

How Much Information Do Icelandic Men Receive on Pros and Cons of Prostate-Specific Antigen Testing Prior to Undergoing Testing?

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Valgerdur Kristin Eiriksdottir¹ , Birna Baldursdottir¹ ,
Jon Orn Fridriksson², and Heiddis B. Valdimarsdottir^{1,3}

Abstract

Prostate-specific antigen (PSA) testing for asymptomatic men is neither encouraged nor discouraged in most countries; however, shared decision-making is emphasized prior to PSA testing. The objective of this study was to examine to what extent Icelandic men receive information about the pros and cons of PSA testing. Furthermore, to explore if patient–provider communication about pros and cons of PSA testing has improved in the last decade during which time more emphasis has been placed on shared decision-making. All Icelandic men diagnosed with prostate cancer in the years 2015 to 2020 were invited to participate, and a total of 471 out of 1002 men participated (response rate 47.0%). Participants' age ranged from 51 to 95 years ($M = 71.9$, $SD = 7.3$). Only half of the men received information about the pros and cons of PSA testing, a third did not receive any information prior to testing and, alarmingly, 22.2% of the men did not even know that they were being tested. A majority of the participants lacked knowledge about the testing with half of the men reporting that they had no knowledge about pros and cons of PSA testing prior to testing. The findings have major public health relevance as they indicate that information provided prior to PSA testing continue to be deficient and that there is a pressing need for interventions that educate men about the benefits and limitations of PSA testing before men undergo medical procedures that can seriously affect their quality of life.

Keywords

PSA testing, shared decision-making, prostate cancer, information

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Introduction

Prostate cancer is the second most common cancer in men worldwide (Bray et al., 2018) and the most frequent cancer among Icelandic men, with approximately 200 men being diagnosed with prostate cancer yearly (The Icelandic Cancer Society, 2017). Early detection of prostate cancer is possible with a blood test measuring the prostate-specific antigen (PSA) and with a digital rectal exam (National comprehensive cancer network, 2020). Early detection is, however, controversial, and evidence from randomized clinical trials have reported mixed results of the benefits of prostate cancer screening with PSA testing as it does not affect overall

mortality and only leads to a minor reduction in 10-year disease-specific mortality (Andriole et al., 2009; Djulbegovic et al., 2010; Hayes & Barry, 2014; Ilic et al., 2018; Lin et al., 2008; Schröder et al., 2014). In addition, PSA testing identifies tumors that do not

¹Department of Psychology, Reykjavik University, Reykjavik, Iceland

²National University Hospital of Iceland, Reykjavik, Iceland

³Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Corresponding Author:

Birna Baldursdottir, Department of Psychology, Reykjavik University, Menntavegur 1, 102 Reykjavik, Iceland.

Email: birnabaldurs@ru.is



necessarily become clinically relevant and therefore, screening can cause over-diagnosis and overtreatment. In fact, estimations indicate that around 20% to 50% of prostate cancer is over-diagnosed and that one in five PSA tests gives false-positive result (Fenton et al., 2018; Pathirana et al., 2019). Over-diagnosis can cause harm, such as anxiety, stress, and excess diagnostic evaluations and in some cases lead to overtreatment that can further lead to lasting treatment side effects like erectile dysfunction and urinary problems (Ilic et al., 2018). Therefore, it is important that men understand the pros and cons of PSA testing before undergoing testing. PSA testing for asymptomatic men is neither encouraged nor discouraged in most countries and universal recommendations for PSA testing are not available (Carter et al., 2013; Djulbegovic et al., 2010; Fenton et al., 2018; Hoffman & Helitzer, 2007; The Icelandic Directorate of Health, 2017; Lin et al., 2008; Regionala cancercentrum i samverkan, 2020; US Preventive Services Task Force et al., 2018; Wolf et al., 2010). With increased focus on patient involvement and shared decision-making, most medical organizations encourage asymptomatic men, from the age of 55 to 69, to engage in a shared decision-making with a health care provider to discuss the risks and benefits of PSA testing before making a decision to be tested (Carter et al., 2013; US Preventive Services Task Force et al., 2018). Despite this, the few existing studies demonstrate that the information men receive before PSA testing is limited and shared decision-making is lacking (e.g., Cooper et al., 2019; Fridriksson et al., 2012; Han et al., 2013; Hoffman et al., 2009; Lamplugh et al., 2006; Leyva et al., 2016). A majority of previous studies were done in North America, but the results from the only study that was conducted in a Nordic country (Fridriksson et al., 2012) revealed that information provided before PSA testing was deficient with about 27% of the men receiving no information about pros and cons of PSA testing, and 10.2% were not aware that their PSA levels were being tested.

