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## TABLE OF CONTENTS

Front Cover.....	1
Standard Form (SF) 298.....	2
Foreword.....	3
Table of Contents.....	4
Introduction.....	5
Body.....	6-11
Key Research Accomplishments.....	12
Reportable Outcomes.....	12
Conclusions.....	12-13
References.....	14
Appendices.....	15-35

## **Introduction**

### **The Role of African American and Caucasian Wives in Prostate Cancer Screening Decisions**

African American men have both higher incidence of and mortality from prostate cancer (PC) than Caucasian men. While the benefits of screening remain controversial, there is considerable acceptance of the need to improve screening among African American men in order to reduce the disparity between African American and Caucasian men. Previous research, aimed at promoting screening among African American men, may have neglected an important source of health behavior motivation of African American men: their wives. Using a conceptual model largely based upon the Health Belief Model, this study inquired about the role of wives in relation to the screening decision of their husbands. The specific objectives of this study were: (1) To examine the role of wives as health promoters or motivators of men's screening behavior. (2) To write a follow-up grant that further investigates the role of wives as health promoters or motivators of men's prostate-related decision-making. We used qualitative methods to address the first objective. We analyzed focus group interviews with African American and Caucasian wives and their husbands. The transcribed data were analyzed and then summarized to represent the perceptions, attitudes, and reported behaviors of wives associated with their husbands' decision-making. The second objective of this project was accomplished through the submission of a two year follow-up grant on prostate-related treatment decision-making.

In this report, the various steps that had been outlined in the Statement of Work are described in more detail.

### **Phase 1: Project Startup**

#### **+ meet with collaborating established investigator to outline tasks and time line**

The outcome of this discussion with Dr. Clark can be summarized into two study objectives that guided this project:

1. analyze existing data on prostate cancer decision-making by men and their wives.
2. write a grant that focuses on the role of wives in prostate cancer decision-making.

#### **+ secure access to existing data from Dr. Clark's study and arrange for transcription of relevant parts**

The proposed qualitative study on spouses' perceptions of prostate cancer and their role in prostate cancer screening decision making for their mates was conducted without collecting new data. Instead, the close collaboration with the established investigator, Dr. Jack Clark provided access to existing data on men with prostate cancer and their wives. The focus group data were transcribed and stored in text format. The data were transferred to Dr. Boehmer's computer for further analysis.

#### **+ make preliminary contact with consultant Dr. Concato**

Contrary to the initial plan of consulting Dr. Concato, the decision was made to rely on a number of others who are immediately involved in the development of the VA follow-up grant. Dr. Boehmer gained the collaboration of Dr. Lewis Kazis. Dr. Kazis who is a nationally known expert of outcome research on veterans agreed to serve as a consultant to Dr. Boehmer. In this capacity, he informed Dr. Boehmer's development of a follow-up VA grant, discussions about other possible funding agencies for a grant on the role of spouses in prostate cancer decision-making and the analysis of existing qualitative data on men with prostate cancer and their wives.

#### **+ discuss possibility of other sites (e.g., Washington, DC) and make contacts with gate keepers**

In collaboration with the established investigator Dr. Clark the possibility of including multiple sites into a VA grant on prostate cancer treatment decision-making were discussed. Later, the grant entitled "Deciding on Treatment for Early Prostate Cancer: Patients' Perceptions" was submitted to the VA (Jack Clark, PI, Ulrike Boehmer, Co-Investigator). The grant outlined: "The study will be conducted in three settings: the Department of Veterans Affairs Medical Centers in Washington, DC, East Orange, NJ, and Buffalo, NY. The three VA Medical Centers are all large (570-708 beds), high volume (7,000 to 10,000 inpatient admissions and 192,000 to 236,000 outpatient visits per year), university affiliated teaching hospitals with active research programs, including oncology. Moreover, they are the sites of the current study of age and race-related variation in men's quality of life following treatment for early prostate cancer. The selection of these sites will enable this project to capitalize on their substantial resources for clinical research in prostate cancer, as well as the collaborative relationships established for the current study of quality of life. The three sites ensure an adequate patient population for the proposed study. Tumor registry data indicate that the racial

composition of prostate cancer patient population seen in these settings ranges from 26% black in Buffalo to approximately 75% black in the Washington VA Medical Center. The estimated numbers of early prostate cancer patients diagnosed each year in these settings are as follows: Washington, DC VAMC, 115; East Orange, NJ VAMC, 115; Buffalo, NY VAMC, 84.”

**+ review literature relevant to grant**

An extensive literature search was performed using data bases such as Medline, PsycLit and Sociofile. The literature search generated a large number of research studies. The various studies can be divided into the following bodies of literature: 1. Literature on medical decision-making. 2. Gender and health including studies on social support in couples and studies on marital status and health. 3. Literature on prostate cancer or breast cancer that focused on diagnosis, treatment decision-making, or quality of life issues.

**+ review requirements of appropriate grant funding agencies (DOD, NIH, VA)**

As possible funding agencies were determined the Department of Defense, the VA, Massachusetts Department of Public Health, and the National Institutes of Health. The VA was selected as especially suitable for a follow-up grant on treatment decision-making in prostate cancer, since the established investigator Dr. Clark has an on-going VA grant that focuses on patients’ perceptions of the outcomes of treatment (ECV 97018-1). To further understand current agency policies and funding priorities of different agencies, Dr. Boehmer attended the 16<sup>th</sup> Annual meeting of the Association for Health Services Research in Chicago where a large number of agencies presented their current research agendas. Agencies such as the Centers for Disease Control and Prevention, the Robert Wood Johnson Foundation, the Kaiser Family Foundation, and the Agency for Health Care Policy and Research presented their agendas, explained their requirements, and gave helpful information for new investigators who seek funding through these agencies.

