Oncology Patient. (Review) *ONS Nursing Scan in Oncology*, 1 (3), 15.
71. Powel, L (1992). Oncogenes and Cancer Suppressor Genes. (Review) *ONS Nursing Scan in Oncology*, 1 (2), 12.
72. Powel, L (1992). Assessment of Acute Pediatric Pain: Do Child Self-Report, Parent Ratings, and Nurse Ratings Measure the Same Phenomenon? (Review) *ONS Nursing Scan in Oncology*, 1 (1), 8.
73. Powel, L (1992). Companion Studies. (Review) *ONS Nursing Scan in Oncology*, 1(1), 21.

GUEST EDITOR:

74. Powel, L. (2000). Incontinence morbidity after prostate cancer treatment. *Journal of Wound, Ostomy, & Continence Nursing*, 27 (3).

In Press:

75. Powel, L. (2005). Cancer Survivorship. In: J. Fitzpatrick & M. Wallace (Eds.) *Encyclopedia of Nursing Research*, New York: Springer Publishing Company.
76. Powel, L. & Palmer, MH. (2005). Prostate cancer. In: J. Fitzpatrick & M. Wallace (Eds.) *Encyclopedia of Nursing Research*, New York: Springer Publishing Company.

VI. PRESENTATIONS

SELECTED REFEREED NATIONAL/INTERNATIONAL (last 6 years only):

- | | |
|----------------|---|
| March, 2004 | Research Paper Presentation. Cognitive Representations and Emotional Responses to Postprostatectomy Urinary Incontinence in Men of Diverse Backgrounds. The Society for Behavioral Medicine's 25 th Annual Meeting & Scientific Sessions, Baltimore, MD. |
| November, 2003 | Research Paper Presentation. It's Not Just Black and White: Examining Perceptions of Urinary Incontinence Postprostatectomy in Men of Diverse Ethnic Backgrounds. The Gerontological Society of America Meeting, San Diego, CA. |
| February, 2003 | Research Paper Presentation. Anything else you'd like to tell me regarding... - Men's characterizations of Treatment for Prostate Cancer. The Veterans Administration Health Services Research & Development Service National Meeting, Washington, D.C. |
| February, 2003 | Research Poster Presentation. Men's Characterizations of Psychosocial Effects of Radical Prostatectomy. The 7 th National Conference on Cancer Nursing Research, San Diego, CA. |
| December, 2002 | Research Paper Presentation. Diverse Methods of Evaluating Health Care Disparities: Thinking Outside of the Box. The Primary Care Research Methods & Statistics Conference, The University of Texas Health Sciences Center, San Antonio, TX. |
| October, 2002 | Research Poster Presentation. Incontinence Morbidity Following Radical Prostatectomy: Measuring the Effect on Psychosocial Adjustment to Illness. The 9 th Annual International Society for Quality of Life Research Meeting, Orlando, FL. |
| June, 2002 | Research Poster Presentation. Incontinence Morbidity, Psychosocial Adjustment to Illness, and Quality of Life After Prostatectomy. The Cancer Survivorship Meeting, National Cancer Institute, National Institutes of Health, Washington, D.C. |

- November, 1999 Research Poster Presentation. Urinary Incontinence After Prostate Cancer Surgery: A Threat to Personal and Social Integrity. The Gerontological Society of America, San Francisco, CA.
- May, 1998 Research Poster Presentation. A Pilot Study Describing the Domains of Illness for Women with Ovarian Cancer". The 23rd Congress of the Oncology Nursing Society, San Francisco, California.

REFEREED REGIONAL/STATE/LOCAL PAPERS:

- April, 1999 Research Poster Presentation. Urinary Incontinence After Prostate Cancer Surgery. The Joint Research Conference of Johns Hopkins University and University of Maryland Schools of Nursing. Baltimore, MD.