Surprisingly, very few studies have been conducted in the past 10 years but more than a decade ago, two major trials of PSA screening emerged, reporting that the benefit of prostate cancer screening is minor and controversial (Andriole et al., 2012; Schröder et al., 2014). Following these studies, the U.S. Preventive Service Task Force further emphasized the importance of shared decision-making prior to PSA testing where a patient and health care provider discuss the pros and cons of PSA testing in details (Moyer, 2012; US Preventive Services Task Force et al., 2018). Shared decision-making has also been underscored by the American Cancer Society and the American Urological Association (Carter et al., 2013; Wolf et al., 2010). Given the increased emphasis over the years on shared decision-making prior to PSA testing, it

is important to examine if there have been improvements in patient-provider communications about the pros and cons of PSA testing. Thus, the main objective of this study was to extend former studies, including the only Nordic study, by using more recent data from 2015 to 2020, to examine to what extent Icelandic men received information about the pros and cons of PSA testing from their health care providers. In addition, this study examined knowledge about pros and cons of PSA testing and if asymptomatic and symptomatic men received different information regarding pros and cons of PSA testing. Finally, it was explored if residence affected how the men were informed about the test results (i.e., in an appointment, by phone call or e-mail).

Understanding how information, or lack thereof, is delivered about the pros and cons of PSA testing is critical for development and implementation of interventions to educate men about the benefits and limitations of PSA testing before men undergo medical procedures that can have adverse effects on their quality of life.

Methods

Participants

Participants were men aged 51 to 95 ($M = 71.9$, $SD = 7.3$) and diagnosed with prostate cancer during the years 2015 to 2020. A majority, or 293 men (65.5%), were retired, 115 men (25.7%) worked full time and 39 men (8.8%) were either on a sick leave, on benefits or in school. Almost half of the participants had finished vocational education, or 204 men (46.4%), 46 men (10.4%) had finished secondary education, 125 men (28.4%) had finished a university degree and 65 men (14.8%) had finished primary education or less. Most were married or living with a partner, or 357 men (81.3%), and 272 men (61.1%) had a residence in the capital area of Iceland. The mean age at diagnosis of prostate cancer was $M = 68.1$, $SD = 7.2$.

Procedure

After receiving ethics approval, the names of 1062 men diagnosed with prostate cancer in 2015 to 2020 were obtained via the Icelandic Cancer Registry. Participants were recruited between May 4 and August 16, 2021 by sending a participation invitation by post, including an information letter describing the study and a link to an online questionnaire. If participants used the information to open the link, they first had to give informed consent before they could start the questionnaire. Those preferring a paper version of the questionnaire could contact the researchers and ask to receive it by post.

Of the potential 1062 men, 1002 were sent a study invitation through the postal services, but 60 did not have a registered home address. A total of 208 responded to the invitation and completed the questionnaire. The 794 participants that had not responded within 2 weeks were contacted via telephone. Of those, 438 could be reached and 347 agreed to participate, but of those, 82 never returned the questionnaire, 87 declined participation, two were deceased and two could not participate because of illness. The remaining 356 could not be reached, either because their phone number could not be found or because they did not answer our calls. In total, 471 out of 1002 men participated and therefore the response rate was 47.0% with a completion rate of 95.1%.

