

# Experiences of Uncertainty in Men With an Elevated PSA

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Caitlin Biddle, MA<sup>1</sup>, Alicia Brasel, MPH<sup>2</sup>,  
Willie Underwood III, MS, MPH, MD<sup>3</sup>, and Heather Orom, PhD<sup>1</sup>

## Abstract

A significant proportion of men, ages 50 to 70 years, have, and continue to receive prostate specific antigen (PSA) tests to screen for prostate cancer (PCa). Approximately 70% of men with an elevated PSA level will not subsequently be diagnosed with PCa. Semistructured interviews were conducted with 13 men with an elevated PSA level who had not been diagnosed with PCa. Uncertainty was prominent in men's reactions to the PSA results, stemming from unanswered questions about the PSA test, PCa risk, and confusion about their management plan. Uncertainty was exacerbated or reduced depending on whether health care providers communicated in lay and empathetic ways, and provided opportunities for question asking. To manage uncertainty, men engaged in information and health care seeking, self-monitoring, and defensive cognition. Results inform strategies for meeting informational needs of men with an elevated PSA and confirm the primary importance of physician communication behavior for open information exchange and uncertainty reduction.

## Keywords

psychosocial aspect, cancer, screening and prevention, communication, medical, uncertainty

## Introduction

Since the early 1990s, men have been receiving prostate specific antigen (PSA)-based screening for prostate cancer (PCa), typically annually in men 50 to 75 years, or starting as early as age 40 years in men considered higher risk (e.g., men with family history, African Americans; Behavioral Risk Factor Surveillance System, 2012; Dyche, Ness, West, Allareddy, & Konety, 2006; Scales, Antonelli, Curtis, Schulman, & Moul, 2008). In 2012, prevalence data indicated that, across U.S. states, the median percentage of men older than 40 years receiving a PSA test in the previous 2 years was 45% (Behavioral Risk Factor Surveillance System, 2012). Although in 2012, the U.S. Preventive Services Task Force (USPSTF) recommended against PSA-based screening based on recent PSA screening trials indicating that PSA-based screening resulted in little or no reduction in PCa mortality or all-cause mortality (Andriole et al., 2009; Moyer & USPSTF, 2012), the recommendation appears to have had little impact on rates of PSA-based screening. A recent study demonstrated that 7.6% of men received PSA-based screening in the 6 months after the recommendation was released, compared with 8.6% in the 6 months prior (Cohn et al., 2014). As many men are continuing to receive PSA-based screening, it is important to

understand its psychological risks and benefits and to develop strategies for mitigating risks.

Men receiving a PSA test may find out that they have what is classified as an elevated PSA level. About 30% of men with an elevated PSA level will go on to be diagnosed with PCa as the result of a positive prostate biopsy (Hugosson et al., 2003), leaving about 70% of men with an elevated PSA level without a PCa diagnosis. These men find themselves in a liminal state; they have not been diagnosed with PCa, but they are at increased risk for being diagnosed with the disease in the future (Campos-Fernandes et al., 2009). This may engender considerable uncertainty about their health, well-being, future, and self-concept. Furthermore, the context of PSA-based PCa screening provides structural elements likely to provoke subjective uncertainty. There is objective uncertainty associated with the predictive accuracy of PSA-based

<sup>1</sup>State University of New York at Buffalo, NY, USA

<sup>2</sup>3M Health Information Systems, Troy, NY, USA

<sup>3</sup>Roswell Park Cancer Institute, Buffalo, NY, USA

## Corresponding Author:

Caitlin Biddle, Department of Community Health and Health Behavior, State University of New York at Buffalo, 329 Kimball Tower, 3435 Main Street, Buffalo, NY 14214-8028, USA.  
Email: cebiddle@buffalo.edu

screening (Harvey et al., 2009) and prostate biopsies, such that even a man who is fully informed would only have probabilistic knowledge of his likelihood of having cancer.

Uncertainty in the context of illness has been defined as an inability to find meaning in illness-related events, assign values to objects and events, and/or accurately predict outcomes (Mishel, 1988). Psychological and behavioral responses to uncertainty have been reported to differ as a function of how people appraise uncertainty (Brashers, 2001; Brashers, Hsieh, Neidig, & Reynolds, 2006; Mishel, 1988; Neville, 2003). If uncertainty is viewed as a threat, people may experience anxiety and may seek information to reduce uncertainty and associated anxiety, whereas those who view the uncertainty as an opportunity may find hope in the uncertainty and avoid obtaining further information (Mishel, 1988).