INVITED NATIONAL/INTERNATIONAL PRESENTATIONS:

- June, 2005 Invited Speaker, The Influence of Cancer on People's Lives: 323 Lives and Counting. Kaunas University of Medicine, Kaunas, Lithuania.
- September, 1999 Invited Speaker, Prostate Cancer Screening and Quality of Life. Chamber of Commerce, Rancho Mirage, CA.
- September, 1999 Invited Speaker, Quality of Life and Colon Cancer. San Diego Chapter of the Oncology Nursing Society, La Jolla, CA.
- January, 1999 Invited Speaker, Interpretation of Quality of Life Research in Cancer Clinical Trials. National Sales Meeting of Pharmacia & Upjohn Pharmaceutical Company. Dallas, TX.
- August, 1997 Invited Speaker, Measuring Quality of Life in Patients with Cancer. Medical Grand Rounds, Good Samaritan Hospital, Oregon Health Sciences University, Portland, OR
- May, 1997 Invited Speaker, Real Patients, Real Nurses, Real Quality of Life. 22nd Congress of the Oncology Nursing Society, New Orleans, LA

INVITED REGIONAL/STATE/LOCAL PAPERS:

- April, 2005 Invited Speaker, Cancer Survivorship. Oncology Nursing Society Certification Review Course. Palm Beach Cancer Institute, West Palm Beach, FL.
- March, 2005 Invited Speaker, Building a Program of Research. Sigma Theta Tau International Honor Society for Nursing Research Day. Winter Park, FL.
- April, 2003 Invited Speaker, Men's Experiences After Prostate Cancer Surgery: Examining the Marginalia. Qualitative Colloquium, Boston University Schools of Medicine & Public Health, Boston, MA.

VII. AWARDS

- 2002 *American Journal of Nursing* Book of the Year Award
- 2002 Who's Who in American Colleges and Universities

VIII. PROFESSIONAL ACTIVITIES & COMMUNITY SERVICE

PROFESSIONAL ORGANIZATIONS:

Oncology Nursing Society

National

1996-1998 Program Director, National Chemotherapy Education and Training Program
1991-1994 Member, Clinical Practice Committee

Local

1997-2001 Member, Baltimore Chapter
1992-1997 Member, Bay Area Chapter
1987-1991 Member, Boston Chapter
Chair, Research Committee
Member, Program Committee
1985-1987 Founding Member, Central Connecticut Chapter Member
Chair, Program Committee

Society of Behavioral Medicine

2003-present Member

AcademyHealth

2003-2004 Member

International Society for Quality of Life Research

2003-present Member,

Gerontologic Society of America

1999-present Member,

Sigma Theta Tau International Nursing Honor Society, Alpha Eta and Pi Chapters

1997-present Member

American Nurses' Association

1980-1997 Member

JOURNAL EDITOR & EDITORIAL REVIEW BOARDS

Oncology Nursing Forum

1997-2000 Associate Editor
1995-2000 Review Board Member

ONS Nursing Scan In Oncology

1996-1999 Associate Editor
1992-1996 Abstractor

Quality of Life – A Nursing Challenge

1991-1999 Editorial Board Member

PROFESSIONAL SERVICE ACTIVITIES

- 1991 Co-Chair, Chemotherapy Education Consortium, Boston, Massachusetts.
Developed revenue generating program with 13 Boston hospitals that trained more than 800 nurses.
- 1990 Co-Chair, National Invitational Conference on the Future of Advanced Practice in Oncology Nursing, Boston, Massachusetts.
(see publications section for proceedings).
- 1989 Co-Chair, National Conference Addressing the Advances in [Cancer] Treatment, Rehabilitation, and Quality of Life. Boston, Massachusetts.

COMMUNITY SERVICE ACTIVITIES

American Cancer Society

- 1995-1997 Co-facilitator Ovarian Cancer Support Group, San Francisco, CA
- 1988-1990 Member, Professional Education Committee, , Boston, MA Chapter
- 1987-1991 Program Chair and Conference Chair-Elect, Northeast Regional Oncology Nursing Committee (NERON).
Developed 3 biannual Oncology Nursing Regional Conferences in New England
- 1985-1987 Member, Hartford, CT Chapter Public Education Committee
Championed smokeless tobacco effort, cancer screening in teens

IX. CONSULTATION

- 2004-present Associate Clinical Scientist, The Phyllis F. Cantor Center for Research in Nursing & Patient Care Services, Dana Farber Cancer Institute, Boston, MA
- 2004 Cancer and Leukemia Group B (CALGB) National Clinical Research Group, Chicago, IL
Provided Research Consultation to the Oncology Nursing Committee
- 2000-2002 Wyeth-Aherst Pharmaceuticals/Genetics Institute, Philadelphia, PA
Advisory Board Member
Provided Consultation Regarding Oncology Professional and Patient Education
- 1999-2000 Wound, Ostomy, & Continence Nurses Society Center for Clinical Investigation
Provided Research Consultation to Membership
- 1997-1998 Krames Communication, San Bruno, CA
Developed Patient Education Booklets Related to Chemotherapy and Cancer Therapy Side Effects
- 1996-1997 Oncology Nursing Society, Pittsburgh, Pennsylvania & Rhone-Poulenc Rorer Pharmaceuticals, Philadelphia, PA
Developed Metastatic Breast Cancer Slide Package and CE Program for Nurses