Measures

Standard sociodemographic variables were collected via the questionnaire, that is, age, relationship status, vocational status, and residency. Based on the questionnaire by Fridriksson et al. (2012), the following questions were included in this study: (a) what was the reason for your first PSA test (possible answers being, e.g., I had voiding symptoms, I was worried about having prostate cancer, my doctor recommended it), (b) did you receive any information about the pros and cons of PSA testing prior to testing (i.e., verbal, written, verbal, and written or none or was not aware of PSA testing had been done), and (c) how did you receive the results from the PSA testing (i.e., at an appointment with your doctor, via telephone, and via e-mail). In addition to the questions from Fridriksson et al. (2012), the participants were also asked how they would rate their knowledge of PSA testing prior to the testing and also, if they had any symptoms of prostate cancer prior to the PSA testing. Information about year of diagnosis was provided by the Icelandic Cancer Registry.

Ethics Approval: The study received ethical approval from the Icelandic Cancer Registry and The National Bioethics Committee (Reference number: VSN-21-050).

Results

Majority of participants, or 285 (63.3%), did not have symptoms of prostate cancer prior to the PSA testing. The largest proportion of men, 163 (36.2%), had a PSA test because their physician recommended it (see Table 1). Other common reasons for having a PSA test were that participants had voiding symptoms, or 117 men (26.0%), 116 men (25.8%) sought medical care for something else and 102 men (22.7%) had regular health examination, including a PSA test.

Of the participants, 178 (40.7%) recalled that they received verbal information about the pros and cons of PSA testing while only eight (1.8%) received written

information and 32 (7.3%) received both verbal and written information about the pros and cons of PSA testing prior to testing. However, 122 men (27.9%) received no information prior to PSA testing and 97 men (22.2%) were not even aware that a PSA test had been done (see Table 1 and Figure 1). Most of the men received the results from the PSA test at an appointment with their physician, 317 men (70.4%), and 114 men (25.3%) received the results via a telephone call. Additional analysis revealed that more than half of those that got their results by telephone call lived in the capital area or 64 men (55.7%).

Regarding knowledge, participants reported a low level of knowledge of pros and cons of PSA testing prior to testing, as 224 men (49.8%) reported that they had no knowledge, 86 men (19.1%) reported very little knowledge, 58 men (12.9%) reported little knowledge, 40 men (8.9%) had neither little nor much knowledge, 24 men (5.3%) reported much knowledge and only five (1.1%) reported having very much knowledge.

Figure 2 demonstrates that there was little difference, between asymptomatic and symptomatic men, in how and if they received the information prior to the PSA testing. In both groups, around one in four did not get any information of pros and cons of PSA testing prior to testing (67 asymptomatic men [23.5%] and 30 symptomatic men [18.2%]). This was also examined for age and level of education, but those variables did not have any effect on how much and what kind of information men received prior to PSA testing.

Discussion

The objective of this study was to examine if and to what extent Icelandic men received information about the pros and cons of PSA testing prior to undergoing the test. Furthermore, to explore, by comparing the results to earlier studies, if patient-provider communication about pros and cons of PSA testing has improved in the last decade during which time more emphasis has been placed on shared decision-making.

The results from this study revealed that the patient-provider communication about pros and cons of PSA testing continues to be deficient. Only half of the men received information about the pros and cons of PSA testing, a third did not receive any information prior to testing and, alarmingly, 22.2% of the men did not even know that they were being tested. Only 9.1% received the information in a written or both verbal and written format, which is concerning as knowledge about pros and cons of PSA testing was generally low with 49.8% of the men reporting that they had no knowledge about pros and cons of PSA testing prior to testing and 32.0% reporting little or very little knowledge. The results also demonstrated that the information participants received prior to PSA

Table 1. Questions About PSA Testing Reported by Year Diagnosed and Total Findings.

