

2015

Decision-making Processes among Prostate Cancer Survivors with Rising PSA Levels: Results from a Qualitative Analysis

M. J. Shen

C. J. Nelson

E. Peters

S. F. Slovin

S. J. Hall

*See next page for additional authors*Follow this and additional works at: <https://academicworks.medicine.hofstra.edu/articles> Part of the [Urology Commons](#)

Recommended Citation

Shen M, Nelson C, Peters E, Slovin S, Hall S, Hall M, Herrera P, Leventhal E, Leventhal H, Diefenbach M. Decision-making Processes among Prostate Cancer Survivors with Rising PSA Levels: Results from a Qualitative Analysis. . 2015 Jan 01; 35(4):Article 172 [p.]. Available from: <https://academicworks.medicine.hofstra.edu/articles/172>. Free full text article.

This Article is brought to you for free and open access by Donald and Barbara Zucker School of Medicine Academic Works. It has been accepted for inclusion in Journal Articles by an authorized administrator of Donald and Barbara Zucker School of Medicine Academic Works. For more information, please contact academicworks@hofstra.edu.

Authors

M. J. Shen, C. J. Nelson, E. Peters, S. F. Slovin, S. J. Hall, M. Hall, P. C. Herrera, E. A. Leventhal, H. Leventhal, and M. A. Diefenbach



Published in final edited form as:

Med Decis Making. 2015 May ; 35(4): 477–486. doi:10.1177/0272989X14558424.

Decision-Making Processes among Prostate Cancer Survivors with Rising PSA Levels: Results from a Qualitative Analysis¹

Megan Johnson Shen, Ph.D.¹, Christian J. Nelson, Ph.D.¹, Ellen Peters, Ph.D.², Susan F. Slovin, M.D., Ph.D.³, Simon J. Hall, M.D.⁴, Matt Hall, M.A.⁴, Phapichaya Chaoprang Herrera, M.A.⁴, Elaine A. Leventhal, M.D., Ph.D.⁵, Howard Leventhal, Ph.D.⁵, and Michael A. Diefenbach, Ph.D.⁴

¹Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center

²Department of Psychology, Ohio State University

³Department of Medicine, Memorial Sloan-Kettering Cancer Center

⁴Department of Urology, Mount Sinai

⁵Department of Medicine, Robert Wood Johnson Medical School, Rutgers

Abstract

Background—Prostate cancer survivors with a rising prostate specific antigen (PSA) level have few treatment options, experience a heightened state of uncertainty about their disease trajectory that might include the possibility of cancer metastasis and death, and often experience elevated levels of distress as they have to deal with a disease they thought they had conquered. Guided by self-regulation theory, the present study examined the cognitive and affective processes involved in shared decision making between physician and patients who experience a rising PSA after definitive treatment for prostate cancer.

Methods—In-depth interviews were conducted with 34 prostate cancer survivors who had been diagnosed with a rising PSA (i.e., biochemical failure) within the past 12 months. Survivors were asked about their experiences and affective responses after being diagnosed with a rising PSA and while weighing potential treatment options. In addition, patients were asked about their decision-making process for the initial prostate cancer treatment.

Results—Compared to the initial diagnosis, survivors with a rising PSA reported increased negative affect following their diagnosis, concern about the treatability of their disease, increased planning and health behavior change, heightened levels of worry preceding doctor's appointments (especially prior to the discussion of PSA testing results), and a strong reliance on physicians' treatment recommendations.

Conclusions—Prostate cancer survivors' decision-making processes for the treatment of a rising PSA are markedly different from those of the initial diagnosis of prostate cancer. Because

¹Financial support for this study was provided entirely by grants from the NCI (R01-CA118682, PI Michael A. Diefenbach; T32-CA009461, PI Jamie Ostroff; 5R25-CA081137, PI Guy Montgomery). The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

Author contact information: Michael A. Diefenbach, Ph.D., Associate Professor, Department of Urology and Oncological Sciences, Box 1272, Icahn School of Medicine at Mount Sinai, New York, NY 10029, Michael.diefenbach@mountsinai.org.

patients experience heightened distress and rely more heavily on their physicians' recommendations with a rising PSA, interactions with the health care provider provide an excellent opportunity to address and assist patients with managing the uncertainty and distress inherent with rising PSA levels.

Introduction

Despite advances in prostate cancer treatment and favorable five-year survival rates, a growing number of prostate cancer survivors experience a rise in prostate specific antigen (PSA) levels without evidence of widespread disease (e.g., metastases to other sites). A rising PSA refers to an elevated PSA level after initial prostate cancer treatment (1). The widespread use of PSA testing for the detection of prostate cancer has resulted in a substantial shift in detection of the disease such that an increasing number of men are diagnosed and treated with clinically localized disease at a younger age (2,3) and eventually are more likely to experience a disease recurrence. It has been estimated that 40% of patients initially treated with surgery or radiation will eventually experience rising PSA levels, resulting in approximately 60,000 new cases per year (4,5). A rising PSA in this instance suggests recurrence of the cancer, although it might take months or even years to manifest clinically. During this time, most survivors are asymptomatic until bone metastases, which are associated with increased levels of pain, are detected through a scan.