**Phase 2: Data analysis**

**+ analyze transcripts**

**+ consolidate themes that emerged in interviews**

**+ write preliminary data section for grant and background section**

The data analysis of the existing transcript of focus groups with men with prostate cancer and their wives was an important part of this project. The principal investigator spent considerable time and effort to code the interviews using the qualitative analysis software HyperResearch. The interview analysis focused on the specific aims of this project, to determine the role of wives in prostate cancer related decision-making. The perceptions of women on diagnosis and treatment decision making were investigated through the identification of passages in the interviews with wives that express these women’s reactions to the diagnosis and the process that led to a treatment decision. These interview passages were assigned codes that refer to women’s specific experiences with treatment decision-making. The same coding procedure was applied to their husbands’ interviews. The availability of separate husbands’ and wives’ interviews allowed the comparative usage of interviews that led to the emergence of interesting differences in

the perspectives of couples. In particular, our analysis found that secrets existed between spouses with regard to prostate cancer treatment decision-making.

The careful analysis of the collected data resulted in significant findings related to the process of decision-making by heterosexual couples. These findings have already been summarized into a manuscript that is suitable for publication in a medical journal such as *Journal of Urology* (please see a draft of the manuscript in the appendix). Further findings will be summarized into an additional manuscript that is also intended for publication in a medical journal. Some of these findings were also included into the preliminary data section of the grant that was submitted to the VA.

Further, the findings of the focus group data were influential in shifting the research focus of the follow-up grant. Prior to the data analysis it was assumed that a follow-up grant will focus on the role of wives in men's **screening** decisions. However, the analysis of focus group data of men with prostate cancer and their wives shifted the research focus towards the role of wives in **treatment** decision-making. The women who recalled their experiences with their husbands' prostate cancer diagnosis made statements that appeared to indicate that their involvement in their husbands' treatment decisions only begun **after** the husbands had been told they have prostate cancer. Generally speaking, women tended to have little knowledge about their husbands' prostate-related choices prior to the diagnosis. Maybe the time prior to the diagnosis and wives' roles in men's preventive decision making has been truncated from these women's recollection in the face of the diagnosis with metastatic prostate cancer. Nevertheless, the findings persuaded us to focus a follow-up grant on treatment decisions in early prostate cancer rather than screening decisions.

### **Phase 3: Interview Questionnaire Development**

- + **develop focus group protocols and discuss with established investigator and co-investigators at sites**
- + **prepare interview questionnaire using themes that emerged from existing data**
- + **discuss questionnaires with established investigator and consultant**
- + **finalize selection of sites**
- + **finalize interview questionnaire**
- + **finalize focus group protocol**
- + **write methods section for grant**

In collaboration with the established investigator Dr. Jack Clark a VA grant entitled "Deciding on Treatment for Early Prostate Cancer: Patient Perceptions" has been submitted to the VA. In the context of the grant submitted to the VA, it was decided not to use focus group interviews as the statement of work assumed for a future grant. Instead, the submitted grant contains a survey part and an in-depth interview part with men with prostate cancer and their wives. In preparation of this grant many instruments have been reviewed. For instance, the Patient Treatment Preferences questionnaire developed at the Dana Farber Cancer Institute, the Decisional Conflict Scale and instruments that measure quality of life such as the SF-36, the Medical Outcomes Study (MOS) Marital Function scale and the brief profile of mood states have been reviewed for their inclusion into the survey part of the grant. Further, the literature review of studies that include spouses in studies of specific diseases detected the important work that had been performed in the area of heart disease. After contacting Dr. James Coyne, the

instrumentation of the original heart project was obtained. The spouse version of the Family Heart Questionnaire includes two spouse coping scales, the protective buffering scale and active engagement.

In discussions with the established investigator an interview protocol for wives of men with prostate cancer was decided. Wives to men with prostate cancer will be selected for in-depth interviews, lasting approximately two hours. The interviews will be open-ended, but semi-structured. They are designed to elicit extended narratives of wives' experiences with their spouses' cancer. Wives will be asked about their perceived role in the process, their perceptions regarding interactions with physicians and the health care system, and their understanding of the treatment options and risks. Wives will be asked about the level of communication they actually had with their husbands' physicians and the type of conversations they had with their spouses. The goal is to assess whether couples openly share their worries regarding the cancer diagnosis and the treatment consequences, such as sexual dysfunction. This assessment is considered an especially important research goal in the light of the findings of the qualitative analysis of focus group interviews with men with prostate cancer and their wives who were rather secretive about their prostate cancer diagnosis and treatment decision-making.