X. UNIVERSITY SERVICE

University

2005 to present Alternate Member, Institutional Review Board

School of Nursing

2004 to 2005 Member, Masters Curriculum Committee, School of Nursing, University of Central Florida, Orlando, FL

2005 to present Member, Doctoral Curriculum Committee, School of Nursing, University of Central Florida, Orlando, FL

RESEARCH PROJECT ADVISING:

Year	Role	Student/Project
2005	Advisor <i>Master's Scholarly Project</i>	Adonirei Alvarenga, BSN, RN: Factors that influence breast feeding duration in low-income women in the United States
2005	Advisor <i>Master's Scholarly Project</i>	Delanne Amonett, MS, BSN, RN: Effective pediatric provider communication strategies in primary care: A preliminary review
2005	Advisor <i>Master's Scholarly Project</i>	Frankie Bailey, BSN, RN: What factors prevent accurate documentation of pain?
2005	Advisor <i>Master's Scholarly Project</i>	Carrie Bertram, BSN, RN: Should minors have the right to consent?
2005	Advisor <i>Master's Scholarly Project</i>	Marisa Bracero, BSN, RN: Childhood fever: What parents believe
2005	Advisor <i>Master's Scholarly Project</i>	Susan Denton, BSN, RN, OCN, CCRP: Factors that influence participation in adult cancer clinical trials
2005	Advisor <i>Master's Scholarly Project</i>	Cindy B. Dillard, BSN, RN: The impact of hyperglycemia on critically ill patients
2005	Advisor <i>Master's Scholarly Project</i>	Stacey Hawes, BSN, RN: Mentoring: Professional support for novice nurses

2005	Advisor <i>Master's Scholarly Project</i>	Heather Henderson, BSN, RN, BSH, LMT: The Use of Fresh Frozen Plasma in Anticoagulated Patients Having Non-Emergent, Elective Invasive Procedures
2005	Advisor <i>Master's Scholarly Project</i>	Kerri Knoll, BSN, RN: Provider-Related Barriers to Pediatric Obesity Identification and Treatment
2005	Advisor <i>Master's Scholarly Project</i>	Carolyn V. Lightner, BSN, RN, CDDN: Health Beliefs, Attitudes, and Behaviors to Breast Cancer Screening in African American Women
2005	Advisor <i>Master's Scholarly Project</i>	Denise Lopez, BSN, RN: Factors that affect the health of the female adolescent athlete: An integrated literature review
2005	Advisor <i>Master's Scholarly Project</i>	Nalini Singh, BSN, RN: The impact animals have on the psychosocial well-being of the elderly
2005	Advisor <i>Master's Scholarly Project</i>	Evelyn Walker, BSN, RN: Barriers to effective pain management in preschool aged children
2005	Advisor <i>Master's Scholarly Project</i>	Glenda Wichick, BSN, RN: The Impact of Articulation Agreements on Student Success in Florida RN-to-BSN Programs
2005	Advisor <i>Master's Scholarly Project</i>	Ruth Wilson, BSN, RN: Maternal Breastfeeding Confidence and Self-Efficacy as Predictors of Breastfeeding Exclusivity or Duration

The value of the marginalia as an adjunct to structured questionnaires: Experiences of men after prostate cancer surgery

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Abstract

In both research and clinical settings, men who survive prostate cancer emphasize the need for more open communication about the challenges they face. They explain that symptomatic dysfunction associated with treatment is grounded in complex social situations and relationships. Yet, structured quality of life questionnaires preclude expressions of the elaborate accounts they often evoke. We explore this in the case of prostate cancer. Seventy-one patients who had undergone radical prostatectomy at a mid-Atlantic University Medical Center, a Veterans Affairs medical center affiliated with the same university, or were US members of an international prostate cancer support group completed a survey protocol including assessments of urinary morbidity, psychosocial adjustment to illness (PAIS), and health status (SF-36). At the conclusion, a single open-ended item was offered; 48 offered an extended response. The open-ended item was recorded and analyzed qualitatively. Data were summarized according to four main themes: (1) quality of patient–physician communication; (2) change in sexual identity; (3) fear of cancer; and (4) the humiliation of urinary incontinence. Future research on outcomes of treatment and clinical inquiry must focus on methods that systematically capture patients' experiences.