Few studies have examined uncertainty in men with elevated PSA levels, although there have been several studies of men's experience and management of uncertainty in the context of being diagnosed with cancer, including PCa (Bailey, Corner, Addington-Hall, Kumar, & Haviland, 2004; Kelly, 2009; McCaughan & McKenna, 2007; Oliffe, Davison, Pickles, & Mroz, 2009; Seale, 2006; Wallace, 2003; Wenger & Oliffe, 2014). Little is known about why men with elevated PSA levels experience uncertainty or the behavioral and affective consequences of uncertainty prior to a cancer diagnosis or in the cancer screening process. It is known that many men who undergo PSA testing receive little information about PSA screening when they are tested (Guerra, Jacobs, Holmes, & Shea, 2007; Lamplugh, Gilmore, Quinlan, & Cornford, 2006; Pan & McCahy, 2012) and that many men undergoing PSA-based screening experience anxiety (Carlsson, Aus, Wessman, & Hugosson, 2007; Fowler et al., 2006; Macefield et al., 2010), which is a common sequela of uncertainty (Awsare et al., 2008; Mroz, Oliffe, & Davison, 2013). Although little research directly attributes the anxiety reported in men undergoing PCa screening and follow-up to uncertainty, research from similar settings, such as women undergoing breast biopsy who go on to receive benign results has demonstrated that anxiety is associated with uncertainty (Deane & Degner, 1998).

With regard to PSA testing, much of the research on uncertainty has pertained to objective uncertainty and the probabilistic nature of the test and not the subjective uncertainty evoked and experienced in the men receiving the PSA test (Ransohoff, McNaughton Collins, & Fowler, 2002). In one of the only studies on the topic, uncertainty emerged as a main theme in interviews with seven men with elevated PSA levels. The men remained uncertain about the likelihood of being diagnosed with cancer in the future. The process of testing and retesting was viewed as

a protracted, and for some, an anxiety-provoking waiting time, in part because the men viewed PCa as a significant health threat and that it was important to diagnose PCa early in order to avoid death (Archer & Hayter, 2006).

With a large proportion of the male population older than 50 years receiving PSA-based screening, it is important to understand its psychosocial consequences. This knowledge is needed to better support informed decision making in men deciding whether to engage in PSA-based screening, and patient care for the many who are receiving PSA-based screening. The goals of the present study were threefold. The first goal was to examine the domains in which men experienced uncertainty. This will help identify those events and topics, and in particular, information deficits, that commonly evoke uncertainty in men with an elevated PSA level. The second was to examine the role of health care provider communication in uncertainty exacerbation or reduction. Uncertainty can be affected by "structure providers" or the resources available to an individual to aid in the interpretation of an event (Mishel, 1988). When facing a health issue, health care providers are a primary structure provider; therefore, physician-patient communication may be one of the most important influences on patient uncertainty. Results will help identify physician communication behaviors that can help men cope with uncertainty. The third goal was to examine strategies men used to manage uncertainty. Understanding how men with an elevated PSA level manage uncertainty will inform how to support these men. For example, knowing more about their information-seeking behaviors will be helpful for designing information sources that are more accessible. One may also be alerted to uncertainty reduction strategies that could have unintended negative consequences.

## Method

### *Study Participants and Recruitment*

Participant recruitment took place in two stages between June 2011 and May 2012. Men who were being seen in the urology clinic of a comprehensive cancer center because they had an elevated PSA or rapidly rising PSA level were approached (hereafter referred to as men with an elevated or rapidly rising PSA as having an elevated PSA level) to determine their potential interest in participating in the study. The clinic criterion for an elevated PSA level was PSA > 3.5 ng/mL or a 0.75 ng/mL increase within a year. A PSA > 3.5 ng/mL is a commonly used cutoff, although other cutoff values have been used: >2.5 ng/mL (Fowler et al., 2006);  $\geq 3$  ng/mL (Macefield et al., 2010); >4 ng/mL (Dyche et al., 2006). Men were approached and asked if they would be willing to be contacted in the future to participate in the study if they were