Although multiple treatment options are available to survivors with a rising PSA, there is little agreement on a definitive or uniform approach to treatment as there is insufficient data to guide treatment recommendations. Existing data on the efficacy of various treatment options are sparse and derived primarily from single institution studies or retrospectively analyzed data sets (6). Most physicians recommend careful monitoring of PSA levels, especially in the early stages of a rising PSA. Intermittent or traditional hormone treatment is the most commonly chosen approach, although external-beam radiation and salvage prostatectomy are also available. The choice of one of these options is usually determined by clinical factors shown to influence progression from biochemical failure to metastatic disease (7–9). These factors include: PSA doubling time, PSA velocity, time of PSA recurrence, pathologic stage, Gleason score of the initial tumor at diagnosis, and presence of recurrent disease on biopsy after radiation treatment.

Based on such clinical factors, patients and their physicians ideally evaluate available options and balance the potential benefits of treatment with possible side effects (e.g., for hormone treatment: loss of libido, hot flashes, loss of lean muscle mass, etc.) that negatively impact a patient's quality of life. The difficulty patients face in making a treatment decision is often compounded by inconsistent physician recommendations for patients with a rising PSA (10,11) and by elevated levels of distress caused by the realization that the disease they thought they had conquered is returning, very likely leading to metastatic disease and eventually to death (12). Thus, physicians and patients face a complex array of factors in deciding which treatment pathway, if any, to pursue. Although much research has examined treatment decision making among prostate cancer patients at initial diagnosis (e.g., 10–12), no prior studies have identified the decision-making processes at this later stage of the

disease trajectory (13–15). The goal of the present study was to examine these factors by qualitatively interviewing patients during the time of a rising PSA diagnosis.

Guided by self-regulation theory (16,17), our interview approach emphasized the importance of both cognitive and affective factors influencing information processing and decision making. Cognitive processes include patients' representations of prostate cancer, such as their perceptions and beliefs about the causes of the disease, its consequences on quality of everyday life, and its treatability. The simultaneously occurring affective distress arising from the uncertainties of the efficacy of treatment, its impact on quality of life, and its potential efficacy in extending life add an additional layer of factors impacting the decision-making process (18). Because of the uncertainty and emotional distress surrounding a rising PSA diagnosis, it is possible that patients strongly rely on physicians' counsel and recommendations. The main objective of the present study was to engage patients in a detailed retrospective and comparative examination of the processes involved in making treatment decisions following their initial diagnosis of prostate cancer as well as the recent diagnosis of a rising PSA.

Methods

Participants and Recruitment

Eligible participants for this study were prostate cancer survivors who were treated for early stage disease, had been diagnosed with biochemical failure within the past 12 months (indicating a possible recurrence), were not castrate resistant, and were able to provide informed consent and speak and understand English well enough to complete the interviews. Biochemical failure for surgical patients was defined as two consecutive PSA measurements of $\geq 0.2\text{ng/mL}$ after a nadir of $< 0.1\text{ng/mL}$ (7,19,20). Failure for radiation patients was defined by criteria set by the ASTRO consensus panel (1997) of three consecutive elevations of the PSA level after a stable nadir, independent of baseline level. All survivors were recruited through their treating physicians (i.e., urologists or oncologists) at major medical centers in the New York metropolitan area between January 2011 and December 2011. After patients expressed interest and consented to the study, they completed a baseline questionnaire, which was distributed prior to their scheduled appointment. The Institutional Review Boards (IRBs) of all participating institutions approved this study.

Procedures

The patients providing the current interview data were a simple random sample of participants from a longitudinal study involving data collection at four time points (3, 6, 9, and 12 months) following a diagnosis of a rising PSA. Patients were included regardless of the time and kind of treatments they had (e.g., surgery alone, or surgery followed by a course of radiation treatment) prior to the diagnosis of a rising PSA. Patients were personally interviewed at two possible study mile-stones: 1) once they made a treatment decision to address their rising PSA, or 2) at the end of the 12-month study period if the patient continued to be monitored but no treatment decisions had been made. Interviews were conducted until thematic saturation occurred (i.e., no new themes or topics emerged).

Interviews

A random sample of 42 patients from the larger study sample ($n=125$) were approached to participate in a follow-up phone interview. Of those approached, 34 patients participated, resulting in an 80% recruitment rate and a sub-sample that represented 27.2% of the entire study sample. Phone interviews averaged 25 to 30 minutes in length. Structured interview guides were developed based on our self-regulation theoretical framework, with an emphasis on cognitive and affective processes that have been shown to influence decision making. All interviews were conducted by a trained psychologist (MD).