#### **Phase 4: Final Report**

- + **write a final report for grant funding agency, summarizing the accomplished tasks**
- + **discuss grant with consultant and established investigator, and future co-investigator**
- + **confirm research team**
- + **finish writing grant**
- + **apply for human subjects approval**

In collaboration with the established investigator Dr. Jack Clark a VA grant entitled "Deciding on Treatment for Early Prostate Cancer: Patient Perceptions" has been developed. An important part of this proposal is the inclusion of wives in treatment decision-making. The specific aims of the grant specified:

"we propose to study the first outcome of care for prostate cancer: the decisions men reach regarding treatment. Our approach is patient-centered and sociological. We will focus on the problems that men perceive when presented with a diagnosis and set of treatment options. We will examine men's perceptions of their social interactions with physicians and significant others as they work to resolve *their* problems of prostate cancer, and come to a decision regarding treatment. *We will examine variation in men's significant others with whom they discuss treatment decisions, perceptions of their decision making and their satisfaction with their decision making, with respect to the treatment choices they ultimately make, and their age and race.* We will accomplish these goals through a combined quantitative and qualitative research strategy. Using a survey instrument developed in our previous research, we will conduct a survey of VA patients with a recent diagnosis of early prostate cancer. *We will then conduct in-depth interviews with a subsample of the survey respondents and one group of significant others, wives, in order to elicit their accounts of their experiences dealing with prostate cancer and reaching a treatment decision.* These data will enable us to accomplish the following specific aims:

1. Examine differences in men's perceptions of their decision making regarding treatment for early prostate cancer by their choice of treatment, their age, and their race.
2. Examine variation in satisfaction with treatment decisions with respect to their perceptions of treatment alternatives and the process through which they reached treatment decisions.
3. ***Determine the qualities of satisfying and unsatisfying treatment decision making experiences for men with prostate cancer and their wives.***

The background section of the grant entailed a section that specifically addressed the role of spouses in the treatment decision process:

"Prior research on prostate cancer indicates that wives appear to play an important role. However, so far research that understands the role of wives in prostate cancer decision making and determines how much of a role spouses have in the final treatment decision is largely nonexistent. In the clinical practice, physicians are used to the situation that prostate cancer is among married men experienced as a disease that affects the dyad. Some wives even make statements such as, "we have prostate cancer, what will we do about it." Clinicians frequently find themselves explaining treatment options to patients and their wives or as one study put it, answering the wife's questions regarding self-care and prostate cancer treatment [1, 2]. In some clinics or by a large number of individual physicians, men are encouraged to bring their wives to all prostate related appointments.

Many studies of health behavior and health decisions support this view. They find that older men tend to rely heavily on their spouses with regard to health related decisions and tend to avoid responsibility for their own health [3]. Instead, the men rely on their wives to collect health information and to schedule their medical appointments [3]. Another study that focused on older couples' decision making on health issues concluded that most couples stated they made health decisions jointly. However, in the event that a final decision needed to be made, wives were identified as the primary deciders, whereas none of the men had made any final decisions [4]. A study that pursued the question of ethnic rather than gender differences in decision making found that ethnic and cultural differences exist among the elderly. This study found that ethnic minority patients are less likely to self-express his or her health care wishes regarding end of life decisions compared to white patients [5].

Whether these differences in decision making apply to prostate cancer treatment decisions as well, will be determined by the proposed study. Prior studies that have a specific focus on prostate cancer largely neglected to examine the role of wives and their input in the final treatment decision. One of the few studies that considered wives' roles in the prior to treatment phase, reported that wives focused on the marital relationship and interpreted their role of wife as being an agent for their husbands [2]. Another study focused on differences between men and women regarding screening behavior. The findings of this study suggest variability in evaluations of prostate cancer treatment outcomes and that men and their wives have different preferences. Not screening is the strategy, men favored, while having their husbands screened was the wives preferred strategy. Couples differed in their decision making styles. In some cases, the husband would have the final say and the wife deferred to him, whereas in other couples, the wife would argue forcefully for not trading time together, regardless of the complication a diagnosis and more importantly, prostate cancer treatment might cause [6]. In this study,

wives took clearly a more aggressive stand. They associated little burden with complications of treatment, preferring to maximize their husbands' quantity of life regardless of complications. This study indicates that an understanding of the couple's decision making styles, and knowing who the couple's main decision maker is, is paramount for a patient centered approach to prostate cancer.

Some prostate cancer treatment can cause sexual dysfunction. The threat of experiencing a major change or loss of sexuality will have implications for the marital relationship and might affect treatment choices. However, men and women might weigh the threat of sexual dysfunction differently and therefore, favor different treatment choices. The specific threat of sexual dysfunction and the prostate cancer diagnosis itself burdens the marital relationship. Through other studies we know that couples may not communicate about the implications of a particular treatment choice, either because they are lacking appropriate language or adequate knowledge to initiate a marital discussion [7]. Many studies that focus on marital status and cancer, neglect the first outcome of cancer care, the decision making process. Instead, many studies focus on the post treatment aspect such as the adjustment to living with a cancer patient and the marital distress that might occur after the chosen treatment [8]. Hence, the proposed study's focus on understanding decision making in the marital context will make an important contribution to the first outcome of patient centered care.”

For the submitted VA grant, an IRB application was submitted and the decision pending at the time of the grant review. Despite an excellent research team that agreed to participate in this multi-site study and considerable preliminary data that underscored the significance of this research question, the VA grant was not selected for funding. In particular, reviewers questioned the feasibility of a successful recruitment of wives for this proposed study. In spite of the negative outcome of this grant submission, we decided to revise the grant and resubmit it at a later time with the hope of a more positive review.