determined to be eligible. Forty-seven interested men signed a consent to be contacted about research, a HIPAA authorization, and a contact information form. Eligibility was confirmed via medical record review. In order to be eligible to participate, men with an elevated PSA result either had to have gone on to receive a PCa biopsy that was negative for cancer or were not scheduled for a biopsy. The eligible men were recontacted by telephone to determine if they were still interested in participating. Some men were not interested or could not be contacted again. Of the original 47, 13 (28%) men agreed to continue participation and interviews were scheduled. Participant date of birth was collected via self-report and race was observed during the interview. All participants were males between the ages of 52 and 80 years, 1 man was African American and the remaining 12 men were White. The study was institutional review board–approved and all ethical standards and guidelines established by the university IRB were adhered to.

### Data Collection

A semistructured interview lasting 45 to 120 minutes was conducted with each of the men, with the exception of two participants who participated in a joint interview. Participants were asked questions regarding their experiences with, responses to, and perceptions of PSA testing, perceptions of PCa, and physician–patient interactions. Example interview questions included “Can you tell me about receiving the results of the PSA test by walking me through what happened?” “How did you initially feel when you received the test result?” “What, if anything, did the doctor do that made it easier for you to understand your result?” and “What, if anything, did the doctor do that made it more difficult for you to understand your result?” All interviews were transcribed verbatim and identifiers were removed.

### Analysis

Data were analyzed using applied thematic analysis (Guest, MacQueen, & Namey, 2012). First, two authors separately performed open coding on all transcripts to identify broad concepts in the data. These were compared and organized, and where concepts overlapped, collapsed, yielding 18 broad data-driven codes. Codes covered four overarching topics: (a) provider behavior (e.g., lack of patient-centeredness), (b) knowledge and perception of the PSA test (e.g., misunderstanding of results), (c) participants’ responses to having an elevated PSA (e.g., anxiety), and (d) strategies used to manage uncertainty (e.g., information seeking). Two authors then collaboratively coded each of the transcripts using the codebook (data were recorded using NVivo 8, QSR International). To identify

themes, the coded text was examined by two of the authors for patterns of repetition and reoccurrence (Owen, 1984). To be included as a theme, a concept needed to be discussed by two or more participants. Once themes were extracted, the authors discussed and agreed on the interpretation of the themes.

## Results

Three salient themes emerged in men’s narratives about receiving an elevated PSA test result. First, nearly all men experienced uncertainty and anxiety after learning that they had an elevated PSA. Second, provider–patient communication both exacerbated and helped reduce men’s uncertainty and anxiety. Third, men engaged in a variety of coping techniques to manage uncertainty and reduce anxiety.

### Uncertainty Domains

Uncertainty was characterized by participants’ lack of, or inability to achieve an understanding about their current or future health. The main reasons why men experienced uncertainty were that they (a) did not understand the cause of their elevated PSA level, (b) they believed that they could reduce their PSA level but did not know how, (c) they continued to wonder if they could have cancer or develop it in the future, and (d) they did not understand their management plan or wondered what might be their management options if they were diagnosed with cancer.

*Uncertainty About the Cause of Their Elevated PSA.* Men expressed frustration over not knowing the cause of their elevated PSA level. A participant stated: “Why was it 8? And nobody could tell me that, so I still had a concern.” Having unanswered questions about the cause of their elevated PSA level was common and persisted throughout the men’s experience. Another man remained unclear as to what caused his elevated PSA, stating “I’m not privy to know exactly what (it) really denotes—this is characteristic of this—this is what you have.” Many men did not receive an answer as to what was causing their elevated PSA. Several men had been, or remained unaware of the factors other than PCa that could result in an elevated PSA level, such as prostatitis, urinary tract infections, or older age. Not having a PCa diagnosis and no apparent cause for what was labeled an elevated PSA level was confusing and unsettling and led some men to continue to wonder if they could have cancer.

