Psycho-Oncology
Psycho-Oncology (2014)
Published online in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3721

Prostate cancer survivors' beliefs about screening and treatment decision-making experiences in an era of controversy†

Heather Orom[1]*, Willie Underwood III[2], D. Lynn Homish[1], Marc T. Kiviniemi[1], Gregory G. Homish[1], Christian J. Nelson[3] and Zvi Schiffman[4]

[1]*Community Health and Health Behavior, University at Buffalo, 3435 Main St. Buffalo, NY 14214, USA*
[2]*Urologic Oncology, Roswell Park Cancer Institute, Elm & Carlton, Buffalo, NY 14263, USA*
[3]*Memorial Sloan-Kettering Cancer Center, 641 Lexington Ave, New York, NY 10022, USA*
[4]*Houston Metro Urology P. A., 4223 Richmond Ave, Houston, TX 77027, USA*

**Correspondence to:*
Heather Orom, Community Health and Health Behavior, University at Buffalo, 3435 Main St. Buffalo, NY 14214, USA.
E-mail: horom@buffalo.edu

†for the LiveWell LiveLong! study

Received: 13 May 2014
Revised: 9 September 2014
Accepted: 15 October 2014

Abstract

***Objective*: Controversy about the costs and benefits of screening and treatment of prostate cancer (PCa) has recently intensified. However, the impact of the debate on PCa patients has not been systematically studied.**

***Methods*: We assessed knowledge of, and attitudes toward, the U.S. Preventive Services Task Force's (USPSTF) May 2012 recommendation against PSA-based screening among men diagnosed with clinically localized PCa, and tested whether exposure to the recommendation and associated controversy about overtreatment of PCa predicted treatment decisional conflict, affected treatment choice, or increased regret about PSA testing.**

***Results*: Accurate knowledge of the USPSTF recommendation was uncommon (19.1%). Attitudes toward the recommendation were negative, and the vast majority (86.5%) remained highly supportive of annual PSA testing in men ≥50. Although exposure to the recommendation and controversy about treatment was associated with lower enthusiasm for screening and treatment, it was not associated with treatment decisions, or greater decisional-conflict, or regret.**

***Conclusions*: Findings may alleviate concern that exposure to PSA-based screening and overtreatment controversies has adversely affected recent cohorts of PCa patients. However, patients remain highly supportive of PSA-based screening. As survivor anecdotes often influence people's medical decisions, it is important to appreciate the scale of opposition to the new recommendation.**

There has been considerable debate in the lay and scientific media about the costs and benefits of prostatic-specific antigen (PSA)-based screening and whether prostate cancer (PCa) has been overtreated, in part, due to widespread screening [1–6]. After two randomized controlled trials assessing PCa screening showed limited, and no reduction in mortality from PSA-based screening [7,8], in October 2011, the U.S. Preventive Services Task Force (USPSTF) released a draft recommendation against PCa screening, changing its previously neutral stance on PSA-based screening [9,10]. The final version was published May 22, 2012 [11].

In the general public, awareness of screening guideline changes is often low [12–14]. Acceptance of new screening recommendations, including the new USPSTF recommendation, is also typically low, and changes in guidelines appear to have limited impact on actual screening behavior [13,15,16]. It is an open question whether limited awareness of, and negative attitudes about, guideline changes will generalize to survivors' reactions to PCa screening recommendation changes. Furthermore, little is known about the effects of the recommendation change controversy on treatment decision-making and survivorship in those diagnosed during times of public debate about cancer screening.

The debate about the PCa screening included claims of faulty science and incorrect interpretation of evidence as well as concerns about government health care rationing on one hand, and health care profit motives on the other [4,5,17]. Exposure to the PCa screening controversy could increase uncertainty about the veracity of the information patients received about PCa, and reduce trust in information sources. If this were the case, those who are newly diagnosed could experience more decision-making conflict if they are aware of the debate. Furthermore, anecdotes from the popular press suggest that those prostate cancer patients who were further along in the survivorship trajectory might regret having had PSA screening that led to their diagnosis [18]. They may also be more inclined to choose active surveillance compared to previous cohorts.

We addressed whether these might be issues faced by men diagnosed with PCa between 2010 and 2013. First, we explored whether PCa patients were aware of

PSA-based screening recommendation changes and controversy about over-treatment as well as their beliefs about screening and treatment. Second, we tested whether the recent controversy about overtreatment of PCa has impacted men's PCa treatment decision making or regret about having had the PSA that resulted in their diagnosis.

Methods

Participants and measures

A more detailed description of the study methods is available in Appendix A (Supporting Information). Participants were newly diagnosed PCa patients recruited from five clinical facilities (two academic cancer centers and three community practices). Demographic and clinical data were assessed with a questionnaire completed at, or near the time of consent. Participants self-reported *years of education* completed, *household income*, *marital status*, date of birth from which we calculated *age at diagnosis*, and perceived *social status* (MacArthur scale of subjective social status [19]). They also self-reported *Gleason score* from the biopsy that led to their diagnosis (≤5, 6, 7, 8–10, 'don't know') and the reason for their biopsy. Those who had received a biopsy due to elevated PSA were categorized as having *PSA-detected cancer*.

Treatment choice was ascertained from medical records and in a small minority, via patient self-report. *Decisional conflict* was assessed with O'Connor et al.'s decisional conflict scale (higher scores = more decisional conflict) [20] in a questionnaire administered after patients had made their treatment choice but prior to receiving treatment.