Questions about PSA testing	2015	2016	2017	2018	2019	2020	Total
What was the reason for your first PSA test?	n = 67 (%)	n = 79 (%)	n = 58 (%)	n = 73 (%)	n = 80 (%)	n = 93 (%)	n = 450 (%)
I had voiding symptoms	19 (28.4)	23 (29.1)	8 (13.8)	19 (26.0)	20 (25.0)	28 (30.1)	117 (26)
I had other symptoms from the urine or genital organs	4 (6.0)	4 (5.1)	3 (5.2)	4 (5.5)	8 (10.0)	4 (4.3)	27 (6.0)
I was worried about having prostate cancer	7 (10.4)	6 (7.6)	3 (5.2)	4 (5.5)	4 (5.0)	8 (8.6)	32 (7.1)
I was worried about having prostate cancer as I have relatives diagnosed with prostate cancer	7 (10.4)	5 (6.3)	2 (3.4)	7 (9.6)	5 (6.3)	8 (8.6)	34 (7.6)
My wife/girlfriend/partner urged me	5 (7.5)	10 (12.7)	4 (6.9)	8 (11.0)	7 (8.8)	7 (7.5)	41 (9.1)
My physician recommended that I should have the PSA test	28 (41.8)	30 (38.0)	23 (39.7)	35 (47.9)	26 (32.5)	21 (22.6)	163 (36.2)
Media coverage	2 (3.0)	4 (5.1)	1 (1.7)	7 (9.6)	5 (6.3)	6 (6.5)	25 (5.6)
I had sought medical care for something else	16 (23.9)	22 (27.8)	20 (34.5)	20 (27.4)	15 (18.8)	23 (24.7)	116 (25.8)
I had a regular health examination	14 (20.9)	17 (21.5)	12 (20.7)	11 (15.1)	20 (25.0)	28 (30.1)	102 (22.7)
Not sure	0 (0.0)	1 (1.3)	2 (3.4)	1 (1.4)	2 (2.5)	1 (1.1)	7 (1.6)
Other	2 (3.0)	3 (3.8)	2 (3.4)	3 (4.1)	10 (12.5)	8 (8.6)	28 (6.2)
What information did you receive before the PSA test?	n = 64 (%)	n = 78 (%)	n = 56 (%)	n = 68 (%)	n = 78 (%)	n = 93 (%)	n = 437 (%)
Verbal information on the pros and cons of PSA testing	23 (35.9)	37 (47.4)	21 (37.5)	30 (44.1)	31 (39.7)	36 (38.7)	178 (40.7)
Verbal and written information on the pros and cons of PSA testing	9 (14.1)	4 (5.1)	2 (3.6)	2 (2.9)	6 (7.7)	9 (9.7)	32 (7.3)
Written information on the pros and cons of PSA testing	2 (3.1)	0 (0.0)	1 (1.8)	0 (0.0)	2 (2.6)	3 (3.2)	8 (1.8)
No information on the pros and cons of PSA testing	18 (28.1)	18 (23.1)	23 (41.1)	18 (26.5)	24 (30.8)	21 (22.6)	122 (27.9)
No information that the PSA test had been done	12 (18.8)	19 (24.4)	9 (16.1)	18 (26.5)	15 (19.2)	24 (25.8)	97 (22.2)
How did you receive information on the result from the PSA test?	n = 67 (%)	n = 79 (%)	n = 58 (%)	n = 73 (%)	n = 80 (%)	n = 93 (%)	n = 447 (%)
At an appointment with my physician	47 (70.1)	60 (75.9)	43 (74.1)	52 (71.2)	52 (65.0)	63 (67.7)	317 (70.4)
At an appointment with a health care provider	2 (3.0)	5 (6.3)	3 (5.2)	1 (1.4)	2 (2.5)	5 (5.4)	18 (4.0)
With a telephone call	16 (23.9)	17 (21.5)	13 (22.4)	22 (30.1)	20 (25.0)	26 (28.0)	114 (25.3)
By a letter	2 (3.0)	3 (3.8)	0 (0.0)	1 (1.4)	0 (0.0)	2 (2.2)	8 (1.8)
With an e-mail	0 (0.0)	2 (2.5)	0 (0.0)	1 (1.4)	3 (3.8)	0 (0.0)	6 (1.3)
I was not informed about my PSA value	1 (1.5)	0 (0.0)	0 (0.0)	1 (1.4)	1 (1.3)	5 (5.4)	8 (1.8)
Other	1 (1.5)	0 (0.0)	0 (0.0)	0 (0.0)	2 (2.5)	1 (1.1)	4 (0.9)
Cannot remember/not sure	3 (4.5)	2 (2.5)	2 (3.4)	2 (2.7)	2 (2.5)	0 (0.0)	11 (2.4)