Interviews were comprised of three main parts. The first part of the interview focused on patients' initial prostate cancer diagnosis and initial treatment decision. Patients were asked about the circumstances of their initial diagnosis, how they decided on their initial treatment (including the physician's role in discussing prognosis and decision making), experiences with treatment and potential side effects, and whether they experienced any continued urinary or sexual problems. Patients were also asked about their initial emotional reaction to the diagnosis.

The second part of the interview addressed patients' concerns about their rising PSA levels. Patients were asked about their emotional state after they heard that their PSA levels were rising, whether they thought much about the rising PSA levels, how they made sense of it (i.e., causes, consequences, where it comes from), what they thought could be done about their rising PSA, and what their priorities and goals were in dealing with the condition. When appropriate, patients were probed for negative emotions and experiences following their diagnoses.

The third part of the interview focused on patients' treatment options, especially hormone therapy (i.e., androgen deprivation therapy; ADT) and salvage radiation therapy. Patients were asked whether they knew when they would begin treatment, which factors prompted them to do something about their rising PSA (if they had), and how long it took them to make their decision (if they already made a decision). Patients were also asked what information and resources contributed to their decision making, including the physicians' role in decision making. Finally, patients were asked about the emotional impact of the new diagnosis of rising PSA. Because this "watch and see" approach of monitoring PSA levels is a valid treatment choice, all patients were asked the same questions regardless of whether they had made a decision to start active treatment. The interview concluded by thanking participants for their time and dedication to the study.

Data Analysis

All interviews were audio-recorded, transcribed by a professional transcription service, and validated by study investigators to ensure accurate and complete transcription. A theoretically derived preliminary coding sheet was developed to aid in the coding of answers. Two members of the study staff read all transcribed interviews and coded responses based on this coding sheet. New codes were added if both coders agreed on their necessity. Initial inter-rater reliability indicated moderate agreement between the two coders with a Cohen's Kappa of .58 for the entire interview from the full sample. The coders then

discussed and resolved their coding discrepancies and achieved perfect agreement (Cohen's Kappa = 1.0).

Results

Sample Characteristics

Pertinent patient demographics and clinical characteristics are summarized in Table 1 and the coded themes are summarized in Table 2. A detailed description and discussion of themes follows.

Reactions to a Rising PSA Diagnosis: Negative Affect and Optimism

A majority of patients reported experiencing higher levels of negative affect when told their PSA was rising compared to the time when they were initially diagnosed with prostate cancer. Specifically, patients reported disappointment, discouragement, worry, and fear of death.

“Well you know my first reaction was disappointed...obviously I go through a major surgery and then you find out that it worked to a point, but it was something that wasn't complete. So the first few months I wasn't really angry or depressed, I was disappointed.” [Patient 209]

“I felt disturbed and crazy...I was already hurt by it [rising PSA] ...” [Patient 229]

“Now, trying to figure out this maze, that I got cancer, you know – you're gonna – the first thing you think of is, 'I'm gonna die' ...you know, or your life's shortened.” [Patient 215]

Although patients with a rising PSA reported feeling more worried, fearful, and disappointed than they did at initial diagnosis, they also reported being more grateful to be alive and expressed optimism about the future.

“I got a positive outlook on life and that's...I think it helps me.” [Patient 215]

“I am optimistic too. I know [we have talked to] the best doctor.” [Patient 20]

The expressed optimism appears to help patients cope with their current situation and might counteract negative emotions that were present when they found out that their PSA started to rise. Whereas fighting the disease was often of utmost importance at the initial diagnosis, most patients expressed acceptance of their situation and being more aware about their potentially limited future. This translated into new plans for the foreseeable future:

“I'm spending more, traveling more, and donating more to charity at a faster pace than I might have otherwise. So I've kind of sped up my time horizon on doing things that I want to do while I can do it.” [Patient 224]

“But it also can be triggered by decisions about even silly things, like 401k plans and retirement. 'What am I saving for?' Other kinds of unusual situations force you to sort of reframe your future.” [Patient 201]

Processing Diagnosis: Belief about Treatability of Disease

The changes among patients to engage in actively planning and being more accepting of their situation may have been a consequence of the realization that their cancer was no longer curable. At initial diagnosis, most patients believed their initial treatment would be successful. Not one patient reported thinking their cancer would be fatal or would return post-treatment at the time of initial diagnosis. However, once diagnosed with a rising PSA, some patients expressed beliefs about the fatality of their condition. Specifically, patients focused on the potential incurability of their disease.