*Uncertainty About How to Reduce Their Elevated PSA.* Some experiences of uncertainty stemmed from misunderstanding the nature of the PSA test and believing that one should reduce a PSA level to be healthier, as one might

reduce a cholesterol level. For example, one man questioned what behavioral changes he could make to reduce his elevated PSA level, he said: "I had my number come out to be 4.25; I don't know what I could do to lower my number." This example illustrates how misperceptions about the PSA test can create uncertainty and anxiety. The man's perceptual frame leads him to think he can reduce risk but that he does not know how: "not knowing exactly if I'm doing something right or if I'm hurting myself, is a little scary." Although a minority of men, others specifically questioned if there were ways that they could reduce their PCa risk by lowering their PSA. Although this belies a false belief that PSA might cause PCa, it also demonstrates the additional uncertainty experienced by these men because of their misunderstanding about the PSA test.

**Uncertainty About PCa Risk.** Several men wondered if they could have PCa. A man stated:

There is no clear picture. I'm not privy to know exactly what it is, this is a characteristic of this, and this is what you have. But I'm reading reports that say if your PSA levels are elevated and a certain number equals a certain percentage, the more likely that you have prostate cancer.

This man was unsure what his PSA level meant in respect to his health and PCa risk. Some men continued to live in a state that has been referred to as the "worried well" (Curran & Wagner, 1984). They had not been diagnosed with cancer, but believed that because of their elevated PSA level they could still have cancer and worried about their PCa risk. As one man stated, "I don't feel 100% confident that I'm cancer free." These men wanted to know more about how they could reduce their PSA, how to best monitor for cancer, and their treatment options if they were diagnosed.

**Uncertainty With Regard to Their Management Plan.** Some men had unanswered questions about their management plan. One man said: "I was just looking for, well what are we going to do? What's the game plan?" Others might have had a management plan but, did not understand its rationale. A participant stated: "I went to the urologist, you know, he put me on antibiotics for 30 days . . . for no reason. I don't know why." As stated earlier, men were unsure of the cause of an elevated PSA other than PCa. Antibiotics are used in treatment for men with an elevated PSA to treat or rule out infection, but some men were not aware of this. Not having a clear plan also produced anxiety among the men. One man described his experience about his elevated PSA and management plan in the following way, "(I was) scared, confused, and not sure what to do." Some of the men who felt at increased risk for the

disease also wondered about, but did not know what would be their treatment options if they were to be diagnosed with PCa. One man when referring to the possibility of being diagnosed with PCa stated: "Okay, it looks like there's cancer' right, I go 'okay, what do you do?'"

### *Men Who Did Not Experience Uncertainty*

Although uncertainty was the dominant theme of most participants' narratives, two men reported experiencing little or no uncertainty related to their elevated PSA result. One had worked in the medical field and the other in a scientific profession for numerous years and said that they had a good understanding of medical tests, recommendations, and results. One man stated: "I understand what the lab levels are so I wasn't concerned; (my doctor) just likes me to make informed choices based on my knowledge and his knowledge combined." The men had a high degree of health-related knowledge that allowed them to understand the PSA test, their results, and its relation to their health.

In sum, uncertainty was common among men receiving an elevated PSA test result, except in men with unusually high health literacy and knowledge. Men experienced uncertainty about the cause of their elevated PSA level, not knowing if they could or should try to reduce their PSA level, not knowing their PCa risk, and not understanding their management plans. Men's unanswered questions centered on the PSA test and its meaning for their present and future health as well as what could help mitigate cancer risk.

### *Poor Provider–Patient Communication Exacerbates Uncertainty*

Men's interactions with their physicians often failed to reduce their uncertainty, and in some instances exacerbated it. Several men explicitly talked about wanting more information from their physician. One participant depicted his need for information in the following way: "I go in hoping, one of these (days), I'll have the doctor when he's not busy, and then I'll get a little more in-depth information." When asked if he had received all the information he needed from his physician, another man replied:

No I didn't. He said "listen, we need to get a biopsy" that was it. He didn't—we didn't—he didn't talk to me too much about the score itself, you know, why. He just said that the increase was too quick. He didn't say 5 is good, 5 is bad, you know. He didn't talk to me about it. I did that on my own.

Even after talking with their physicians, some men were left with unanswered questions and remained uncertain,

including about the meaning of their PSA results for their health.

It was fairly common for patients to feel that their physicians had not taken enough time to fully explain the implications of the elevated PSA result for their health and how they could safeguard their future health. Not only did they continue to believe that they were at risk but they also felt a lack of control over future risk and that the physician was not giving them the information they needed to regain control. One man stated:

The physician doesn't have all the answers, but at least the answers that he does have he could explain. That's what I'm looking for. I've already accepted the fact; I just want to know, is there something we could do?