Variables related to PSA-based screening were assessed in a third questionnaire referred to as the PSA questionnaire. All data for this third questionnaire were collected between June 22, 2012 and August 26, 2013. Items included *Attention paid to the recommendation change*: 'How much attention have you paid to the PSA screening recommendations that were released by the U.S. Preventive Services Task Force (USPSTF) in May 2012? (none or didn't hear about it/a little/some/a lot)'; *Confidence in the new recommendation*: 'How confident are you that the new U.S. Preventive Services Task Force (USPSTF) recommendation that men NOT receive PSA tests to screen for prostate cancer is in the best interest of men's health? (1 = not at all confident…5 = extremely confident)'; *Beliefs about PSA screening*: 'Do you think men who are 50 years or older should receive an annual PSA to determine if they are at increased risk for prostate cancer? (never/in some cases/always/I don't know).' *Attention given to media controversy about PCa treatment* was assessed with, 'How much attention have you paid to controversy in the media about whether prostate cancer should be treated? (none or didn't hear about it/a little/some/a lot),' and *Beliefs about PCa treatment* with, 'Do you think men should be treated for prostate cancer? (never/in some cases/always/I don't know).' *PSA regret* was assessed with 'Do you regret having had a PSA test or PSA tests that led to your diagnosis with prostate cancer? (1 = never…5 = always)'.

Finally, we coded *survivorship stage* (pretreatment/<1 year post-treatment/1–2 years post-treatment) during which participants completed the questionnaire about PSA screening and calculated *days since the release of the recommendation* (time between May 22 recommendation publication and when participant completed the PSA questionnaire).

Statistical analyses

Our goals were to (a) identify unique predictors of knowledge of the USPSTF recommendation, and having paid attention to the controversy about overtreating PCa (Table 1 Models A–C); (b) identify unique predictors of confidence in the recommendation and beliefs about screening and treatment (Table 2, Models D–F); and (c) test whether knowledge of the recommendation change or attention paid to the overtreatment controversy predicted treatment choice, decisional conflict, or PSA regret.

For the multivariable analyses, several outcomes were collapsed into binary variables: beliefs about PSA screening (always vs. never/in some cases); beliefs about PCa treatment (always vs. never/in some cases); and PSA regret (never vs. rarely/about half the time/usually/always). Continuous outcomes were analyzed with linear regression, dichotomous outcomes with logistic regression and knowledge about the recommendation, a 3-level categorical outcome, with multinomial regression. Robust standard errors were used for all statistical models. To prospectively predict treatment choice and decisional conflict as a function of awareness of the PSA recommendation and treatment controversy, we only analyzed these outcomes for participants who made their treatment decision after having been administered the PSA questionnaire. Regret about having had a PSA was only modeled in those for whom PSA-based screening had led to their PCa diagnosis.

Results

Descriptive analyses

Participant demographic and clinical characteristics are described in Appendix B (Supporting Information). The majority of the participants were white, had a college education or greater, and a household income greater than $75,000/year. Mean age at diagnosis was 62.8 years. The modal self-reported biopsy Gleason score was 6; modal PSA was 6–9; and 92% had screen-detected cancer. Summary scores for predictors and outcomes are found in Appendix C (Supporting Information).

DOI: 10.1002/pon

Table 1. Factors associated with knowledge of the 2012 USPSTF recommendation and attention to the prostate cancer treatment controversy

Predictors	Model A B (95% CI) $n = 917$	Model B RR (95% CI) $n = 917$		Model C B (95% CI) $n = 903$
	Outcomes			
	Attention paid to recommendation	Identified recommendation		Attention paid to treatment controversy
		Incorrect versus correct	'Don't know' versus correct	
Attention to recommendation change	_____	0.65§(0.55, 0.78)	0.29§(0.24, 0.36)	_____
Married	−0.18 (−0.38,0.02)	0.64 (0.34, 1.19)	0.66 (0.34, 1.28)	0.14 (−0.18, 0.21)
Education	0.04 (−0.02, 0.11)	0.63§(0.52, 0.77)	0.70‡(0.58, 0.86)	0.06 (−0.01, 0.12)
Social status	0.07‡(0.02, 0.11)	0.90 (0.78, 1.04)	0.93 (0.80, 1.08)	0.08†(0.03, 0.13)
Age	0.01†(0.01, 0.02)	1.02 (0.99, 1.04)	1.03† (1.01, 1.06)	0.01†(0.01, 0.02)
Race/ethnicity				
Black	0.02 (−0.21, 0.25)	1.56 (0.68, 3.59)	1.64 (0.67, 4.01)	0.17 (−0.10, 0.44)
Hispanic	0.01 (−0.25,0.28)	1.02 (0.41, 2.54)	1.04 (0.40, 2.72)	0.27 (−0.05, 0.58)
Survivorship stage				
Treatment to 1 year	0.18†(0.01, 0.35)	0.52†(0.31, 0.86)	0.51†(0.30, 0.87)	0.24† (0.06, 0.41)
1 to 2 years	0.37§(0.20, 0.53)	0.55†(0.34, 0.88)	0.49‡(0.29, 0.82)	0.30† (0.13, 0.47)
Days since recommendation	−0.00§(−0.00, −0.00)	1.00 (1.00, 1.00)	1.00 (1.00, 1.00)	−0.00† (−0.00,−0.00)
PSA-detected cancer	−0.02 (−0.26, 0.21)	1.04 (0.52, 2.08)	1.08 (0.54, 2.19)	0.00 (−0.24, 0.23)
Gleason score				
7	0.07 (−0.09, 0.22)	0.98 (0.64, 1.49)	0.89 (0.57, 1.38)	−0.07 (−0.24, 0.09)
8–10	0.12 (−0.15, 0.39)	1.80 (0.72, 4.49)	1.56 (0.61, 4.04)	−0.08 (−0.38, 0.22)
Don't know	−0.26†(−0.49, −0.02)	2.18 (0.83, 5.76)	2.19 (0.82, 5.91)	−0.48§(−0.74, −0.22)

Note: reference categories for the categorical variables were married, white, pre-treatment for survivorship stage, and ≤6 Gleason score;
*$p = .05$,
†$p < .05$,
‡$p < .01$,
§$p < .001$. A blank line denotes that the variable was not included in the model.

Who paid attention to the recommendation change, knew the new recommendation, and paid attention to controversy about overtreating PCa?