Key words: Marginalia, Prostate cancer, Quality of life, Structured questionnaires

Accurate, reliable, and complete information about quality of life plays a central role in helping patients make informed treatment decisions and manage the often problematic side effects of prostate cancer treatment. Patients themselves are the best source of information in this area. For many years information about treatment outcomes was based on physician's queries of their patients that could be unsystematic, with the resulting data subject to various biases. Patients' reports were subjective, open to inaccuracies of perception and recall, and influenced by aspects of the patient–physician relationship, including patients' wishes to appear competent, avoid embarrassment, and perhaps express appreciation to the physician who might have cured their cancer [1–3].

Standardized, patient-administered questionnaires completed in a confidential survey setting

have resulted in improved information about the outcomes of treatment [3]. Instruments developed by Litwin et al. [4], Wei et al. [5] Giesler et al. [6] and Clark and Talcott [7] focus on measuring the severity of prostate cancer symptoms and the extent to which they affect well-being by asking about 'bother' or how much symptomatic dysfunction is a 'problem'. Yet these instruments can still fail to capture fully how men appraise the physical changes brought about by prostate cancer treatment and their impact on quality of life. What might be complex problems of urinary leakage or impotence for men are necessarily reduced to narrowly defined but reliable rating scales, such as frequency of leakage or firmness of erections. Respondents are asked to perform a complex task: searching the question for meaning, recalling their experience and deciding which parts are relevant

and significant, and glossing their recollection, perhaps in the form of a mentally calculated 'average'. These problems are typical of standardized, focused questionnaires [8, 9].

The very construction of structured questionnaires that necessarily distills from the broader construct to specific attributes of a domain makes it inevitable that study participants will interpret survey questions in ways unique to their own circumstance [9]. Likewise, questionnaires can evoke complex responses that are excluded from the data record. When given a chance, respondents are likely to offer additions, elaborations, or qualifications in order to relate the essence of their own experience [10]. A not uncommon remedy is to include open-ended items designed to collect information beyond that collected by the focused items. These items can include requests for accessory comments, such as 'is there anything else...?'

We present an analysis of the accessory comments men offered after participating in a survey on their experience with urinary incontinence after prostate cancer. They were asked whether there was more, after completing a comprehensive questionnaire that addressed postoperative urinary symptoms, quality of life, and emotional adjustment. Although this questionnaire was designed to be broadly encompassing, men still had more to say. Thus, rather than focusing on the participants' responses to the questionnaire, we examine those patient concerns and experiences the questionnaire did not address – the marginalia.

Methods

Subject recruitment

Following review and approval of study materials by the Institutional Review Boards of a mid-Atlantic university medical center, and a Veterans Affairs medical center affiliated with the same university, a database of men treated for prostate cancer at these institutions was searched to identify those men treated with radical prostatectomy as primary treatment for prostate cancer 12–18 months previously. This time period was chosen to identify the influence of the urinary symptoms on quality of life and emotional adjustment in patients in whom the likelihood of

long-term morbidity had become more certain, i.e., after the 1-year time period in which men typically regain continence had passed [11].

A letter was then sent from the participating institutions' Urology Department Chairmen and the study investigator to eligible men. The letter acknowledged the potential subject's care at the Center, introduced the work of the principal investigator (LLP) and the study, and invited their participation. Men in the prostate cancer support group, US TOO! International who met the same eligibility criteria were also invited to participate. Information was provided to support group members through an US TOO! International newsletter.

Men who were interested in participating in the study telephoned the principal investigator. After screening the caller to re-establish eligibility, the study was explained using a scripted dialogue so that all potential subjects received the same information. Those who expressed an interest in participating, identified a convenient date and time for a telephone interview, and were sent a study packet that included a cover letter, the study questionnaire, and a research informational sheet.

Telephone survey methodology

Telephone survey methodology was selected to reduce distress that might arise from talking about personal feelings with a health care professional previously unknown to them in a personal interview [12, 13]. Telephone interviews have also been shown to create less probability of social desirability effects when discussing potentially threatening items [14], and the added boundary of the telephone between the interviewer and respondent lends to the more likely scenario that the respondent will report truthfully [15]. Protocols for telephone logs and study procedures were established.