“In thinking back [to initial diagnosis] I don’t know that I put the cancer label on it. It was just I had a bad prostate, they took it out, and I got on with my life.” [Patient 238]

“Now I am very nervous about it because I was sure we could take care of it, but now I’m no longer sure they can take care of it.” [Patient 29]

“I’m no longer considered cured. I was considered cured, I felt, for that first year. But now that we’ve had our chemical recurrence, I feel what I would say is I’m in remission, I’m not cured, and anything could happen at any time and we just have to closely monitor it.” [Patient 36]

“Well, I know that I have – or I’m pretty sure I have metastatic disease...I know that I have biochemical recurrence.” [Patient 208]

The Role of Follow Up Appointments: Promoting Worry

Although many patients reported being worried about their rising PSA levels and the possible recurrence of cancer, they did not report thinking about it on a daily basis. Rather, patients stated that they predominantly worried about their rising PSA levels only when prompted by a physician visit to get their PSA levels tested. Patients’ positive feelings seemingly served as a buffer against stress and anxiety; however, worry returned when they were visiting their physician to check on their PSA levels. This is consistent with past research indicating that physician visits serve as “worry promoters” among cancer patients (21).

“But at this point every time I go for a PSA test the week or ten days before the test I notice that I’m becoming more tense, more irritable, more distracted, and until I hear the results I may stay that way.” [Patient 32]

“I don’t ruminate about cancer all the time. It’s just on occasion, you know, especially on going back to the check-ups to remind you when you walk into a cancer hospital about who you really are.” [Patient 201]

“You know it’s like I go, I am at ease, and then I know I have to go for a blood test, when the time comes for that blood test, I start getting nervous again, and I get nervous, you know, until I see the results on the computer.” [Patient 01]

This worry expressed prior to follow-up appointments that monitored rising PSA levels might prompt some patients to develop action plans. For instance, patients reported that

being worried about their cancer's progression actually motivated them to live better lives and enjoy their lives more.

“Well, I know that I have – or I'm pretty sure I have metastatic disease...I know that I have biochemical recurrence. I don't know exactly how I deal with it. I think I can deal with it a lot of different ways. One is, I try to accept the fact that life is finite. I try to live as well as I can.” [Patient 208]

Decision Making Processes: Monitoring PSA Levels and the Role of the Physician

A distinct feature of being diagnosed with a rising PSA was that patients were not offered multiple treatment options. Rather, they had the choice between monitoring their PSA levels and deciding when to go on hormone therapy. Perhaps due to the unique features of decision making during this phase, most patients reported being concerned with tracking their PSA levels upon receiving a diagnosis of a rising PSA. They tracked and compared their own PSA levels to pre-designated “milestones,” such as the time it took for a value to double or certain upper limits upon which treatment would be initiated. Patients' perceptions of such values were not necessarily medically accurate or based on physician recommendations (e.g., PSA above 10). However, there is no gold standard cut-off PSA value to initiate hormone treatment, thus patients adopted physicians' suggestions or invented their own “rules” on what is considered a cut-off for PSA levels.

“I think there's a cut off [for PSA levels] of 4.0.” [Patient 204]

“Well, I mean, it's in the back of my head if it gets to a certain point, they didn't give me a specific number, but I would assume if it went, like, 1 or 2 that would be quite an increase.” [Patient 220]

“So it [PSA level] is going to somewhere around 9 or 10, when it gets to that point, we will probably do the hormone therapy.” [Patient 20]

Perhaps due to the unique nature of the limited number of options with rising PSA versus initial diagnosis as well as the developed relationship with their treating physician, patients relied much more heavily on their physicians' recommendations in making a treatment decision upon receiving a diagnosis of a rising PSA. At initial diagnosis, many patients described themselves as having an independent and active voice in treatment decisions. They also reported seeking second opinions.

“I decided that surgery was probably the most surest way of attacking it and feeling comfortable.” [Patient 260]

“After the diagnosis...I went to get a second opinion.” [Patient 234]

In contrast, patients reported relying on their physicians' advice more after they had been diagnosed with a rising PSA than they did at initial diagnosis. In fact, more patients with a rising PSA made their treatment decision based solely on their physician's preferences or advice than at initial diagnosis.

“I would just go and do whatever she [the doctor], you know, whatever she would suggest.” [Patient 205]

“And the decisions have been easy because I much more put myself in [the doctor’s] hands.” [Patient 208]

There are several reasons why patients may have relied on physician recommendations for treatment decisions with rising PSA levels. First, most patients reported having strong positive feelings toward their physicians:

“...if she tells me to fly to the moon, I’d fly to the moon. I’m in love with that woman [the doctor].” [Patient 238]

Second, patients explicitly reported trusting their physicians’ skills and opinions.

“You put your hands in people who understand fully and better than you exactly what the best course of action to take and you accept that.” [Patient 260]

“It was a world-class doctor. He was published. He came out of [university], so I felt confident in his background.” [Patient 201]

Third, it seemed that patients happily transferred decision-making responsibilities to their physicians.