Just over half of participants (54.2%) said that they paid at least a little attention to the PSA screening recommendations released by the USPSTF in May 2012. Longer-term survivors were more likely to have paid attention to the recommendation; being one or two years post-treatment, rather than newly diagnosed, was associated with having paid more attention to the recommendation change, as was being older, having higher social status, and having completed the PSA questionnaire sooner after the release of the recommendation. Those who said that they did not know their Gleason score compared to having a score of ≤6 had paid less attention to the recommendation. See Table 1, Model A.

Few participants (19.1%) could accurately identify the new USPSTF recommendation (Supporting Information; Appendix C). Paying more attention to the recommendation release was associated with correctly identifying the recommendation change, as was having more education and being one or two years post-treatment, rather than newly diagnosed. Being older was associated with being more likely to report not knowing the recommendation compared to correctly identifying the recommendation (Table 1, Model B).

We also asked participants how much attention they paid to the media controversy surrounding whether PCa should be treated. Most participants (73.9%) had at least heard a little about the treatment controversy (Supporting Information; Appendix C). Having higher social status and being one or two years post-treatment, rather than newly diagnosed, were associated with paying more attention to the controversy, as was being older and completing the PSA questionnaire a longer time after the release of the recommendation (Table 1, Model C).

Patients' beliefs about the USPSTF PCa screening recommendation and screening

When told the new USPSTF recommendation, most men (74.3%) felt 'not at all confident' that the recommendation was in the best interest of men's health. Confidence in the recommendation was consistent with men's diagnosis and treatment experiences. Men whose cancer was diagnosed subsequent to an elevated PSA result (screen-detected cancer) were slightly less confident in the recommendation compared to others (Table 2, Model D).

The majority of survivors (86.5%) believed that all men over 50 should receive annual PSA screening tests (see Appendix C). However, exposure to the USPSTF recommendation against screening appears to have dampened enthusiasm

DOI: 10.1002/pon

Table 2. Factors associated with beliefs about the recommendation, PSA-based screening and prostate cancer treatment, and decision-making regret in prostate cancer survivors

Predictors	Model D B (95% CI) n = 896	Model E OR (95% CI) n = 865	Model F OR (95% CI) n = 849	Model G OR (95% CI) n = 837
	Outcomes			
	Confident in new recommendation	Men ≥ 50 should receive PSA-based screening	All men with PCa should be treated	Ever regret PSA that resulted in diagnosis
Attention to recommendation change	0.05 (−0.02,0.13)	0.69†(0.53, 0.91)	_____	0.93 (0.72, 1.20)
Recommendation knowledge				
Incorrect	0.14 (−0.05, 0.32)	1.98*(1.01, 3.94)	_____	2.08†(1.02, 4.24)
Don't know	0.07 (−0.12, 0.25)	1.10 (0.54, 2.24)		1.98 (0.94, 4.17)
Attention to overtreatment controversy in media	_____	_____	0.82‡(0.70, 0.94)	1.22 (.96, 1.55)
Married	−0.16 (−0.37, 0.04)	1.41 (0.70, 2.82)	1.14 (0.74, 1.77)	0.92 (0.49, 1.74)
Education	−0.03 (−0.09,0.03)	0.87 (0.68, 1.11)	0.66§(0.58, 0.77)	1.01 (.83, 1.23)
Social status	0.02 (−0.03, 0.07)	0.92 (0.78, 1.08)	1.00 (0.91, 1.11)	1.03 (.89, 1.19)
Age	0.00 (−0.01, 0.01)	1.01 (0.98, 1.04)	1.01 (0.99, 1.03)	0.97 (0.94, 1.01)
Race/ethnicity				
Black	0.17 (−0.07, 0.41)	1.87 (0.56, 6.24)	2.87†(1.49, 5.51)	0.70 (0.30, 1.63)
Hispanic	0.19 (−0.12, 0.51)	0.81 (0.28, 2.38)	1.31 (0.64, 2.70)	2.45†(1.11, 5.37)
Survivorship stage				
Treatment to 1 year	−0.04 (−0.20, 0.12)	1.32 (0.66, 2.62)	1.20 (0.82, 1.75)	0.62 (0.33, 1.14)
1 to 2 years	−0.02 (−0.16, 0.13)	0.83 (0.46, 1.49)	0.99 (0.68, 1.43)	1.41 (0.84, 2.35)
Days since recommendation	0.00 (0.00, 0.00)	0.99* (0.99,0.99)	1.00 (1.00, 1.00)	1.00 (1.00, 1.00)
PSA-detected cancer	−0.30†(−0.58, −0.03)	1.45 (0.62, 3.39)	1.14 (0.65, 2.00)	_____
Gleason score				
7	−0.04 (−0.18, 0.10)	2.17†(1.19, 3.95)	1.55† (1.11, 2.17)	0.61*(0.36, 1.01)
8–10	0.05 (−0.22, 0.31)	1.53 (0.49, 4.74)	3.05‡ (1.52, 6.14)	0.64 (0.28, 1.48)
Don't know	0.18 (−0.07, 0.42)	0.83 (0.32, 2.15)	1.10 (0.60, 2.01)	0.68 (0.29, 1.60)

Note: reference categories for the categorical variables were married, white, pre-treatment for survivorship stage, and ≤6 Gleason score;
*$p = .05$,
†$p < .05$,
‡$p < .01$,
§$p < .001$. A blank line denotes that the variable was not included in the model.

for screening somewhat. Attention paid to the recommendation and knowledge of the recommendation were associated with reduced odds of supporting screening for all men. Completing the PSA questionnaire a longer time after the release of the new recommendation was also associated with reduced odds of supporting screening for all men. Having more aggressive disease (Gleason 7 vs. 6) was associated with greater odds of supporting screening. See Table 2, Model E.

What are survivors' beliefs about treatment and predictors of these beliefs?

Many participants (61.3%) believed that men diagnosed with PCa should always be treated, and 31.1% believed that men should be treated in some cases (see Appendix C). Being African American compared to white and having more aggressive disease were associated with higher odds of believing that men should always be treated compared to treated in some cases. Again, exposure to the controversy appears to have affected beliefs to some degree. Exposure to the controversy about PCa treatment and higher education were associated with lower odds of believing that men should always be treated rather than treated in some cases/never. See Table 2, Model F.