Structured questionnaire

The structured questionnaire included scales developed in a pilot study to assess incontinence morbidity (i.e., the severity, disability, and duration of urinary incontinence), referred to as the Incontinence Morbidity Index (IMI), as well as the PAIS, which assessed domains of health care orientation, vocational environment, domestic

environment, sexual relationships, extended family relationships, social environment, and psychological distress) [16] and the SF-36, focusing on attributes of general health perceptions, physical functioning, role performance with physical limitations, emotional limitations, bodily pain and pain-related limitations, general mental health, vitality, and social functioning [17] for a total of 121 items. Reliability estimates computed by coefficient α for the total scales of the IMI, the PAIS, and the SF-36 in this sample were 0.90, 0.85 and 0.85, respectively. The mean time to complete the structured questionnaire was 32 min (range: 15–50 min).

Procedure

At the established study interview time, the principal investigator called the subject, re-established the subject's availability and interest in participating, reviewed the protocol for the interview, and proceeded using the study questionnaire. Since the survey packet used in this study included instruments that contain multiple response options, the study packet was sent in advance of the scheduled telephone interview. This allowed the subject to follow along as each question was asked during the interview, thereby reducing confusion that might occur if multi-part response choices had been read over the telephone. At the end of the interview participants were asked a single open-ended question: 'Is there anything else related to your prostate cancer or its treatment that you would like to discuss?' No other prompts were used. Responses to the open-ended question were recorded as verbatim hand-written accounts.

Analysis

The hand-written accounts were transcribed into Microsoft Word™ and translated into Ethnograph v5.07™, a software program which assists with the coding and sorting of qualitative data [18]. Responses were analyzed using procedures informed by grounded theory methodology. The transcripts were read and marked for passages that referred to men's experience with the diagnosis or treatment of cancer, postoperative experiences, and feelings regarding their experiences. Passages were orga-

nized into these categories and were then further distilled into code words or themes that depicted the content and context of the passages. A codebook was developed and all coding decisions were logged. In order to ensure valid and reliable results, another investigator (JAC) independently reviewed the transcripts and the original coding. Coding discrepancies were resolved through consensus and discussion.

Participants

Of the 71 participants in the parent study, 48 participants who had undergone radical prostatectomy at a mean time of 16 months previously responded to the open-ended question. On average, these participants were aged 57 years (range: 49–72 years), and were predominately white (90%). African American and Hispanic men each accounted for 4% of the sample, and there was one man who identified himself as Asian (2%). Thirty-nine percent had advanced degrees (masters or doctorates), 43 and 4%, respectively, had college and junior college degrees, whereas 12% had high school diplomas, and 2% ($n = 1$) did not complete high school.

Results

The open-ended question elicited substantive responses from 48 respondents; 23 said they did not have anything more to add. These two groups were not significantly different with respect to time since surgery, age, or with specific outcome parameters of the original structured questionnaire, i.e., postoperative urinary control and sexual function, overall psychosocial adjustment to illness, and the physical and mental summary scores of the SF-36. Responses to the open-ended question ('Is there anything else related to your prostate cancer or its treatment that you would like to discuss?') were grouped according to four main themes: (1) the quality of patient–physician communication regarding prostate cancer treatment, (2) change in sexual identity, (3) fear of cancer, and (4) the humiliation of urinary incontinence. Typically, each response was characterized by one predominant sentiment, with seven participants contributing two distinct entries (e.g.,

change in sexual identity and humiliation of urinary in continence)

Quality of patient-physician communication

The most frequent comments expressed complaints about the care received from physicians, mentioned by 20 of the respondents. These men said their physicians provided little help in dealing with the diagnosis, choosing a treatment approach, and managing the outcomes of treatment. One man said, 'As a nonprofessional, I don't think we're given the range of information we need to make intelligent decisions - that information means data'. Men repeatedly recounted that physician failure to meet basic expectations regarding prostate cancer care was inconsistent with good medical care, and they struggled to explain it, as seen in the following quotation:

Surgeons must do a better job of working with patients prior to surgery to tell them about treatment options and what to expect. ...[T]he first two weeks after surgery were no picnic. I felt as though I was handed a real bill of goods. I would also have liked to have had more information regarding postoperative care.

Some men recalled disappointment as they learned that they had to turn elsewhere for information. Most men supplemented information they received from their physician by asking peers or acquaintances who had undergone prostate cancer treatment how they had gone about their treatment decision, what treatment they chose, and what to expect after treatment. Some searched the Internet for additional information. Although some of these men were able to piece together enough information to make a treatment decision, others indicated that often there was no one to help them sift through the information and make the treatment choice. One man said:

I felt like I received enough information from the medical staff but there was no ombudsman to help with the decision.