As exemplified by this participant, the men understood that their physicians could only give them probabilistic information about prognosis but many still discussed the fact that the way that they communicated did not make it easier for them to understand the PSA results and their implications for their health.

Men experienced several barriers to communication with their health care provider that might have reduced their uncertainty, including the lack of a personal relationship with the physician, lack of accessibility to the physician, lack of opportunities to raise questions, and inadequate explanations. Some men commented that a lack of personal connection or relationship with their physician was a barrier to communicating their informational needs to these physicians. One man stated: "That office is an assembly line for urology. So, you know, I would never go back for that reason, there's no personal (connection). You know the fact that I couldn't get him on the phone to talk about it." Sometimes, lack of access to their providers left men with unanswered questions. In other instances, physicians failed to give the men adequate opportunities to ask questions. One man stated: "My main concern was to get answers from the doctor, which I wasn't given the opportunity." Some men said that their physicians communicated in vague or confusing ways that maintained uncertainty. One participant remarked: "All the information I was getting was vague." Not having the physician provide adequate answers to questions left the men uncertain and continue questioning their experiences. A participant characterized the experience in the following way: "But you don't know because the answer, he just created . . . I thought he was creating a little bit of a mystery."

Physician communication could have powerful effects on men, exacerbating concern and anxiety when men had unanswered questions. One participant explained: "I started worrying like that. That's my concerns, right? Because I couldn't get facts and no one had any facts. My

doctor didn't have facts. He had opinions too." Another participant echoed this: "When you don't get the answers that you want, it creates . . . that mental disparity in the mind. You know . . . and you worry." Health care provider communication behavior, whether failing to provide adequate information or opportunities for question asking or clarification, or unclear explanation, appears to play a critical role in maintaining participants' uncertainty. As men expected health care providers to help them manage their uncertainty, failure to do so was frustrating and could be anxiety provoking.

### *Provider–Patient Communication Patterns That Reduced Uncertainty*

Health care provider communication could also alleviate or prevent men from experiencing uncertainty after receiving an elevated PSA result. A few of the men had experiences with physicians and health care facilities, where their interactions helped reduce uncertainty and anxiety. Aspects of the provider–patient communication that prevented or reduced men's uncertainty included giving in-depth information about the nature, strengths, and weaknesses of the PSA test, including educating patients that PSA levels increase with age and that other clinical conditions can cause elevated PSA levels. Men also noted that receiving information in lay terms, feeling listened to by their providers, and being treated by a team of health care providers rather than a single physician were also important for helping them understand their PSA results. In contrast to previous examples, some participants discussed having received adequate information from their providers. In particular, they found health care facilities with providers who they believed gave them the information they needed to understand their PSA results and its relevance for their health. One man who sought a second opinion described his second health care interaction in the following way:

Like I said when I went to [Hospital X] everything was explained . . . they took a whole read out on me from my medical records . . . you know, going step-by-step. So, I mean when you're that thorough, that—I think that does put a patient at ease.

Men appreciated and benefited from the physician and health care team giving an in-depth explanation of the PSA test and its results and alternate explanations for their elevated PSA level. In addition, when the health care provider explained the medical information in lay terms, the men were able to comprehend it better:

He was very detailed in his explanation. Yeah. Um, he wasn't cavalier about it, but he was very professional and he

had a way about him of explaining things in medical terms that was understandable to the average lay person.

When providers communicated in lay terms rather than medical jargon this increased men's comprehension of their PSA result and its implications, and they were generally more satisfied with these encounters.

One man indicated that he appreciated feeling "listened" to by his physician. An important component of this was the patience and respectfulness with which the health care provider answered all of his questions:

You know, I think that helped, but he just listened and talked, you know. We voiced our concerns and he addressed the concerns, he didn't shoot them down or make us sound like we were stupid in asking those questions.

Physicians who were perceived of as listening to, and respecting their patients laid the foundation for successful information exchange that, in turn, helped reduce or prevent participants' uncertainty. In particular, men indicated that being given the opportunity to ask questions and have them answered allowed them to feel taken care of by their provider. They felt this displayed respect for their particular wants and needs.