Did exposure to the PSA and treatment controversies influence treatment decision-making, treatment decision-making difficulty, or result in regretting having had a PSA test?

Among those who completed the PSA questionnaire prior to being treated, neither paying attention to, nor knowledge of the USPSTF PSA recommendation, nor paying attention to the overtreatment controversy predicted treatment choice ($n = 378$; $ps > .26$; not shown in Tables). Knowledge of the PSA screening recommendations did not predict decisional conflict. There were two associations between exposure to the media controversy about treatment and the decisional conflict subscales. Paying more attention to the treatment controversy was associated with *greater* values clarity ($B = -2.33$, 95% CI = −3.58, −1.07; $p < .001$) and perceiving oneself to be *more* informed ($B = -2.28$, 95% CI = −3.87, −0.70; $p = .005$) (models not shown in Tables).

Among participants whose cancer was PSA screen-detected, a small percentage (10.8%) ever regretted having had the PSA test that resulted in their diagnosis (see Supporting Information; Appendix C). Being Hispanic rather than white and, contrary to expectations, having misidentified rather than correctly identified the USPSTF

DOI: 10.1002/pon

recommendation, were associated with ever regretting having had the PSA test that resulted in their PCa diagnosis. Having more aggressive disease (Gleason 7 compared to ≤6) was associated with lower odds of regretting the PSA test (Table 2, Model G).

Associations between treatment received and beliefs about the recommendation and screening, beliefs about treatment, and PSA regret

Men's beliefs tended to align with their treatment choice; those who received definitive therapy were more supportive of screening and aggressive treatment. Having been treated with prostatectomy rather than active surveillance was associated with lower confidence in the recommendation (B = −0.23, 95% CI = −0.46, −0.01; $p = .04$). Having been treated with prostatectomy rather than active surveillance was associated with believing men should always be screened, rather than in some cases/never screened (OR = 3.30, 95% CI = 1.42, 7.65; $p = .005$). Having been treated with external beam radiation (OR = 4.29, 95% CI = 1.78, 10.33; $p = .001$) or prostatectomy (OR = 2.99, 95% CI = 1.79, 4.98; $p < .001$), rather than active surveillance, was also associated with believing men should always be treated compared to only treated in some cases/never. Finally, having been treated with external beam radiation (OR = 0.11, 95% CI = 0.01, 0.88; $p = .04$) or prostatectomy (OR = 0.38, 95% CI = 0.18, 0.78; $p = .009$), compared to active surveillance, was associated with lower odds of regretting having had the PSA test that lead to their diagnosis.

Conclusions

Survivors remain strongly supportive of PSA-based screening and treatment for men diagnosed with PCa. The new USPSTF recommendation and controversy about overtreatment of PCa may have had a modest impact on attitudes toward PSA-based screening among those who knew the recommendation; however, most participants seemed to have limited awareness of the new recommendation. We might have expected that PCa patients, most of whom had screen-detected cancer, would have been informed about PSA-based screening recommendations, along with the benefits and risks of screening in their interactions with their physicians. Results are consistent with prior evidence that many men who have PSA tests are not engaged in these discussions by their health care providers [21]. Finding also suggests the significant role of the medical establishment and advocacy groups in informing the public's beliefs about cancer screening, as these sources have often advocated annual PSA-based screening.

Survivors' strong support for screening and treatment are likely partially attributable to cognitive dissonance reduction where people reconcile inconsistencies between their attitudes and behavior. Those who had worse disease or had been treated with definitive therapy (prostatectomy or external beam radiation) rather than active surveillance tended to have more positive attitudes toward PSA-based screening and treatment and lower odds of regretting having the PSA test that led to their PCa diagnosis. Their support for screening and treatment may be a function of commitment to the perceived value of having been screened and treated themselves. It has also been argued that given the public's strong belief in the efficacy of screening and early detection, patients with screen-detected cancer naturally feel grateful that the cancer was caught early, [6,22] which would reinforce positive attitudes toward screening.

Survivors play an important role in publically discussing [23–25] and often advocating for screening [26,27] and are sources of advice and information for other men deciding on whether to be screened or how to treat their cancer [28]. It is important for the public health and medical communities to understand that PCa survivors remain very supportive of annual PSA testing to screen for the disease, although over time, public opinion may follow that of the scientific community regarding treatment of PCa.

Clinicians and researchers might be heartened by findings indicating that controversy about PSA testing and overtreatment of PCa may not have impacted participants' treatment decision-making processes. Exposure to the controversies did not predict treatment choice and seems to have a relationship, albeit limited, with decisional conflict in the direction opposite to that which was expected. A possible explanation is that those men who knew more about the treatment controversy were generally more informed about PCa and treatment and consequently experienced less decisional conflict. Furthermore, contrary to our expectations, having believed that PSA-based screening was recommended by the USPSTF rather than not recommended, was associated with greater PSA regret. In sum, although we expected to find that the extent to which patients were aware of the USPSTF screening recommendation and controversy about treatment would be associated with experiencing more decisional conflict and PSA screening regret, and were powered to do so, we did not find this. One caveat is that it is possible that as time passes and survivors become more aware of the screening and treatment controversies and have to cope with long-term side-effects, that awareness of the arguments against PCa screening could begin to play a role in regret.

Limitations and strengths

Our study had a number of limitations. Due to data collection constraints, participants were not presented with the entire statement released by the USPSTF for consumers [29]. They were told that the Task Force now recommended against PSA screening for men at average risk for PCa prior to being asked about their confidence in

DOI: 10.1002/pon

the recommendation. Low confidence in the recommendation might have been tempered had participants read the entire Task Force statement. Our results do not necessarily indicate that men in our study who had been screened lacked knowledge of any screening recommendations. The American Urologic Association (AUA) and the American Cancer Society (ACS) both recommend that men make informed decision about PSA-based screening but do not recommend against screening [30,31]. Our measure of disease severity was self-reported Gleason score, assessed with an item that included a 'don't know' response option. Although patient-reported Gleason score is not always accurate, it has the advantage that it should be associated with patients' perceptions of disease severity, the construct of greater interest for the present study. We do not know if men are only supportive of screening for men under a certain age. Future research might investigate the extent to which patient preferences motivate the surprisingly high rates of screening in men older than 75 [32], for whom screening would be rarely recommended [30,31]. Finally, we concluded that regret about having had the PSA test that lead to their diagnosis was uncommon; however, we might have found that patients regretted other aspects of their care if we had asked about side-effects or quality of life.