“...I feel comfortable with the decisions that we’ve made and I trust [the doctor] and the care that he has given me, so I will continue with that.” [Patient 3001]

“I have a lot of confidence in both of them [doctors], in particular [the doctor] with whom I’ve had much more contact. And I would actually pretty much leave it in their, in his hands to decide if going to hormone therapy were either necessary or appropriate.” [Patient 32]

Discussion

The present study provides new insight into decision-making processes that occur among prostate cancer survivors with rising PSA levels, an increasing large segment of cancer survivors (4,5). As expected and in accord with self-regulation theory (16,17), the data suggest that both patient-based cognitive and affective processes and interpersonal processes (i.e., the physician-patient relationship) shape the decision-making processes. Specifically, results indicated the three most distinct features of the decision-making processes upon diagnosis of a rising PSA are: 1) patients’ experience an increase in negative affect and worry and are also more skeptical of the curability of their disease, 2) follow-up appointments during which patients’ PSA levels are monitored are triggers for increasing worry and anxiety surrounding their prognosis, and 3) patients rely heavily on their physicians during the decision-making process. These three main findings suggest that physicians ought to be attuned to patients’ increased emotional vulnerability upon receiving this diagnosis; be aware that follow-up appointments, even though considered routine, will likely exacerbate distress; and know that they play a crucial role in recommending treatment options and guiding patients through the treatment decision-making process. These results are discussed in detail below within a cognitive and affective processes framework.

Cognitive Processes

As expected, patients with a rising PSA level were more skeptical of their treatment being curative than they were at initial diagnosis (13). The shift in the perception of many prostate cancer patients from believing that their cancer was curable following the initial treatment to realizing that the cancer has returned following a diagnosis of rising PSA, was associated with a marked change in the perception of control over their cancer (22). This change in illness perception was associated with changes in patients' action plans, such as changes in everyday behavior including increased spending and saving less money, and attempts to enjoy life more. These are all indications of the assumption that life will be shorter than previously expected

In addition to reporting they were no longer cured, patients also reported that they closely monitored their PSA levels and compared them to a "cutoff" or doubling rate. These values, however, were not always medically accurate. This suggests that physicians may want to provide medically accurate targets to patients, even in the absence of gold standards, in order to increase their understanding of the disease and its time trajectory. Additionally, although gold standards for PSA levels do not exist, most urologists would provide ADT for a rising PSA, especially if the PSA is rapidly increasing. Prior treatment, however, may factor into which options are available to patients (e.g., radiation patients are unlikely to have further radiation). As such, physicians should incorporate these concerns into treatment option discussions with patients.

Affective Processes

Patients also reported feeling disappointed, discouraged, or fearful upon being diagnosed with a rising PSA level. Despite this increase in negative affect, patients with rising PSA levels also reported being hopeful, optimistic, and happy to be alive. The presence of positive affect is an indication of acceptance of the situation and the desire to enjoy life despite the specter of a worsening disease. In short, patients did not seem to let worry and distress influence their day-to-day activities. Rather, patients reported feeling worried predominately prior to check-up visits where they would receive results of their PSA tests, a finding previously reported for breast cancer survivors (21). Heightened affective processes are likely to influence disease and treatment-relevant information processing and by extension treatment decision making through compromised processing and integration of information (23). Supporting this conclusion, prostate cancer patients have listed emotions as more reliable and valuable in treatment decisions than risk-based information (24).

Physician-Patient Relational Processes

Perhaps the most unique finding from the present study is that patients relied more heavily on their physicians' recommendations when making treatment decisions for a rising PSA than they did at initial diagnosis. Whereas many patients at initial diagnosis get second opinions (25) and reported doing so in the present study, some patients with rising PSA levels reported relying solely on their physicians' advice in making treatment decisions. In the present study, patient-physician relationships ranged from patients having known their current physician for up to 18 years to being referred to them upon receiving a diagnosis of a rising PSA. Despite length of relationship, many patients reported full reliance on their

physicians' opinions and recommendations, underscoring the important role that physicians play in decision making in this situation.

The present study does not provide sufficient data to fully explain this shift in decision making behavior. However, patients indicated that relying on their physicians' recommendations reduced the amount of burden they felt in making a decision about treatment. It is certainly possible that some patients, after having dealt with the disease for a number of years, felt ready to turn over "responsibility" for their disease to their physician, effectively experiencing decision fatigue. Moreover, patients may have relied more on their physicians' recommendations because the treatment options were less varied than they were at initial diagnosis or because they viewed the physicians' recommendations (to go on hormone therapy or keep monitoring PSA levels) as less severe than other options such as surgery. Future research should examine why there is a major shift in how much patients rely on their physicians' recommendations when diagnosed with a rising PSA versus initial diagnosis.

These findings are in line with previous research which indicates that both the experience and stage of illness influence the degree to which patients desire to be involved in decision making surrounding their care (26). For instance, past research indicates that cancer patients whose condition had recently worsened were more likely to desire less involvement in decision making than those whose condition remained unchanged (27). Similarly, the present study found that once patients' conditions had progressed with a rising PSA, they more frequently reported relying on physicians to aid in decision making. Health status has also been shown to influence patients' desire for information. Several studies have shown that patients with severe illness may prefer to be less involved in decision making than patients with minor illnesses (26). As such, patients who face a more progressive and possibly more severe diagnosis than they did initially may desire less involvement in their treatment decision making.