Two participants explained that knowing what to expect preoperatively made the occurrence of postoperative symptoms seem less emotionally distressing. For example, one man said, 'I was extremely fortunate to have good and well-trained

physicians. They did not spare any detail. Everything they said was going to happen happened'. Generally speaking, however, men believed that the medical care they received before surgery left them unprepared for their postoperative experience. Consequently, when they encountered symptoms of incontinence and erectile dysfunction after surgery, they were stunned and perceptibly distressed as illustrated in the following quotation:

The biggest thing was the information - I got no information from the doctor. I didn't expect to be totally incontinent. It totally blew me away.

Another man added, 'I would guess the lay person is 60% in the dark going into these things'. In addition to having insufficient information prior to surgery, some felt misinformed by their physicians. Many men who recollected what they were told or not told before surgery seemed to experience a sober remorse as they began to appreciate their situation:

I thought the chances of incontinence were 1% to 2%. I found out that was wrong. I felt trapped due to the treatment options. I would have traded off living to 68 or 69 for 3 years of not worrying about incontinence.

Others, while regretful, searched for solutions to help manage their symptoms. In this case, the respondent sought out solutions despite the lack of support he received from his physician:

The International Continence Society gave me referrals of men with artificial sphincters. My urologist gave me nothing like that. When I told him [urologist] what I had read in the literature, he said that he had no use for what other surgeons were doing.

One man wrote and published a book for men undergoing prostate cancer treatment so that men facing future prostate cancer treatment would have a source for relevant accurate information. Another man collaborated with other prostate cancer survivors in his community to establish a computerized database of types of treatment men had and what they were told before treatment.

The preoperative interaction with the treating physician proved to be a pivotal point in the treatment experience. The men's construction of

this experience provided a backdrop from which they considered their postoperative experience, including physical symptoms, the loss of premorbid function and roles, and expectations of a future with incontinence and/or erectile dysfunction.

Change in sexual identity

While some men were undone by their experience with urinary incontinence, other men ranked erectile dysfunction as the single, most important problem they faced postprostatectomy. Men had various levels of dysfunction; some were able to obtain and sustain an erection sufficient for intercourse but described a diminution or change of sensation, whereas others described a flaccid penis and were unable to have intercourse. Besides changes in sexual function, they also spoke of variations in desire and libido, the frustration of having libido but no capacity to function as they had previously, or shrinkage of their penis. Some confided their frustration that sex had become a very dissatisfying experience, whereas others acquiesced to life with physical intimacy that did not involve intercourse.

Men tried erectile aids such as sildenafil citrate (Viagra); however, most were uneasy with its side effects, such as headache, or said that it just did not work. One man believed that taking and planning for the effects of Viagra felt staged and took away from the spontaneity and thus, the emotional experience of sex. Some men spoke of their belief that sexuality was linked to feelings of masculinity. Consequently the lack of ability to perform sexually caused them to feel less manly. For example, one man said, 'The impotence is the thing that is really bothering me now. I feel like I've lost my manhood. I always will second-guess my decision for treatment'. Another found that he was so troubled by the link between his ability to perform sexually and his masculine identity that he became clinically depressed as a result of his experience. He said,

The male has been socialized to be a sexual performer and that is related to feelings of masculinity and identity. I'm overwhelmed by the strength of the socialization. I can overcome anything. I figured - I need the surgery, I can overcome this - but I cannot. That is a critical issue.

One man spoke of the impact erectile dysfunction and the associated perceived changes in masculinity had on the role they played with their sexual partner:

My biggest fear was that my wife was going to leave me because I wasn't a man. The women with breast cancer - it's the same type of thing.

Another man, also concerned about the role he would play with his sexual partner, expressed ambiguity about having or revealing such feelings: 'I feel anxiety about what sexual role I will play and will my wife support that. Will I be reduced to heavy petting? Cancer is such that you're lucky to be alive. It's not as if it's a heart attack, and then you're dead, or like Alzheimer's.' It as though worrying about the role one plays with a sexual partner seems comparatively frivolous to surviving cancer and therefore should not be legitimized or voiced.

The loss of sexual function was sometimes weighed within the context of other life experiences. Several older men were content to measure their loss of sexual function against the tally of other losses of aging, acknowledging that they would have taken a different view had they been younger.