This study is one of the first investigations of the impact of controversy about cancer screening and treatment on those diagnosed with the disease and informs our understanding of how these controversies impact the cancer experience. As we grapple with the complexities of the role of early detection in cancer survival, we can anticipate continued debate in the lay and scientific literatures on the topic. Although survivors may have limited awareness of these debates, we must take into consideration the possibility that for many, the debate engenders significant opposition. When opposition to recommendations is likely, response strategies might include understanding the sources and reasons for this opposition and taking these into account when creating messages for new recommendation, as well as building consensus and support in the medical and survivor communities during the development and release of new recommendations.

Acknowledgements

The LiveWell LiveLong! research group includes Integrated Medical Professionals, site-PIs, Carl A. Olsson and CEO Deepak A. Kapoor; Memorial Sloan Kettering Cancer Institute, site-PI, Christian J. Nelson; Urology San Antonio, site-PI Juan A. Reyna; Houston Metro Urology, P.A., site-PI Zvi Schiffman; Roswell Park Cancer Institute, site-PI, Willie Underwood, III; and the University at Buffalo, site-PI, Heather Orom. We would like to acknowledge the cooperation and efforts of the staff and physicians at these sites for their significant contribution to participant recruitment. R01 #CA152425

Conflict of interest

None of the authors of this manuscript has any actual, perceived, or potential conflicts of interest that would interfere with the accurate reporting of the results.

References

1. Friedrich MJ. Debate continues on use of PSA testing for early detection of prostate cancer. *JAMA* 2011;**305**:2273–2275. DOI: 10.1001/jama.2011.777.
2. Beck M. Should men get PSA tests to screen for prostate cancer? Vol **2014**. Wall Street Journal 2014.
3. Barry MJ. Screening for prostate cancer — the controversy that refuses to die. *N Engl J Med* 2009;**360**:1351–1354. DOI: 10.1056/NEJMe0901166.
4. Brawley OW. Prostate cancer screening: What we know, don't know, and believe. *Ann Intern Med* 2012;**157**:135–136. DOI: 10.7326/0003-4819-157-2-201207170-00460.
5. Catalona WJ, D'Amico AV, Fitzgibbons WF *et al*. What the U.S. Preventive Services Task Force missed in its prostate cancer screening recommendation. *Ann Intern Med* 2012;**157**:137–138. DOI: 10.7326/0003-4819-157-2-201207170-00463.
6. Esserman L, Shieh Y, Thompson I. Rethinking screening for breast cancer and prostate cancer. *JAMA* 2009;**302**:1685–1692. DOI: 10.1001/jama.2009.1498.
7. Andriole GL, Crawford ED, Grubb RL *et al*. Mortality results from a randomized prostate-cancer screening trial. *N Engl J Med* 2009;**360**:1310–1319. DOI: 10.1056/NEJMoa0810696.
8. Schröder FH, Hugosson J, Roobol MJ *et al*. Screening and prostate-cancer mortality in a randomized European study. *N Engl J Med* 2009;**360**:1320–1328. DOI: 10.1056/NEJMoa0810084.
9. U.S. Prevent Services Task Force (USPSTF). Screening for prostate cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2008;**149**:185–191.
10. U.S. Prevent Services Task Force (USPSTF). Screening for prostate cancer: Recommendations and rationale. *Am Fam Physician* 2003;**67**:787–792.
11. Moyer VA. Screening for prostate cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2012;**157**:120–134. DOI: 10.7326/0003-4819-157-2-201207170-00459.
12. Kiviniemi M, Hay J. Awareness of the 2009 US Preventive Services Task Force recommended changes in mammography screening guidelines, accuracy of awareness, sources of knowledge about recommendations, and attitudes about updated screening guidelines in women ages 40-49 and 50+. *BMC Public Health* 2012;**12**:899. DOI: 10.1186/1471-2458-12-899.
13. Squiers LB, Bann CM, Dolina SE, Tzeng J, McCormack L, Kamerow D. Prostate-specific antigen testing: Men's responses to 2012 recommendation against screening. *Am J Prev Med* 2013;**45**:182–189. DOI: 10.1016/j.amepre.2013.04.005.
14. Squiers L, Holden D, Dolina S, Kim A, Bann C, Renaud J. The public's response to the U. S. Preventive Services Task Force's 2009 recommendations on mammography screening. *Am J Prev Med* 2011;**40**:497–504. DOI: 10.1016/j.amepre.2010.12.027.
15. Pace LE, He Y, Keating NL. Trends in mammography screening rates after publication of the 2009 US Preventive Services Task Force recommendations. *Cancer* 2013;**119**:2518–2523. DOI: 10.1002/cncr.28105.
16. Cohn JA, Wang CE, Lakeman JC *et al*. Primary care physician PSA screening practices before and after the final U.S. Preventive Services Task Force recommendation. *Urol Oncol-Semin Ori* 2014;**32**:41 e23–41 e30. DOI: 10.1016/j.urolonc.2013.04.013.
17. Bankhead C. USPSTF says 'no' to PSA testing. Vol **2014**: medpagetoday, 2012.