Limitations and Directions for Future Research

The present study provides novel insight into the treatment decision-making processes of prostate cancer survivors diagnosed with rising PSA levels; however, it does have some limitations which must be considered in interpreting the results. One limitation is the retrospective description of patients' treatment decision-making processes at initial diagnosis. Given that the average amount of time since initial diagnosis among this sample was approximately 9 years ago, it is possible that patients misremembered the cognitive, affective, or physician-patient relational processes that originally guided their treatment decision making. However, retrospective accounts of prostate cancer treatment decision making have been a common form of inquiry (14). The added advantage of asking patients to retrospectively recall their decision making is that it allows for a comparison of the same patient's treatment decision making for a rising PSA rather than comparing two distinct groups to one another. Because emotional reactions attenuate over time leading to errors in recall of emotional experiences (28), it is possible that the more recent emotional reactions to rising PSA levels may be reported as higher than those associated with the initial diagnosis simply because less time has passed.

Another limitation of the present study is that the data are qualitative and thus cannot be used to formally test hypotheses. Although qualitative data allows for exploration of themes and is hypothesis generating, it should be noted that the present sample was not representative of the majority of prostate cancer patients, which limits the generalizability of the data. Rather, the results from the present study provide a framework in which to continue developing and ultimately testing hypotheses using quantitative methods.

Another limiting factor of this study is that we did not fully probe all individuals for negative themes. For instance, some patients were probed about potential worry or uncertainty more deeply, when appropriate, but not all patients were asked about these potential concerns to the same extent.

Additionally, this study has limited generalizability given that the sample consisted of predominately White, well-educated men. Patient populations with lower levels of education may also exhibit lower levels of health literacy that, in turn, influences information processing and decision making. Future research should examine more racially and ethnically diverse samples as well as samples of individuals with lower levels of education to determine how these variables influence the decision-making processes of prostate cancer survivors with rising PSA levels.

Finally, another limitation of the present study is that the decision-making and physician-patient relational processes examined in this study were only explored from the patient point of view. Examining these processes from the physician's standpoint would add another layer of information that would be crucial in informing future intervention development. By examining the physicians' attitudes and beliefs surrounding this situation, future research could create more targeted interventions to improve communication and shared decision making among patients and physicians.

Practice Implications

In short, patients' reactions and decision making upon receiving a rising PSA diagnosis differed from those at the initial diagnosis across three broad themes. First, patients are likely to experience strong negative affect and are more skeptical about the treatability of their disease. Even if such feelings are not communicated to the consulting physician, health care providers need to be aware that patients are more emotionally vulnerable and potentially in need of support. A systematic review of physician-patient communication demonstrated that physicians' abilities to communicate well with patients positively affected a multitude of patient outcomes, including emotional well-being, physical symptoms, and physiological measures (29). Thus, a physician's ability to communicate empathically (e.g., acknowledging, praise, reassuring, encouraging; (30) with patients during this time will improve patients' emotional and physical well-being and by extension improve information processing and decision making.

Second, follow-up appointments that are designed to monitor patients' PSA levels often lead to high levels of worry and anxiety about the potential progression of their disease. Health care providers should be sensitive to the signs of distress and the psychosocial needs of their patients at this point in the disease trajectory. Physicians' appointments with patients

diagnosed with a rising PSA provide an opportunity to respond to these psychological needs. PSA levels have been cited as a source of great uncertainty (and thus added worry and distress) for prostate cancer patients (31). Thus, patients might benefit from physicians providing a trajectory of how long to watch their PSA levels as well as giving them more certainty and information regarding criteria for taking action once a patient reaches a certain PSA level. These trajectories could be based on PSA doubling rates that have been shown to be effective in monitoring disease progression (32). Although providing guidelines might be helpful, focusing on addressing uncertainty and how to make decisions under uncertainty might be most helpful to patients with rising PSA levels.

Finally, patients rely heavily on their physicians for making decisions. This gives the health care provider a unique opportunity to introduce programs to support patients' decision-making processes as well as emotional well being. Specifically, physicians' providing additional information could help reduce the burden of decision making that patients often face at this later point of their disease.

Conclusion

This study illustrates that decision-making processes vary depending on the time and nature of patients' prostate cancer diagnoses. The present results highlight which components of the decision-making process are distinctly different for prostate cancer survivors diagnosed with a rising PSA compared to those at the time of initial cancer diagnosis. Given the differences in decision-making processes, it is important for physicians and other medical staff to be aware of the specific needs of patients at each stage. Understanding the increased role of importance that physicians play among prostate cancer survivors with rising PSA levels as well as the increased distress experienced by patients during follow up appointments could allow for better patient care, physician-patient communication, and support of needs. Ultimately, addressing the added distress from uncertainty surrounding rising PSA levels might improve patients' outcomes, including quality of life and satisfaction with care.