Finally, men told of interactions with physicians that might be instructive for clinicians as when considering types of issues that may be difficult but important to discuss as a feature of postoperative care. The following account provides such an example:

I get conflicting stories and statistics about sex. Men don't talk about sex. It's emotionally attached to masculinity. I told my doctor [that I had erectile dysfunction] and he asked if it was a problem. I told him, well, it's not really a problem. So he said if it becomes a problem let him know.

That this man told his physician he had erectile dysfunction insinuates that it had become a problem. Indeed, this passage from his narrative reveals changes he is grappling with in his sexual identity. Yet the physician's response closes the door on any conversation between physician and patient, confirming his original premise...men do not talk about sex.

Fear of cancer

Men described their fear of cancer in general, and specifically, their fear of dying from cancer, throughout their cancer experience, that is, when their cancer was diagnosed, after they were treated, and for those few with metastatic disease, when their disease recurred. One man said, 'Psychologically, I was a mess when I was diagnosed'. Even though surgery is thought to be curative for early stage prostate cancer, these men were abruptly confronted by their own mortality. For most men, it was the first time they had seriously considered death. Some men found they were so fearful of cancer and its intimation of death, they had trouble discriminating the implications of treatment-related information. One man said, 'I was just not fully aware before surgery that I would have less likelihood of [sexual] performance. I was pressured by thinking cancer may take my life'. Other men, while able to distinguish treatment-related information, perceived treatment choices as a trade-off. 'There is a great deal of uncertainty in all the treatments, but surgery was the best choice for cure. Knowing that the cancer is out, I can deal with the incontinence', and 'There's really no choice as I see it. It's life. I'm looking at survival versus complications'.

Men who completed treatment indicated that they had, in effect, dodged a bullet, as indicated by this quote, 'I was lucky. I was very scared at first because I didn't know anything about this.' Another man said, 'I'm just lucky to be alive after cancer.' Men with newly metastasized disease were sobered and thoughtful about cancer. One man told of spending time thinking about what causes cancer and trying to figure out what could have gone wrong. Another man said, 'I am cautiously optimistic about the future.'

The humiliating experiences of urinary incontinence

Eight of the respondents used the open-ended question as an opportunity to elaborate on the troubles caused by incontinence. Urinary incontinence marked their abnormality and caused shame. One man said, 'It's weird because you're going in [to surgery] normal and you come out abnormal'. Some men thought that urinary incontinence made them feel infantilized. One man

reported, 'The main thing is that I always have to wear a pad - it's like a diaper'. Others said they felt like old men. Both images underscore their emasculated associations of the inability to control one's bladder, the act of wetting oneself, or the indication for personal protection to avoid soiling one's clothing.

Men also told of the nuisance of using protective devices, indicating that the day-to-day management of incontinence is often aggravating. Others spoke about other habitual problems, like how uncomfortable pads are in the summertime because excess sweating makes it hard to determine when or if leakage has occurred, and the combination often results in skin irritation or rash.

The ubiquitous worry of trying to conceal their incontinence was an added nuisance. Whereas some learned to manage the personal indignity of incontinence, they went to great efforts to keep their 'secret' from society. This outlook seemed to require personal reflection, negotiation and reconciliation:

I was a very active person. I used to trout fish, go boating, play tennis. Now I wear long pants because of the bag. I can't play volleyball. At a dinner party the bag blew off. I'm not going to let it ruin my life. At home it's no big deal, but in a social environment not everyone knows. To me it's a damned nuisance. I gave up a significant portion of my life.

The physical and emotional aspects of urinary incontinence frequently compromised intimate personal relationships. One man said, 'The hardest thing about this was not the cancer, but the incontinence. I wanted to be in a relationship, but it was as though I had to say, well, at any moment I could leak. I wasn't comfortable being alone with someone. I was in a relationship, but it ended.'

Some were able to provide constructive feedback and commentary on the type of support they desired from their physician. This man's remarks provide an example of what physicians might do to help patients address the emotional difficulty of facing and managing a problem like urinary incontinence:

I think doctors generally underestimate men's problems with incontinence and push them aside. The good doctors say, 'In the scope of

things – incontinence isn't a big deal. Don't let this define you.' Some doctors don't even deal with it. They are giving a lot of attention to erectile dysfunction, and that's great, but they also need to address incontinence. I wish my doctors had prepared me mentally; for example, [by telling me] BPH will increase your risk [of incontinence]. That would have been nice to know.