Note. PSA = prostate-specific antigen.

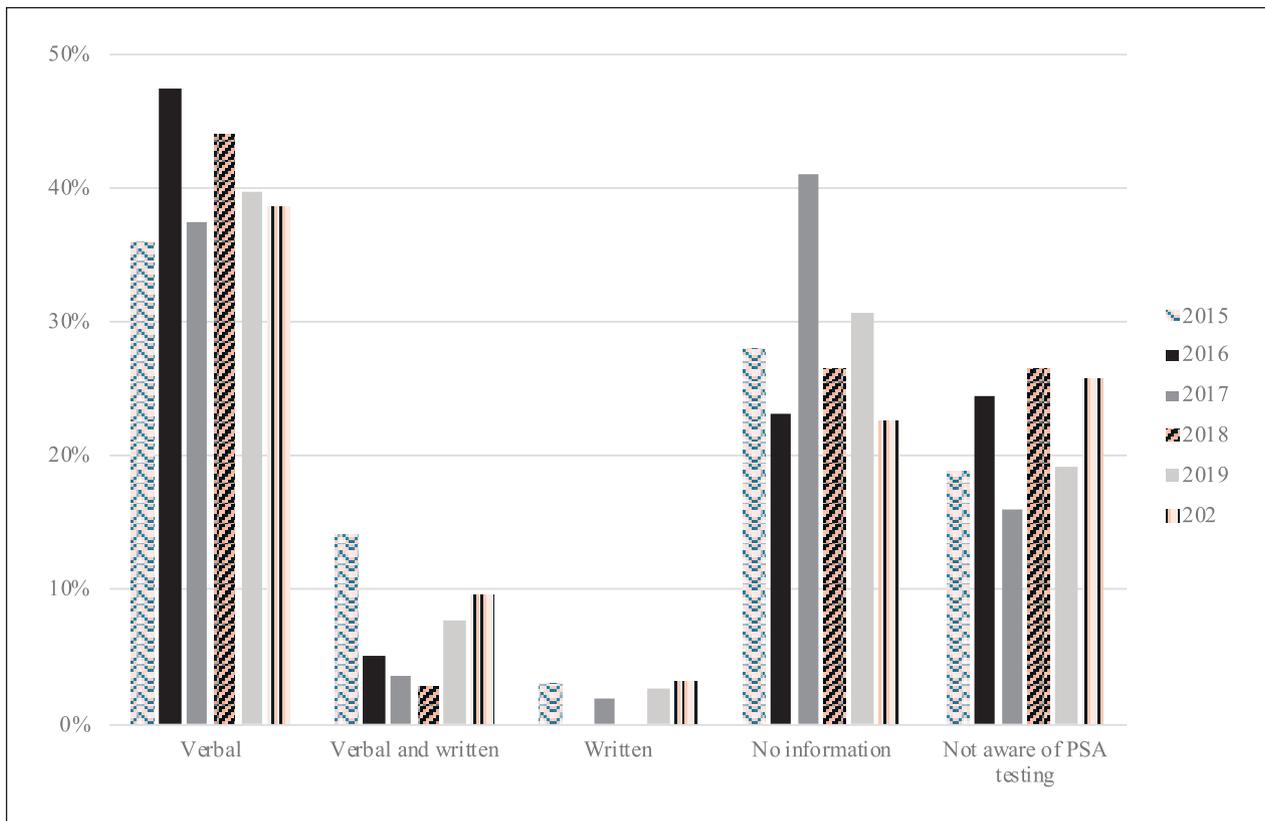


Figure 1. Information Received Prior to PSA Testing by Year of Diagnosis.
 Note. PSA = prostate-specific antigen.