An empathetic and friendly demeanor positively affected the patient–health care provider relationship and created a better environment for the patient–physician communication to be successful. As one man described:

When I went to [Hospital X] . . . I met some nice people there. And from the nice people in one day I learned more than I learned in . . . let's say, the past 5 or 6 years about all this. But at [Hospital X] they not only discussed it, but they calmed me down.

Another participant noted that he benefited from, and appreciated being taken care of by a team of health care professionals. Perhaps, having access to more comprehensive care gives patients more opportunities to ask questions and receive clarification on topics about which they are uncertain.

Physicians and the larger health care setting played important roles in either exacerbating/maintaining or helping men reduce or prevent uncertainty. From men's discussions about problematic and helpful interactions with physicians one can glean a core set of physician behaviors that may help men's anxiety by reducing uncertainty because they result in more open communication, and greater information exchange and participant comprehension. These include providing ample opportunities to ask questions, providing detailed, clear, nonjargonistic explanations, and establishing a respectful rapport and empathetic manner. Men talked about not having opportunities to ask questions of health care providers. Multidisciplinary-based

comprehensive cancer care may benefit patients, in part, because patients interact with more providers and therefore have more opportunities to ask questions and seek clarification.

### *Uncertainty Management*

Men employed four main coping techniques to manage their uncertainty and anxiety: (a) information-seeking behaviors, (b) seeking additional health care, (c) monitoring their PSA results, and (d) defensive cognitive strategies such as avoidance and discounting.

*Information and Health Care Seeking.* A majority of participants had engaged in information seeking. They searched for information on the Internet (e.g., Google searches), medical journals, newspapers, television media, chat rooms, medical brochures, men with similar experiences, and family and friends to answer their questions. One of the men described the sources he used for information about the PSA test and PCa:

Well I mean, just Google high PSA levels, you know, is what I did. Look for chat rooms—if people are on there, talk about their experience with testing . . . if your PSAs are elevated. I looked at ways to treat prostate cancer, those types of things.

Men would also seek out additional health care services, including obtaining a second opinion and visiting their physician more frequently. This seemed to have given men opportunities to find additional information and answer previously unanswered questions, which helped reduce uncertainty and anxiety. For example, a number of men learned that elevated PSA levels could be caused by reasons other than cancer when they sought a second opinion. One man characterized his response to the new information as follows: "(it) put me a little bit more at ease and again I did not realize that there's other things that causes problems and gives you levels . . . it just put me at ease."

*Self-Monitoring.* Most men received PSA tests on an ongoing basis and many monitored their PSA level, documenting the results of their PSA tests, and watching for changes. One man stated, "I'm more mindful of the charting of the PSA level now." This man uses his PSA records to monitor the changes and uses this to validate or cope with his concerns. This may have given men a sense of control that helped them cope with uncertainty. Furthermore, those who saw a drop in their PSA level were often relieved and were less likely to wonder if they might have cancer. Several men acknowledge that they receive their own personal copies of their PSA test and one man stated: "I obsess over my bloodwork and if something is just not

perfect, or if something is low or something's high, I badger the clinical nurse." This man uses his monitoring to make himself aware of the results and as a starting point to ask questions to alleviate his uncertainty.

**Defensive Cognition.** Some men engaged in defensive cognitive strategies to reduce uncertainty; they actively avoided thoughts regarding PCa and PSA testing and focused on "controllable" factors. One man described his strategy in the following way: "I've always said, 'listen, worry about the things you can control.'" Some men used the controversies surrounding PSA-based screening to discount their PSA results, reducing concern that they could have cancer. There were two main ways men discounted the PSA test. They viewed it as, "a money-maker—it's money-making, that's all it is," and/or questioned the validity of the PSA test. One participant stated:

There's a whole school of thought that the PSA test is ridiculous—doesn't mean anything, and there's too many doctors that overreact to a high PSA number and they'll start treating men for prostate cancer whether they have it or not.

Some men who were aware of the objective uncertainty associated with PSA testing or controversy surrounding the PSA test and overtreatment appraised their uncertainty as opportunity. They discounted the validity of the PSA test and appraised their PCa risk to be average.

