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

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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.

†for the LiveWell LiveLong! study

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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.

Supporting information

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

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).

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 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 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 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.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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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) <i>n</i> = 917	Model B RR (95% CI) <i>n</i> = 917	Model C B (95% CI) <i>n</i> = 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.

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 B (95% CI) n = 865	Model F B (95% CI) n = 849	Model G B (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.