## **Key Research Accomplishments**

- Developed a productive collaboration with the established investigator, Dr. Clark
- Developed an in-depth understanding of research in the area of family decision-making in cancer.
- Analyzed existing data.
- Consolidated findings of data analysis into two manuscripts suitable for publication in medical journals
- Increased grant writing ability through the joint work on a VA grant.
- Submitted a follow-up grant to the VA
- Produced a grant that can be revised and resubmitted to another funding agency

## **Reportable Outcomes**

- Developed two manuscripts that will be finalized and submitted for publication:  
Ulrike Boehmer, Jack A. Clark, et al. (in preparation). "Secrets between spouses and prostate cancer treatment decision-making."  
Ulrike Boehmer, Jack A. Clark, et al. (in preparation). "Don't ask, don't tell in heterosexual couples with prostate cancer."
- Applied for VA funding
- Training in family-related decision-making in cancer led to the design of a similar grant in the area of breast cancer that will be submitted to the Massachusetts Department of Public Health on August 26, 1999

## **Conclusions**

This project generated findings that indicated the importance of including wives in studies on prostate cancer. Our findings displayed how much information would be lost without the inclusion of the spouses' perspectives in attempts at understanding the meaning and process from prostate cancer diagnosis to choosing a treatment. Our finding that men chose to keep quiet about their prostate-related problems raised important questions about the influence third persons, and wives in particular can have on health-related decision-making.

The focus of this project was on understanding the influence of wives on their mates' screening decisions. Prior research indicated that certain health behaviors (e.g., prevention) or decision-making about treatment were influenced by significant others [9, 10]. For instance, research found that older men preferred to avoid responsibility for their own health and often rely on the women in their lives to collect health information and sometimes even schedule appointments with their physicians [3]. However, the married men in our study who kept their health problems from their wives appeared to put themselves at a disadvantage in that they forego the benefits of marriage that prior research indicated. In that sense our finding appears to contradict the dominant belief that married men are in better health because their wives take on a major role in maintaining health. Therefore, future studies with a larger sample and also more specialized data (on men without prostate cancer and their wives) need to be conducted to understand the role of wives on men's screening decisions. The tendency of men to avoid disclosure of their

prostate-related health problems to their wives and sometimes to even postpone doctor visits requires clarification by future studies with regard to the stage of the disease at diagnosis.

We found it of interest that we detected a preference for nondisclosure among men who were almost exclusively diagnosed with advanced prostate cancer. Hence, our future research is focused on determining whether the level of secrecy we detected in men with mostly advanced disease, can be found in men with localized prostate cancer as well. We decided to explore the issue of wives' influence on treatment decision-making among men with early stage of the disease in a grant that was submitted to the VA.

However, we still believe it is also an important question to investigate the influence of wives on men's preventive decision-making in prostate cancer. Unfortunately, the limited data available to us prevented us from contributing considerably to answering this question. Hence, future grants ought to collect data on men without prostate cancer and their wives to reach a more in-depth understanding of this important research question.

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## Appendices

**Manuscript in preparation** Ulrike Boehmer, Jack Clark, et al.  
Secrets between spouses and prostate cancer treatment decision-making

Research on prostate cancer diagnosis and treatment has predominantly explored men's perspectives. Only few researchers considered the perspectives of spouses on prostate cancer diagnosis and their involvement in treatment decision making. One study found that married men gave low preference to information on self-care and the researchers concluded the reason for this may be that these men expected their wives to elicit this type of information [1]. Further, two thirds of the men in this study preferred a passive role in treatment decision-making. However, wives were encouraged to be present for clinic appointments, but the role of wives in the treatment decisions was unclear [1]. Another study evaluated the decision-making process of prostate cancer treatment of couples and found that while some men claimed decision ownership, their wives and physicians influenced the decisions that were made [2]. One study that tried to understand treatment choices of men with advanced prostate cancer found that wives are more frequently part of discussions among men who chose hormonal therapy, whereas men who chose surgical treatment involve most frequently their physician alone [3]. Further the study indicated that the views of men and their wives were closely aligned regarding reasons for treatment choices and satisfaction with the chosen treatment [3].

Commonly, treatment decisions are made in medical encounters that involve at least two parties, the doctor and the patient. However, especially elderly patients are known to frequently involve a third person into their medical encounters with physicians [4, 5]. Sociologists, foremost Georg Simmel, argued that a change in group size, i.e.,

from a dyadic to a triadic relationship alters the dynamic of interactions. Compared to the traditional physician-patient dyad, the presence of a third party changes the interaction because members of triads form coalitions, such as patient and third person vs. doctor, third person and doctor vs. patient, patient and doctor vs. third person [6]. While one medical encounter allows for many different kinds of coalitions, it was also suggested that fewer coalitions will be formed when treatment decisions have to be made under time constraints, such as electing a treatment for a post surgery woman with breast cancer [5]. Others' conceptualizations focused on the role function the third person performs during the medical encounter [7, 8]. Adelman et al. suggested three roles for third persons: the advocate, the passive participant, and the antagonist [4]. Charles et al. outlined the following roles for third persons that partake in treatment decision-making: 1. Information gatherer, recorder or interpreter, 2. Coach who prompts the patient to ask physicians more questions, 3. Advisor who advises on selecting a treatment option, 4. Negotiator who arranges the timing or place of the treatment, 5. Caretaker who supports the patient's treatment decision [5]. Empirical research investigated the effects of a third person on the content and the process of medical visits [7]. In triadic visits patients raised fewer topics, were less assertive and there was less joint decision-making compared to dyadic visits [9].

The present study analyzed prostate cancer diagnosis and treatment decision-making from both men's and their wives' perspectives. Our research investigated how men with prostate cancer and their spouses described retrospectively their involvement in the prostate cancer diagnosis and the treatment decision-making that followed.