**Reduction in Uncertainty due to Misperceptions.** Although misperceptions about the PSA test and the implications of its results were common among the men, nearly all understood that they had not been diagnosed with cancer. However, one man, after receiving his elevated PSA results and interacting with his physician believed he had PCa. Although the experience was only described by one participant, it is reported because it demonstrates the serious consequences of clinical miscommunication. Also, this may not be uncommon; Archer and Hayter (2006) interviewed men who believed they had cancer after receiving an elevated PSA test result, but negative biopsy. During our interviews, the interviewer asked the participant if he ever thought about what he would do if he had cancer, and the participant then told the interviewer:

Well, you should think of that, because there wasn't any cancer in our family until my sisters had it. And then I end up with it. So it makes you wonder how it can all of a sudden crop up in a family where there wasn't any.

Although this led to new uncertainties (e.g., What causes cancer?), it also reduced uncertainties about the meaning of an elevated PSA. It is noteworthy that the

man's misunderstanding may have been partly because of poor communication on the part of the physician who had first raised the issue of PCa. The man recounted that the physician had accused him of lying that he did not have urinary symptoms and ultimately he did not return to that doctor: "My doctor said to me I lied. That turned me off." Although an extreme example, it illustrates how essential relationship satisfaction and respectful and open communication are for laying a foundation for information exchange between physicians and patients.

## Discussion

Men with an elevated PSA level, but not a PCa diagnosis, tended to experience uncertainty and related anxiety after receiving their PSA results. A majority of men lacked information about the PSA test and PCa. Communication with the health care provider influenced the degree of uncertainty experienced by the men via how much information they provided and their communication style (e.g., patient-centeredness and approachability). The men engaged in coping strategies, such as information-seeking, health care-seeking, self-monitoring, and defensive cognitive strategies to manage their uncertainty and anxiety.

Men's uncertainty stemmed, in large part, from information deficits, and in particular, from not understanding how the PSA test relates to PCa risk. One of the primary informational needs of men with elevated PSA levels seems to be better understanding the role and limitations of the PSA test in early detection. Participants' experiences were consistent with studies demonstrating that many patients who receive PSA-based screening are not engaged in shared decision making by their physicians (Guerra et al., 2007) and have little understanding of the implications of PSA test results (Olliffe, 2006). Knowledge deficits have significant implications for men with an elevated PSA. On one hand, misunderstanding the role of PSA level in cancer risk (marker rather than cause), and not understanding that PSA can be elevated for reasons other than PCa can result in unnecessary anxiety and concern about the need for lifestyle change and medical management (Ransohoff et al., 2002). Anxiety could also lead to subsequent avoidance of follow-up PSA tests (Roumier et al., 2004). On the other hand, men who completely discount PSA test validity might also not have follow-up PSA tests that are clinically warranted.

Many men sought additional information as a way of reducing their uncertainty. Several men who were dissatisfied with the information they received from their first physician sought a second opinion and some, but not all participants ultimately were satisfied with how much information they had received from health care providers. Men also searched for information on the Internet, medical journals, newspapers, television media, chat rooms,

medical brochures, men with similar experiences, and family and friends; however, most men focused on needing more detailed and easier to understand information from their physicians.

### *Role of Provider Communication*

Provider communication has been identified as a major driver of health care quality and outcomes (Stewart, 1995). Our data exemplify why this might be the case. For instance, patients perceived that physicians largely determined whether they were able to ask questions, seek clarification, or raise concerns. This depended not only on whether the physician created opportunities for question asking, but whether they had an empathetic or respectful demeanor that empowered patients to ask questions. Being able to ask questions was important for uncertainty reduction as most patients wanted more information about PSA testing than had been offered, at least initially, by their physicians. Detailed, lay-oriented explanations not only helped improve their understanding, but also reassured patients and made them feel less anxious about the possibility of being diagnosed with cancer. Of note, in previous studies, it has been reported that men typically receive less time with the physician and receive briefer explanations from physicians compared with women (Waitzkin, 1984; Weisman & Teitelbaum, 1989).