References

1. National Cancer Institute. Prostate-Specific Antigen (PSA) Test. 2012.
2. Jemal A, Murray T, Samuels A, Ghafoor A, Ward E, Thun MJ. Cancer Statistics, 2003. *CA Cancer J Clin.* 2003; 53(1):5–26. [PubMed: 12568441]
3. Moul JW. Treatment options for prostate cancer: Part I-stage, grade, PSA, and changes in the 1990's. *Am J Manag.* 1998; 4:1031.
4. Djavan B, Moul JW, Zlotta A, Remzi M, Ravery V. PSA progression following radical prostatectomy and radiation therapy: New standards in the new millenium. *Eur Urol.* 2003; 43(1): 12–27. [PubMed: 12507539]
5. Moul JW. Prostate specific antigen only progression of prostate cancer. *J Urol.* 2000; 163(6):1632–42. [PubMed: 10799151]
6. Lassiter LK, Eisenberger MA. The dilemma of patients with a rising PSA level after definitive local therapy for prostate cancer. *Semin Urol Oncol.* 20(2):146–54. [PubMed: 12012301]
7. Pound CR, Partin AW, Eisenberger MA, Chan DW, Pearson JD, Walsh PC. Natural history of progression after psa elevation following radical prostatectomy. *JAMA.* 1999 May 5; 281(17): 1591–7. [PubMed: 10235151]

8. Roberts SG, Blute ML, Bergstralh EJ, Slezak JM, Zincke H. PSA doubling time as a predictor of clinical progression after biochemical failure following radical prostatectomy for prostate cancer. *Mayo Clin Proc.* 2001 Jun; 76(6):576–81. [PubMed: 11393495]
9. Patel A, Dorey F, Franklin J, DeKernion JB. Recurrence patterns after radical retropubic prostatectomy: Clinical usefulness of prostate specific antigen doubling times and log slope prostate specific antigen. *J Urol.* 1997 Oct; 158(4):1441–5. [PubMed: 9302139]
10. Sylvester J, Grimm P, Blasco J, Meier R, Spiegel J, Heaney C, et al. The role of androgen ablation in patients with biochemical or local failure after definitive radiation therapy: A survey of practice patterns of urologists and radiation oncologists in the United States. *Urology.* 2001 Aug; 58(2):65–70. [PubMed: 11502452]
11. Moul JW. Treatment of PSA only recurrence of prostate cancer after prior local therapy. *Curr Pharm Des.* 2006; 12(7):785–98. [PubMed: 16515495]
12. Sartor CI, Strawderman MH, Lin X-H, Kish KE, McLaughlin PW, Sandler HM. Rate of PSA rise predicts metastatic versus local recurrence after definitive radiotherapy. *Int J Radiat Oncol.* 1997 Jul 15; 38(5):941–7.
13. Jani AB, Hellman S. Early prostate cancer: clinical decision-making. *The Lancet.* 2003 Mar 22; 361(9362):1045–53.
14. O'Rourke ME, Germino BB. Prostate cancer treatment decisions: a focus group exploration. *Oncol Nurs Forum.* 1998 Feb; 25(1):97–104. [PubMed: 9460777]
15. Volk RJ, Hawley ST, Kneuper S, Holden EW, Stroud LA, Cooper CP, et al. Trials of decision aids for prostate cancer screening: A systematic review. *Am J Prev Med.* 2007 Nov; 33(5):428–434. e11. [PubMed: 17950409]
16. Cameron, L.; Leventhal, H. *The self-regulation of health and illness behaviour.* New York, NY: Routledge; 2003. p. 362
17. Leventhal H, Diefenbach M, Leventhal EA. Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cogn Ther Res.* 1992 Apr 1; 16(2):143–63.
18. Diefenbach MA, Miller SM, Daly MB. Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychol.* 1999; 18(5):532–6. [PubMed: 10519469]
19. Laufer M, Pound CR, Carducci MA, Eisenberger MA. Management of patients with rising prostate-specific antigen after radical prostatectomy. *Urology.* 2000; 55(3):309–30. [PubMed: 10699599]
20. Zincke H, Oesterling JE, Blute ML, Bergstralh EJ, Myers RP, Barrett DM. Long-term (15 years) results after radical prostatectomy for clinically localized (stage T2c or lower) prostate cancer. *J Urol.* 1994 Nov; 152(5):1850–7. [PubMed: 7523733]
21. Easterling DV, Leventhal H. Contribution of concrete cognition to emotion: Neutral symptoms as elicitors of worry about cancer. *J Appl Psychol.* 1989; 74(5):787–96. [PubMed: 2793775]
22. Clark JA, Talcott JA. Confidence and uncertainty long after initial treatment for early prostate cancer: Survivors' views of cancer control and the treatment decisions they made. *J Clin Oncol.* 2006; 24(27):4457–63. [PubMed: 16983114]
23. Peters E, Lipkus I, Diefenbach MA. The functions of affect in health communications and in the construction of health preferences. *J Commun.* 2006; 56:S140–S162.
24. Han PKJ, Hootsmans N, Neilson M, Roy B, Kungel T, Gutheil C, et al. The value of personalised risk information: a qualitative study of the perceptions of patients with prostate cancer. *BMJ Open.* 2013 Sep 1.3(9):e003226.
25. Ramsey SD, Zeliadt SB, Fedorenko CR, Blough DK, Moynour CM, Hall IJ, et al. Patient preferences and urologist recommendations among local-stage prostate cancer patients who present for initial consultation and second opinions. *World J Urol.* 2011 Feb 1; 29(1):3–9. [PubMed: 20959991]
26. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. *Patient Educ Couns.* 2006 Feb; 60(2):102–14. [PubMed: 16442453]
27. Butow PN, Maclean M, Dunn SM, Tattersall MHN, Boyer MJ. The dynamics of change: Cancer patients' preferences for information, involvement and support. *Ann Oncol.* 1997 Aug 1; 8(9): 857–63. [PubMed: 9358935]