## **Methods**

The data reported here were based on tape recordings of focus groups that were conducted for a larger study that intended to develop scales to measure quality of life in men who have been treated for advanced prostate cancer. The process of developing the measures of quality of life and their subsequent testing is described in detail in Clark et al. [10]. These focus groups of men who have been treated for prostate cancer and focus groups with some of their wives had not the specific purpose of comparing men's and wives' perspectives on diagnosis and treatment of prostate cancer. However, part of the intensive qualitative study that was conducted were interviews with some men and their wives in which the men and women were asked to describe in their own words their experiences with the diagnosis and the treatment decision-making. Hence, for this study we used the transcripts of five couples who have been interviewed separately in focus groups of patients and wives. The interviews of spouses were concurrently on the same day, so spouses could not exchange their feelings about questions or the interview situation in general. The transcripts of the focus groups were analyzed with the purpose of understanding the perspective of both men and their wives on diagnosis and treatment decision of prostate cancer.

### ***Description of the sample***

The five married men and their wives whose interviews have been analyzed had the following sociodemographic and clinical characteristics. Three men were white and two were black. The racial composition of wives was identical since there were no mixed racial couples in this sample. The men's age ranged from 58 to 75 years at the time of the interview in 1993. The length of time since they were diagnosed with prostate cancer

ranged from 6 months to 41 months prior to the interview. One man had localized disease, whereas the other four men had metastatic prostate cancer. One of the men with advanced prostate cancer had just been told that his cancer metastasized to his bones. The treatment these men received varied as well. Two men were exclusively treated with hormonal therapy, two men surgically, and one man with a combination of both treatments.

### **Diagnosis**

Our analysis of couples' recall of the circumstances surrounding the prostate cancer diagnosis illustrated that men had had problems long before they were diagnosed with prostate cancer. Most men recalled that in the time prior to their diagnosis, they experienced problems with urination. The men reported how they suffered from changes such as too frequent or slow urination. Their initial response to the physical problems varied. One man went to see his primary care doctor who prescribed antibiotics for his problem. Other men gave various reasons for postponing a consultation with a doctor. One man explained that he ignored his problem assuming it had to do with growing old. He also ignored his primary care doctor's suggestion to see an urologist for approximately one year. Similarly, another man recounted that he had problems but that he avoided doing anything about it until he was hospitalized for other reasons. He recalled the following circumstances:

I had had problems with my urine. I would get up early in the morning, go to the bathroom and when I get there I would have to stand there, ... after I stand there for a few minutes it would come very slowly. ... And as soon as I would go back to bed I had to get right back in and do the same thing

all over again. ... And my brother had been trying to get me to have a checkup on my prostate but I just, in fact, I put it off. So, uh, the doctor here at the hospital, I was in here for something else, in fact I had surgery on my knee, and I was telling one after I came back I told the doctor about how my urine was getting and my lower back bothered me. So they recommended to go to the urology clinic up here and have a prostate test, you know.

One theme underlies these men's stories, there is no mention of their wives. These men consulted their doctors regarding these physical problems at some point, but generally postponed disclosing their physical problems. Only one couple stood out as an exception to this pattern in that husband and wife both told the same story. She begun her report by stating that that her husband suffered from urination problems and that he had had to see an urologist to undergo some testing. The husband described his self-care behaviors, such as undergoing annual check-ups for 25 years, and that he disclosed problems with urination to his doctor during his annual exam. The doctor advised him to see a urologist. The man recalled in his interview how the urologist was chosen with the assistance of his daughter. This is a departure from other men's accounts in that other men never mentioned their wives, yet alone their children in the context of recalling their urination problems. This lack of references to their spouses was then reflected in the spouses' accounts in that these appeared unaware that there ever was a period prior to the diagnosis during which their husbands experienced physical problems. Hence, most spousal accounts differed. The men spoke of initial health problems prior to their

diagnosis, while the wives began their description with the actual event of prostate cancer diagnosis.

Wives accounts began with a description of how they found out about their husbands' prostate cancer diagnosis. One wife, for instance, stated that her husband's prostate cancer was discovered during a regular annual exam, while her husband told the interviewer that he had problems with his urination for years. Many wives recalled the disbelief or shock they experienced once they found out about their husbands' diagnosis. For instance, one husband told the interviewer that his wife had a car wreck the day she found out that he had prostate cancer. Hence, the accounts of wives and men who described the prostate cancer diagnosis display a systematic discrepancy. Men's accounts included a description of their urination problems, whereas the earliest event in wives' accounts was the diagnosis itself. Since the inconsistencies between men's and wives' accounts were consistent, they could not be explained by variation in their memories. Instead, we interpreted these discrepancies as an indication of secrets between spouses, in that the men were troubled by urination problems, but never disclosed this information to their wives.

More agreement existed between men's and wives' accounts regarding the prostate cancer diagnosis itself. Generally, the physician informed the patient about the diagnosis. Wives found out afterwards through their husbands. Unfortunately, there were few details in men's and wives' accounts about the exact ways in which doctors told their patients and men told their wives. Some wives began their accounts by stating, "He just told me the doctor said that he had prostate cancer and they would treat him." One

couple's account of finding out about the prostate cancer diagnosis, however, showed major discrepancies. The husband told the interviewer the following story:

[The doctor] just said, "*You know, I think that it might be cancerous.*"

And so he wanted to get it checked out real soon. But I, you know, *it was a while before I told my wife about it*, you know.

INT1: Why was that?

MAN: Well you know how women get upset but it never upset me.

INT2: How long is a while was it, you know, a day or a week or?