18. Parker-Pope T. WELL; Prostate test finding leaves a swirl of confusion. *New York Times*. Vol **2014**, 2011.
19. Adler NE, Epel ES, Castellazzo G, Ickovics JR. Relationship of subjective and objective social status with psychological and physiological functioning: Preliminary data in healthy, White women. *Health Psychol* 2000;**19**:586–592. DOI: 10.1037/0278-6133.19.6.586.
20. O'Connor A. Validation of a decisional conflict scale. *Med Decis Making* 1995;**15**:25–30.
21. Han PKJ, Kobrin S, Breen N *et al*. National evidence on the use of shared decision making in prostate-specific antigen screening. *Ann Fam Med* 2013;**11**:306–314. DOI: 10.1370/afm.1539.
22. Ransohoff DF, McNaughton Collins M, Fowler Jr FJ. Why is prostate cancer screening so common when the evidence is so uncertain? a system without negative feedback. *Am J Med* 2002;**113**:663–667. DOI: 10.1016/S0002-9343(02)01235-4.
23. Burnett AL, Morris NS. Prostate cancer survivors speak their minds: Advice on options, treatments, and aftereffects. John Wiley & Sons: Hoboken, New Jersey, 2010.
24. Arkes HR, Gaissmaier W. Psychological research and the prostate-cancer screening controversy. *Psychol Sci* 2012;**23**:547–553. DOI: 10.1177/0956797612437428.
25. Chapple A, Ziebland S, Shepperd S, Miller R, Herxheimer A, McPherson A. Why men with prostate cancer want wider access to prostate specific antigen testing: qualitative study. *BMJ* 2002;**325**:737. DOI: 10.1136/bmj.325.7367.737.
26. The Prostate Health Education Network. Vol **2014**.
27. Us TOO Prostate Cancer Education & Support. Vol **2014**.
28. Boehmer U, Babayan RK. A pilot study to determine support during the pre-treatment phase of early prostate cancer. *Psycho-Oncology* 2005;**14**:442–449. DOI: 10.1002/pon.859.
29. U.S. Prevent Services Task Force (USPSTF). Screening for prostate cancer. Vol **2014**, 2012.
30. Wolf AMD, Wender RC, Etzioni RB *et al*. American Cancer Society guideline for the early detection of prostate cancer: Update 2010. *CA Cancer J Clin* 2010;**60**:70–98. DOI: 10.3322/caac.20066.
31. Carter HB. American Urological Association (AUA) Guideline on prostate cancer detection: process and rationale. *BJU Int* 2013;**112**:543–547. DOI: 10.1111/bju.12318.
32. Bellizzi KM, Breslau ES, Burness A, Waldron W. Prevalence of cancer screening in older, racially diverse adults: Still screening after all these years. *Arch Intern Med* 2011;**171**:2031–2037. DOI: 10.1001/archinternmed.2011.570.

Supporting information

Additional supporting information may be found in the online version of this article at the publisher's web site.

Prostate Cancer Survivors' Beliefs about Screening and Treatment Decision-Making Experiences in an Era of Controversy