There was a subset of men who were utterly demoralized by the changes imposed by urinary incontinence. They saw urinary incontinence as a threat to their identity as a man, as seen in this quotation:

I'm not sure that I would have had a prostatectomy again. It is enough so that I might have taken a chance of dying from cancer.

Other topics

In addition to these predominant themes, other topics warrant mentioning. Men voiced regret about their treatment choice. To many, it was a trade-off that did not play out. Others believed they made a good decision but were misinformed about the incidence and the extent of the symptoms they might experience. Still other men believed they had been short-changed, chose the wrong physician, made the decision too quickly, were fearful of the cancer risk and chose treatment without fully understanding the consequences, or that something must have gone terribly wrong during their surgery. Regardless of the antecedent, men who experienced regret conveyed the impression that they spent countless hours attempting to make peace with themselves, their physicians, or both for what they perceived as a misstep.

Some men spoke of the positive impact that their cancer experience had on their lives, of no longer taking life for granted, not wasting time – becoming more productive at work, having a greater awareness of their spirituality, and being more empathic with people. One man said, 'If you can't find something good in this, than I don't know what... I met a lot of nice people with this illness'. Others spoke of an increased intensity in their personal relationships and better communication

with family members. Another man said, 'After this, I've resolved to help others.'

Finally, several men expressed gratitude for conducting this type of research. While affirming, their comments clearly spoke to the salience of these very personal and intimate thoughts and experiences, and – the value of the marginalia.

Discussion

These parenthetical comments reveal respondents' wish to say more than what the response scale allowed, to get back to the personal story. These stories are retrospective comments that emerged from a thoughtful assessment of the contextual grounds from which the respondents interpreted and made meaning of their experience of treatment, as well as the physical changes that occurred as a result of their treatment. For the participants, initiating this type of discussion might be quite difficult. It represents challenging their medical care and perhaps, by extension, their care provider, confronting their feelings about cancer, and disclosing private experiences, such as changes in sexual and urinary function.

The major issue raised in these findings has to do with the quality of patient–physician communication regarding prostate cancer treatment. Strikingly, they report surprises: things are not what they anticipated. Perhaps the concerns that are difficult to discuss with physicians are the very issues that turn out to be surprises. Indeed, the nature of the patient–physician communication might have been framed by men's fear of cancer, which was plainly articulated. That is, what seems to be sufficient information and communication to undergo a benign medical procedure might change dramatically when the procedure is one used to treat cancer [19, 20].

These findings also indicate that erectile dysfunction and urinary incontinence represent more than a change in function – they are threats to masculine self-esteem and integrity, and as such are integrated into daily life. This methodology allowed for discourse about the contextual backdrop from which these men considered their experience of erectile dysfunction and urinary incontinence.

These data and conclusions, however, should be evaluated in light of the study's limitations. This study was based on interviews that were conducted at an average time of 16 months after prostatectomy; they are retrospective accounts of men who lived with the outcomes of treatment and had time to think about their experiences. As such, they collapse important temporal differences related to dealing with the diagnosis and choosing a treatment, as well as contemporary events, such as managing the outcomes of treatment. Caution should be taken when attempting to predict treatment satisfaction or quality of life when using data collected long after the fact.

Although telephone survey methodology was selected to reduce distress participants might experience in sharing sensitive information, not using the more confidential survey mode of self-administration may have biased the response rate to the open-ended question. Notwithstanding the use of telephone methodology, several participants shared information about their experience and their feelings within the context of the interview that they said they had never revealed to anyone, not even their wives.

It should also be noted that although careful attention was paid to provide a balanced account of both positive and negative outcomes, these findings reflect the comments of men who were unhappy with one or more of their treatment outcomes. That is, there is a relative paucity of positive comments about their experiences. Nonetheless, these were the experiences men chose to share when asked to say more.

The value of these data is in demonstrating the quality of the marginalia that might be collected from men long after the drama of the diagnosis and decision-making has passed, after they have had a chance to chat with other men or their significant others, or participate in support groups. While telling the story is important to the patient, listening to the story improves the science of both the researcher and the clinician. Care must be taken in both research on outcomes of treatment and in clinical inquiry to develop methods that continue to capture patients' experiences systematically. These methods can be designed as open-ended inquiry, focusing, yet avoiding foreclosure, as we seek to understand the multiple changes men can experience as they

deal with a diagnosis of prostate cancer and its aftermath.

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