MAN: No I say *it was about three weeks*. ...

INT1: How did you break the news to her? You said you kept silent for three weeks?

MAN: Well the doctor, uh, he kept calling the house and telling her to tell me that after the report came back that I needed to get in touch with him and at the time I was pretty busy working long hours and everything and *I had her pick up my tests* and everything and that's how she really found out about it.

To the contrary, his wife told a different story:

[T]he doctor had told him *almost a year ago* that he had it [prostate cancer] but he's hard of hearing. And he didn't have a hearing aid, because he had the hearing aid in the layaway at Sears. The week before he got the hearing aid out the doctor gave him the, what men dodge, the finger. He ... went to get a physical ... And the test came back that Friday and *the doctor told me to come by and pick up the test*. And when I got to the

to sit down he wanted to talk to me and had my  
and I told him no, and he said well it's wrong for  
you without him present. And I said if there is  
in my husband I want to know and I want to know  
well your husband has prostate cancer and he didn't  
tell you about it? I said, no, he didn't. So I went home crying.  
... And I asked him, I said, why didn't you tell me that the doctor told you  
seven or eight months ago that you had prostate cancer. ***He said, he didn't  
tell me that.*** So then I knew that he hadn't heard him, you know.

[emphasis added]

Clearly, this couple's descriptions displayed gross discrepancies. They included contradictory statements about who initiated the wife to pick up the test. Further, the amount of time the diagnosis was supposedly known to the husband but not to his wife varied from three weeks in his versus eight months in her account. Most importantly, however, it is unclear whether the husband ever knew about the diagnosis before his wife found out about it. While this appears to be an extreme case of secrecy in a couple, it underscores once more that most of the interviewed men did not disclose physical conditions that were most likely warning signs of prostate cancer to their wives.

### ***Treatment decision-making***

The next part of our analysis focused on the steps that were taken after the diagnosis was known to both, husband and wife. In particular, our analysis focused on the amount of participation of spouses in treatment decision-making and how the couple recalled the triadic relationship of doctor, patient and spouse. After we had determined

that most men were secretive about prostate-related health problems prior to their diagnosis, we analyzed the interview data for indications whether the diagnosis was a turning point in the closeness of the couple. We inquired men's and wives' statements for hints that a prostate cancer diagnosis was such a life changing event that sequentially led to more sharing of health related problems and the treatment decision in particular. The inclusion of spouses in the decision-making that followed the diagnosis of prostate cancer was a particular focal point of the analysis. The interaction processes of doctor, patient, and spouse triad as reflected in the accounts of husbands and wives were categorizable into three types.

The first type of decision-making process was dominated by a negotiation between doctor and patient, while the spouse had a peripheral role at best or was otherwise a nonparticipant. This particular type of decision-making was an extension of the secretiveness that men displayed with regard to initial health problems. In this type of interaction process, the men were heavily focused on the doctor, while their wives appeared to be almost excluded from the decision-making process. While these men mentioned no discussions about treatment choices that took place with their wives, their recall of how they made their treatment choice focused on interactions they had with the doctor and that these determined their treatment decision. Moreover, these men's focus on the doctor was even heightened by the expression of the desire of receiving more guidance from the doctor. One man clearly expressed this with the following words: "My doctor didn't direct me well. He explained then left it up to me." The same man also addressed the importance of trusting his doctor, "If you trust your doctor and you make a

selection, and he says, that's a good choice... It gives you a boost." This man initially wanted his doctor to make all decisions for him,

It would be nice to have someone make all of your decisions for you.

Then you're not responsible. But I'm glad now that I made my decision.

INT1: You are glad now that you made your decision?

MAN: Well, at the time, you're all confused. Frustration, you're running something blind. Here's a guy who knows all about everything, and you want him to tell you what to do. You want him to coach you ... .

These men's strong focus on the doctor was accompanied by the almost elimination of their wives from the treatment decision process. The accounts of wives confirm this in that wives appeared to be so poorly informed about discussions that must have occurred in the context of treatment decisions that it was not clear whether a triadic encounter between doctor, patient, and spouse ever took place. For instance, one wife reported, "the doctor said that he had prostate cancer and they would treat him. And they gave him options. I think that they said the medication and the shots would be better or something." While these men talked to their wives in some capacity about their treatment choice, it was not clear whether the spouses had ever a chance to question the treating doctor. In any event, the final decision was not made jointly by the couple and the wives' perspectives appeared to have little influence on the final treatment decision. One wife stated,

well he wanted to get it over with, that's kinda the way he felt about it. ...

INT1: How much of the decision was made by the doctors versus how much by ...?

SPOUSE: I think it was, uh, it was probably a joint decision but I don't really think my husband would have gone along with anything that he really didn't believe in even if I had been against the treatment and wanted something else. I think that, you know, he would have ended up doing what he really wanted to do.

This type of decision-making excluded spouses from the process, while the decision-making was predominantly negotiated between patients and their doctor whose opinion and preferences they wanted to elicit and use as guidance for their final decision.