APPENDIX A: METHODS

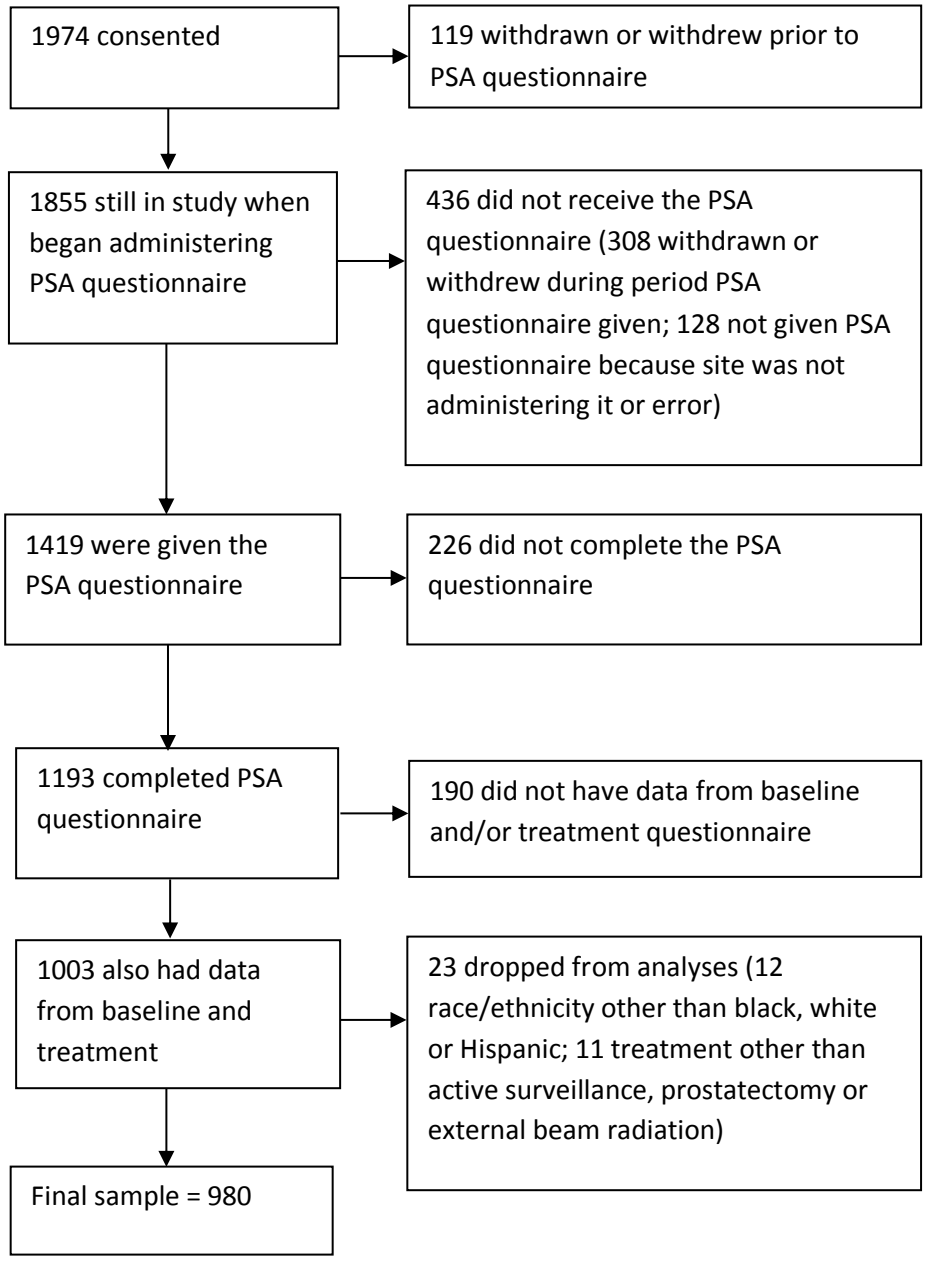
Procedure

Data were from a subset of participants taking part in a larger study of PCa treatment decision-making and survivorship in which they were assessed prior to, and every six months for the two years following treatment. All participants in the parent study were newly diagnosed PCa patients recruited from five clinical facilities (2 academic cancer centers and 3 community practices). Participants in the present study were among those recruited to the parent study between July 2010 and August 2013. For the present study, participants completed self-report paper and pencil questionnaires either in the clinic or mailed in questionnaires prior to treatment and at regular intervals after treatment. 1) Demographic and clinical data were assessed with a questionnaire completed at, or near the time of consent; 2) treatment decisional conflict was assessed in a second questionnaire completed after making the treatment decision, but prior to treatment; 3) knowledge and perceptions of the USPSTF PSA screening recommendation and the PCa treatment controversy were assessed in a third questionnaire referred to as the PSA questionnaire. It was completed after the release of the USPSTF final recommendation either at consent or first point of follow-up after the USPSTF release. All data for this third questionnaire were collected between June 22, 2012 and August 26, 2013. Participants were given the questionnaire at their first regularly scheduled study assessment on or after June 22. As participants differed with respect to how long they had been in the study when we began to administer the PSA questionnaire, they also differed with respect to the point in the treatment/survivorship trajectory when they completed the PSA questionnaire (43.0% completed it prior to treatment, 26.7% within six months of treatment, 15.7% 12 months after treatment, 11.2% 18 months after treatment, and 3.2% 24 months after treatment). For the purpose of including participants' survivorship stage as a variable in the multivariable models, we collapsed the five categories into three: pre-treatment, within 1 year of treatment and 1-2 years from treatment (see Measures section and Appendix A). Study procedures were Institutional Review Board-approved.

Participants

The Figure below presents the number of participants in the original parent study who were not included in the present study and reasons for these losses. In total, 1003 completed all three questionnaires of interest used for the present study and after excluding participants who reported "other" for race/ethnicity (n=12) or treatment (n=11) the final sample contained 980 individuals.

Number of participants not included in the study and reasons



Measures

Knowledge and beliefs about PSA screening recommendations, screening, and treatment

Knowledge and confidence in the PSA screening recommendations were assessed in the PSA questionnaire which was administered after the release of the USPSTF final recommendation. Item wording was as follows. *Knowledge about the recommendation change*: "The U.S. Preventive Services Task Force (USPSTF) recommends men age 50-75 receive an annual PSA test (true/false/I don't know)"; *Attention paid to the recommendation change*: *"*How much attention have you paid to the PSA screening recommendations that were released by the U.S. Preventive Services Task Force (USPSTF) in May 2012? (none or didn't hear about it/a little/some/a lot)"; *Confidence in the new recommendation*: "How confident are you that the new U.S. Preventive Services Task Force (USPSTF) recommendation that men NOT receive PSA tests to screen for prostate cancer is in the best interest of men's health? (1=not at all confident…5=extremely confident)"; *Beliefs about PSA screening* : *"*Do you think men who are 50 years or older should receive an annual PSA to determine if they are at increased risk for prostate cancer? (never/in some cases/always/I don't know)." The questions about beliefs about screening, knowledge of the recommendation, and attention paid toward the recommendation were asked *prior* to stating the recommendation and asking participants about their confidence in the recommendation.

The PSA questionnaire also included items that assessed *Attention given to media controversy about PCa treatment* with, *"*How much attention have you paid to controversy in the media about whether prostate cancer should be treated? (none or didn't hear about it/a little/some/a lot)," and *Beliefs about PCa treatment* with, "Do you think men should be treated for prostate cancer? (never/in some cases/always/I don't know)."

Treatment choice was ascertained from medical records for men who were treated at the facility in which they were consented. Research staff spoke to the participant via phone to confirm the treatment choice of men who were not. *Decisional conflict* was assessed after participants had made their treatment decision, but prior to treatment with O'Connor and colleagues' decisional conflict scale [19] designed to assess uncertainty about choices, vacillation, and delayed decision-making. Higher scores (0-100) indicate more decisional conflict. *PSA regret* was assessed in the PSA questionnaire with the single face-valid item, *"*Do you regret having had a PSA test or PSA tests that led to your diagnosis with prostate cancer?" on a 5-point response item ranging from "never" to "always". This item was assessed in the PSA questionnaire; therefore, it was assessed after the release of the USPSTF guideline.

Demographic and clinical characteristics

When they were initially enrolled in the study, participants were asked to self-report *years of education* completed, *household income*, *marital status*, date of birth from which we calculated *age at diagnosis*, and perceived *social status*. Perceived social status was assessed with an adapted version of the MacArthur scale of subjective social status in which people are asked to indicate on a graphic of a ladder, their relative standing in society with respect to money, education, and jobs [20]. We asked people to rate themselves with respect to "others in their community", instead of relative to "other people in the United States". Participants were categorized as non-Hispanic white, non-Hispanic African American and Hispanic (any race) and are hitherto referred to as white, African American, and Hispanic. Participants were also asked to self-report *Gleason score* from the biopsy that led to their diagnosis (≤5, 6, 7, 8-10, "don't know") and asked, "why did you get a biopsy of your prostate?" (elevated PSA/abnormal digital rectal exam/other). Those who said they had received a biopsy due to elevated PSA were categorized as having *PSA-detected cancer*. We coded *survivorship stage* (pretreatment/< 1 year post-treatment/1-2 years post-treatment) during which participants completed the questionnaire about PSA screening.