28. Wilson, TD.; Gilbert, DT. Advances in Experimental Social Psychology [Internet]. Academic Press; 2003. Affective Forecasting; p. 345-411.cited 2014 Feb 6Available from: <http://www.sciencedirect.com/science/article/pii/S0065260103010062>
29. Stewart MA. Effective physician-patient communication and health outcomes: a review. CMAJ Can Med Assoc J. 1995 May 1; 152(9):1423–33.
30. Bylund CL, Makoul G. Examining empathy in medical encounters: An observational study using the empathic communication coding system. Health Commun. 2005; 18(2):123–40. [PubMed: 16083407]
31. Bailey DE, Wallace M, Mishel MH. Watching, waiting and uncertainty in prostate cancer. J Clin Nurs. 2007; 16(4):734–41. [PubMed: 17402955]
32. Cannon GM, Walsh PC, Partin AW, Pound CR. Prostate-specific antigen doubling time in the identification of patients at risk for progression after treatment and biochemical recurrence for prostate cancer. Urology. 2003 Dec 29; 62(Supplement):2–8. [PubMed: 14747037]

Table 1

Demographics and Clinical Characteristics.

Variable	Mean/Percentage
Demographics	
Average amount of time since initial diagnosis (<i>SD</i>)	9.18 years (5.49)
Average age (<i>SD</i>)	69.56 years (7.98)
Average length of marriage (<i>SD</i>)	34.27 years (14.94)
Race/ethnicity	
White	94%
African-American	6%
Highest level of education completed	
High school degree	17.6%
College degree	29.4%
Post-graduate education	52.9%
Current employment	
Employed	52.9%
Retired	44.1%
Part-time employment	2.9%
Clinical Characteristics *	
Average level of PSA at initial diagnosis (<i>SD</i>)	5.22 (4.70)
Initial treatment	
Surgery	58.8%
External beam radiation therapy (EBRT)	20.6%
Brachytherapy	5.9%
Active surveillance	2.9%
Did not report initial treatment decision	11.8%

* All clinical measures were self-report, so some data is missing or was not reported.

Table 2

Summary of qualitative themes.

Domains
Reactions to a Rising PSA Diagnosis: Negative Affect and Optimism
<i>Negative affect</i>
Expresses fatalistic outlook
Feels depressed
Feels distressed/anxious
Feels disappointed
Feels discouraged
<i>Positive affect</i>
Happy to be alive
Enjoys life
Expresses optimistic outlook
Exhibits hope
Focuses on positive aspects of treatment
Reactions to a Rising PSA Diagnosis: Negative Affect and Optimism
<i>Action Plan</i>
Accepting of situation
Makes future plans in light of illness
Processing Diagnosis: Belief about Treatability of Disease
Believes that treatment will not be successful
Believes that cancer will return
Believes that cancer will be fatal
Role of Follow Up Appointments: Promoting Worry
Worry about quality of life
Worry about rising PSA
Worry about recurrence of prostate cancer
Does not worry about PSA on a daily basis
Only worries about PSA when prompted by a physician visit
Decision Making Processes: Monitoring PSA Levels and the Role of the Physician

Domains
<i>Monitoring</i>
Compares PSA scores to a PSA “cutoff
Compares PSA scores to trajectory/doubling rate
<i>Role of the Physician</i>
Patient less like to make decision independently
Patient more likely to make decision in conjunction with physician
Patient more likely to make decision based on physician’s preference/advice
Has confidence in physician
Trusts physician
Transferred decision making to physician