A second type of treatment decision-making was characterized by an increase in the participation of spouses in decision-making. However, the participation of wives was not initiated by the men, instead, physicians initiated the inclusion of wives into the decision-making discussion. The men's attitudes were not remarkably different from the attitudes and values of men in the first interaction type. These men were not different from the men of the first type in that they made no efforts to elicit their wives participation or to inquire about their wives' preferences. However, the physicians initiated the participation of spouses in treatment decision-making. The physicians contacted their patients' wives because the communication with the patients themselves apparently was difficult. One patient's lack of response to repeated phone calls by the physician caused the physician to disclose the diagnosis to his wife. After that initial disclosure by the physician, the wife was highly involved in deciding on additional diagnostic procedures and finally on a treatment. Similarly, another man's job required him to spend a lot of time on the road. The doctor who tried to get in touch with him was unable to reach him by phone. Finally, the doctor began to deliver messages to the

patient's wife and to communicate with her, thereby pushing her into a more active role when treatment decisions were made. These spouses function as negotiators or interpreters between the physician and their husbands, but it was the physician who enabled them to take on this role.

Finally, the third type of interaction process differed from both of the prior models of triadic decision-making. In this type of interaction process the couple dominated the decision-making, while a physician took on a role of lesser importance. The patient worked with the spouse, it became a joint affair or could even be a family affair. All aspects of his condition and treatment options are disclosed. The spouse participated in medical appointments based on the patient's initiative and by no means the physician's. This type captured, for instance, the man who involved his family early on, while choosing a urologist for undergoing diagnostic testing for prostate cancer. Once, the diagnosis was announced and the exploratory surgery indicated that the cancer was no longer localized to the prostate, the immediate family got even more active, that is, the daughters and the wife got highly involved in finding out and educating themselves about available treatment choices. It appears that his daughters and wife pushed the patient into negotiating treatment choices with the doctor. The patient himself was more prone to follow doctor's orders and appeared to prefer a passive position towards the doctor. He told the interviewers that it took some coaxing before he was convinced to demand a certain treatment from his doctor.

They [the daughters] began to work on me to be sure that I would seriously consider this treatment. Whatever my doctor does, that's what I'm going to go along with. Who am I to try to second-guess? He may

already have the treatment available. They warned me to be sure and talk to him before I chose a method of treatment. So I reluctantly agreed that I would discuss it with the doctor.

In addition to the daughters who did a lot of the background work of finding out about new and successful prostate cancer treatments, the man's wife took on the role of being her husband's advocate in relation to the doctor. She recalled,

so on this Friday night before we were to go into the doctor I started getting nervous because we had not discussed this treatment with our doctor at all. We had not seen him since the two-week recuperation period. So my husband and I were sitting out on the patio. And I said, "I am getting so scared." And he said, "What about?" And I said, "I am so afraid that Dr. X is not going to agree with us on you taking this treatment." I said, "What will we do if he says he doesn't want to give you this treatment?" And he just sat there thinking for a few minutes and he said, "Well we will just change doctors if that is what you want to do." So he said, "Well I tell you what, why don't you just go in there and call him."

Clearly, in this type of triadic interaction a strong coalition was formed between patient and spouse versus doctor. The initiative of this man's family included working on him to give up his more passive inclination towards the doctor. But in the end, the husband himself became an advocate. He reminisced,

I've done a lot of research.

INT1: You think if you had not done that that your doctor would not have recommended it?

MAN: I don't think that he would have recommended it. .... We were so strongly convinced after three or four months that I had the people who manufacture these drugs send information to my doctor. I never had seen it on the wall. I see it in there now, the Lupron brochures and the Flutamide. They are good pamphlets. I pull them up and I give them to people at church when they ask me about it. And I say, tell the doctor, not just the one who treats me, but all the doctors there. Ask them about this treatment ... .

### ***Discussion***

This analysis indicated how much information would be lost without the inclusion of the spouses' perspectives in attempts at understanding the meaning and process from prostate cancer diagnosis to choosing a treatment. One of the important contributions of this research was that it investigated the participation of spouses at the time of diagnosis, whereas most research that considered spouses focused mostly on adjustment to cancer and on spouses as caregivers [need citations]. The spousal perspective is more likely sought during the treatment decision-making process or even later, in the context of quality of life after the treatment of prostate cancer [need citations]. Our finding that men chose to keep quiet about their prostate-related problems raised important questions about the influence third persons, and wives in particular can have on health-related decision-making.

Prior research indicated that certain health behaviors (e.g., prevention) or decision-making about treatment were influenced by significant others [11, 12]. For instance, research found that older men preferred to avoid responsibility for their own

health and often rely on the women in their lives to collect health information and sometimes even schedule appointments with their physicians [13]. Married men are considered to be in better health because their wives encourage positive health behavior, such as visiting a doctor for checkups, screening, and other means that lead to the detection of disease in its early stage [14, 15]. This benefit of marriage was also established in prostate cancer, in that currently married men were more likely to be diagnosed with localized prostate cancer [16] and more knowledgeable compared to men who were not married [17]. Hence, the married men in our study who kept their health problems from their wives appeared to put themselves at a disadvantage in that they forego the benefits of marriage that prior research indicated. In that sense our finding appears to contradict the dominant belief that married men are in better health because their wives take on a major role in maintaining health. Therefore, future studies with a larger sample need to be conducted to confirm our results.

One earlier study that focused on cues to action in prostate cancer screening can be interpreted as a certain confirmation of our finding that men tended to avoid disclosure and tended to postpone doctor's visits [18]. This earlier study used a random sample of men who were over 50 years of age or at high risk for prostate cancer and who had undergone screening for prostate cancer. While no information about the results of these men's tests were provided, we found it of interest that noticing symptoms ranked low in importance for obtaining prostate cancer screening. Noticing symptoms ranked as the 10<sup>th</sup> of 13 reasons and even lower among men who were 70 years of age or older (12<sup>th</sup> of 13<sup>th</sup>) [18].