Days since the release of the recommendation

A final variable, *days since the release of the recommendation,* was calculated for each participant; this was the number of days between the May 22, 2012 release of the USPSTF recommendation and the day a given participant completed the questionnaire about the PSA recommendation change.

Statistical analyses

Our goals were to 1) identify unique predictors of knowledge of the USPSTF recommendation, and having paid attention to the controversy about overtreating PCa (Table 1 Models A-C); 2) identify unique predictors of confidence in the recommendation and beliefs about screening and treatment (Table 2, Models D-F); and 3) test whether knowledge of the recommendation change or attention paid to the overtreatment controversy predicted treatment choice, decisional conflict or PSA regret (regret was analyzed with Model G; results of other analyses are presented in the text but not the Tables). Continuous outcomes were analyzed with linear regression, producing unstandardized B coefficients (Bs), and dichotomous outcomes were analyzed with logistic regression, producing odds ratios (ORs). Knowledge about the recommendation was a 3-level categorical outcome (correct/incorrect/don't

know) and was analyzed using multinomial regression, producing risk ratios (RRs). “Don’t know” responses to the question about knowledge of the recommendation change were included as these responses were deemed to be especially meaningful. For other items that included a “don’t know” response option, “don’t know” responses were not analyzed to increase ease of data interpretation. For the multivariable analyses, several outcomes were collapsed into binary variables: beliefs about PSA screening (always vs. never/in some cases); beliefs about PCa treatment (always vs. never/in some cases); and PSA regret (never vs. rarely/about half the time /usually /always).

Participants were recruited from five clinical facilities; to account for this source of non-independence, robust standard errors were used for each of the statistical models. Multivariable covariates included marital status, race/ethnicity, and age at diagnosis, social status (income was excluded due to low response rate (84%)), educational attainment, self-reported biopsy Gleason score (cancer aggressiveness), time between the release of the recommendation and when participants completed the PSA questionnaire, and survivorship stage except when we stratified by this variable.

We were interested in prospectively predicting treatment choice and decisional conflict as a function of awareness of the PSA recommendation and treatment controversy; therefore, we only analyzed these outcomes for participants who made their treatment decision after having been administered the PSA questionnaire. Regret about having had a PSA was only modeled in those for whom PSA-based screening had led to their PCa diagnosis.

APPENDIX B: SAMPLE DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

Sample demographic and clinical characteristics (Total N=980)

Characteristic	N	% or mean (SD)
Education		
< High school	16	1.63 %
High school	273	27.86 %
Some college	127	12.96 %
≥ College	561	57.24 %
Income		
< $25,000	51	5.20 %
$25,000-49,999	107	10.92 %
$50,000-$74,999	133	13.57 %
≥ $75,000	534	54.49 %
Mean socioeconomic status (range 1-10)	948	6.54 (1.65)
Has health care insurance		
Yes	976	99.59 %
No	2	0.20 %
Marital status		
Married or has partner	833	85.00 %
Single	145	14.80 %
Race/Ethnicity		
Black Non-Hispanic	94	9.59 %
White Non-Hispanic	825	84.18 %
Hispanic	53	5.41 %
Mean age at diagnosis	973	62.81 (7.82)
Self-reported PSA at diagnosis		
≤ 4	328	33.47 %
5-9	469	47.86 %
≥ 10	121	12.35 %
Self-reported Gleason score		
≤6	454	46.33 %
7	343	35.00 %
8-10	88	8.98 %
Don’t know	89	9.08 %
PSA-detected cancer		
Yes	904	92.24 %
No	74	7.55 %
Treatment received		
Prostatectomy	513	52.35 %
External beam radiation	213	21.73 %
Active surveillance	245	25.00 %
Survivorship stage when PSA questionnaire completed		
Pre-treatment		
Treatment to 1 year	418	42.96 %
1 to 2 years	260	26.72 %
	295	30.32 %
Days between release of USPSTF recommendation and completion of PSA questionnaire	980	211 (110)

APPENDIX C: DISTRIBUTION OF OUTCOMES

Distribution of responses to knowledge, attitude, beliefs, decision-making, and regret questions

Characteristic	N	% or mean (SD)
Awareness of 2012 USPSTF PSA screening recommendation and treatment controversy		
Knowledge of USPSTF recommendation		
Correct	187	19.08 %
Incorrect	389	39.69 %
I don't know	403	41.12 %
Paid attention to USPSTF recommendation release in May 2012		
None/ Did not hear about it		
A little	444	45.31 %
Some	215	21.94 %
A lot	190	19.39 %
	126	12.86 %
Attention paid to PCa controversy in the media?		
None/ Did not hear about it	245	25.00 %
A little	242	24.69 %
Some	288	29.39 %
A lot	194	19.80 %
Attitudes toward 2012 USPSTF recommendation		
How confident are you that the USPSTF recommendation is in the best interest of men's health?		
Not at all confident	728	74.29 %
Slightly confident	86	8.78 %
Somewhat confident	73	7.45 %
Moderately confident	36	3.67 %
Extremely confident	28	
		2.86 %
Beliefs about PSA-based screening		
Men ≥ 50 should receive an annual PSA		
Always	848	86.53 %
In some cases	73	7.45 %
Never	6	0.61 %
I don't know	52	5.31 %
Beliefs about treatment		
Do you think men should be treated for PCa?		
Never	0	0.0 %
In some cases	305	31.12 %
Always	601	61.33 %
I don't know	62	6.33 %
Decisional conflict and PSA regret		
Mean decisional conflict		
Total	976	8.00 (10.13)
Informed	978	8.15 (13.95)
Values clarity	977	7.27 (13.12)
Adequate support	979	4.76 (10.41)
Uncertainty	977	14.91 (17.84)
Effective decision-making	978	5.74 (10.40)
Regret having had PSA test that led to PCa diagnosis†		
Never	800	89.19 %

Rarely	65	7.25 %
About half the time	18	2.01 %
Usually	6	0.67 %
Always	8	0.89 %

†responses are only reported for the 904 participants with PSA screen-detected cancer