It may be challenging for physicians to satisfy the informational needs of men with elevated PSA because of the objective uncertainty associated with the test. For those undergoing prostate biopsies, the objective uncertainty also associated with this test (high rates of false negative results) presents yet another challenge for physician–patient communication. As Chapple, Ziebland, Hewitson, and McPherson (2008) also noted, participants with professional backgrounds in health or other sciences had different experiences than most other men. The men with scientific or health-related backgrounds seemed to be able to integrate probabilistic information into their understanding of their present and future health and experienced low uncertainty and anxiety, as was also evident in two of our participants. In contrast, patients with lower health literacy and numeracy may find it especially difficult to understand the probabilistic natures of the information obtained from these tests and the objective uncertainty of the test results may be more likely to translate into subjective uncertainty. PSA tests and prostate biopsies are part of a class of clinical tests that yield probabilistic information (e.g., genetic testing). The challenges associated with communicating results from these tests have been noted (Andriole et al., 2009; Moyer & USPSTF, 2012). Some progress has been made in identifying effective strategies for communicating probabilistic health information (Oloffé & Thorne, 2007; Trevena, Davey, Barratt, Butow, & Caldwell, 2006). Oloffé and Thorne

(2007) reported that providers who display high expertise and compassion promote the development of patient trust and could improve the overall communication process. Presumably, use of decision aids prior to screening could also help meet information needs of men who go on to have an elevated result, but are not diagnosed with cancer. Although considerable resources have been invested in decision-making tools that increase knowledge and decisional satisfaction, dissemination of decision-making aids for PCa screening has been slow (Trevena et al., 2006).

Men enact their masculine identities in their interpersonal interactions, including medical encounters (Courtenay, 2000; Wenger & Oloffé, 2014). The process of enacting, or constantly recreating and reinforcing masculine identity may put male patients at a disadvantage when they need information from their providers. Behaviors (asking questions, seeking clarification, expressing confusion, anxiety, or concern) that demonstrate uncertainty may be categorized as “feminine” and may be avoided by male patients. Furthermore, working from an “identity deficit” because the medical encounter puts them at a power disadvantage with respect to the physician, male patients may be even more likely to engage in behaviors that signal confidence, being knowledgeable, and decisiveness, hence they may be even less likely to give health care providers uncertainty cues (Courtenay, 2000; Seale, 2006). These patterns of behavior may have become normative on the part of male patients, such that they have come to be interpreted as preferences by health care providers who avoid enquiring into male patients’ psychosocial well-being or uncertainty.

### *Uncertainty Management*

Participants engaged in a variety of uncertainty management strategies noted in past research (Fowler et al., 2006). Men sought additional health care, monitored their PSA levels and used avoidance and discounting strategies to manage uncertainty. Participants in our study, as well as in past studies, have indicated using cognitive strategies, such as discounting the validity of the PSA test (Avery et al., 2008). Cognitive avoidance was fairly common in our sample. It is unknown whether it is maladaptive in this context, but work in other health threat contexts indicate that avoidance is associated with negative affect (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006; Gould, Brown, & Bramwell, 2010), anxiety (Görge, Hiller, & Witthöft, 2014), and greater health care usage (Görge et al., 2014).

### *Limitations and Future Directions*

Study limitations include a small sample size and potentially low generalizability, although our findings resonate



with trends in the literature. Additionally, one of the interviews involved two participants at once which may have influenced participants' responses, perhaps reducing willingness to discuss sensitive experiences or dissenting. Even though this could be the case, the responses of these two respondents were similar to the responses of the remaining sample. Future research might include the development of a larger study and the testing of informational materials for men with elevated PSA or testing the effects of using existing PCa screening decision making aids on uncertainty and anxiety among men who go on to have an elevated PSA, but not a cancer diagnosis.

## Conclusion

Uncertainty was a common sequelae of PSA testing among those with elevated PSA, but not diagnosed with PCa. Informed decision making prior to testing could increase men's understanding of the PSA test. One of the most striking patterns in men's experiences of having an elevated PSA was that they desired more informational and emotional support from their physicians. With the American Urological Association and American Cancer Society both recommending informed decision making for men interested in PSA-based screening (Carter, 2013; Wolf et al., 2010), primary care physicians and urologists might welcome additional training on how to talk with their patients about PSA testing and prostate biopsies. Physician training can increase physicians' knowledge of PCa screening and endorsement of informed decision making (Gattellari et al., 2005). Structural changes to care may also be helpful; adopting longer consultations and/or multidisciplinary care allow patients greater opportunities for clarification and question asking.

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