The tendency of men to avoid disclosure of their prostate-related health problems to their wives and sometimes to even postpone doctor visits requires clarification by future studies with regard to the stage of the disease at diagnosis. We found it of interest that we detected a preference for nondisclosure among men who were almost exclusively diagnosed with advanced prostate cancer. Hence, future research ought to determine whether the level of secrecy we detected in men with mostly advanced disease, can be found in men with localized prostate cancer as well.

We also considered that our finding could be related to men's age. May be the nondisclosure we detected is more prevalent among an older cohort compared to younger men. After all, our sample consisted of a group of men whose age ranged from 58 to 75 years. An alternative explanation for our finding is that we interpreted something as secretive behavior by men, but that in fact it served a different function in men's accounts. Sociological studies of illness and for instance, research studies that focused on women with breast cancer, frequently indicated that those who have been diagnosed with a chronic or terminal disease try to make sense of this life-changing event [**whom do I cite?????**]. Hence, we consider the possibility that the men in our sample who told the interviewer that they had urination problems prior to their diagnosis might have reconstructed or reinterpreted their past in order to make sense of their diagnosis. Only an intensive qualitative study of men with prostate cancer will be able to evaluate if "making sense" was the motivating force for men's recall of urination problems that they kept quiet and apparently left untreated for an extended period of time. We chose not to interpret this behavior as "making sense." In our opinion the consistency with which most

wives appeared to be unaware of prior problems their husbands experienced, indicated a lack of spousal communication about men's vulnerabilities.

Other aspects of our analysis confirmed prior research. An earlier study by Cassileth found that while seventy percent of men with advanced prostate cancer discussed the treatment of choice with someone at home, 30 percent either had no one to talk to or elected not to discuss the issue [3]. Our study found evidence of both, discussions with wives and almost exclusion of wives from treatment decision-making. Similarly, our study confirmed that many men prefer their doctor to make decisions for them. An earlier study by Davison et al. that focused on information and decision-making preferences among men with prostate cancer concluded that two thirds of men preferred a passive role in treatment decision-making [1]. Another study that assessed prostate cancer treatment decisions of couples found that while some men claimed decision ownership, their wives and physicians influenced the decisions that were made [2]. We found the same pattern in our sample of men with prostate cancer. For instance, one man whose daughters and wife researched treatment options for him, claimed towards the interviewer in the focus group, "I've done a lot of research." Further, we found that the results of our analysis regarding the triadic treatment decision-making by doctor, patient and spouse were consistent with the findings of prior research on medical encounters that included a third person. We found evidence of different coalitions that we categorized into three types of treatment decision-making interactions. We had coalitions of patient and doctor vs. spouse, spouse and patient vs. doctor, and one type that was formed between physician and spouse vs. patient.

Of most interest in our study was, however, the connection between the initial secrecy by men and the types of coalitions men formed during the treatment decision-making process. Men who initially hid prostate-related problems from their wives were found either in a coalition with the doctor or became the object of a spouse-physician coalition. Not too surprisingly, the coalition of patient and spouse, however, emerged from a spousal relationship that included sharing of health problems prior to the diagnosis of prostate cancer. The exploratory nature of this study prevents us from making more definite statements about this pattern. Later research studies ought to consider the perspectives of physicians as well. Our study was based on both patients' and wives' accounts of the treatment decision-making process and our interpretation of the spouse's position was informed by the patient's perspective. Other studies might include physicians' interviews that would enable one to choose between interpreting the spouse's position from the patient's versus the physician's perspective.

Further the different types of treatment decision-making point to important questions regarding policy implications. Of the three parties, doctor, patient and spouse, that were discussed with regard to decision-making, it is the physician who has most likely the most experience with different decision-making styles. Physicians will have experienced the range of men who decided on their treatment after talking to the physician only to men who include an entire support network into their decision-making. Therefore, on behalf of the care providers a recommendation about the inclusion of trusted others could be expressed as routinely as the suggestion to their patients to obtain second opinions. Physicians might also consider discussing with their patients the implications and benefits of including spouses or significant others into other health-related decisions,

such as prostate cancer screening decisions and not only after a diagnosis of prostate cancer has been made.

Previous prostate cancer research that investigated treatment decision-making pointed out that wives are more likely involved by men who chose hormonal therapy, whereas men who chose surgical treatment involve most frequently their physician alone [3]. Our limited sample size prohibited us from making firm statements regarding the previous findings. In our sample, the two men who primarily involved their physician in their treatment decision one underwent surgical and the other hormonal therapy. The type of treatment decision in which wives got involved based on the physician's initiative applied to men who were both treated surgically, whereby one of them had additional hormonal therapy. In the third type in which spouse and patient presented the physician with their preferred treatment, the chosen treatment was hormone therapy.

As other studies of men with prostate cancer we had only limited data on spouses. An urgent aspect of future prostate cancer research is to investigate the participation of others than spouses in diagnosis and treatment decision-making. So far research completely neglected the perspectives of non-married men. We know little about the degree to which non-married men involve significant others prostate related decision-making or who these others are. It is mandatory for future research to incorporate the multiplicities of men's identities and life situations. Even our limited data on married men indicated that non-spouses were in some capacity part of various crucial decisions in the process beginning with the pre-diagnosis time to the prostate cancer treatment decision. Finally, this analysis indicated that health-related decision-making in prostate cancer does not occur in isolation. Instead, prostate cancer related decisions are a social

process with many dimensions and frequently more participants than the patient and doctor.

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