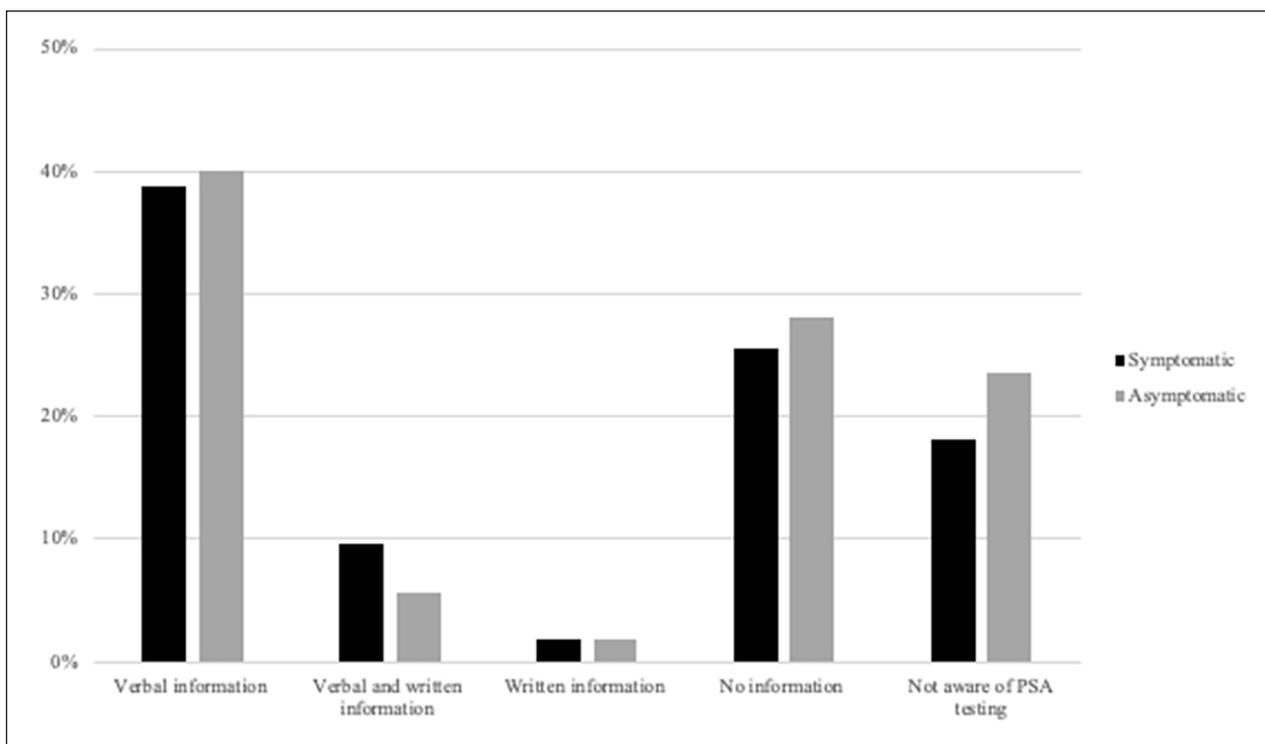


Figure 2. Comparison of How the Information Was Received Prior to PSA Testing for Men With and Without Symptoms of Prostate Cancer.
 Note. PSA = prostate-specific antigen.

testing was similar for men that reported symptoms of prostate cancer prior to PSA testing and those that did not report any symptoms. In addition, the results revealed that a majority of the men received the results from the PSA test at an appointment with their physician or 70.4% and 25.3% via a telephone call, with more than half of the latter living in the capital area.

The findings that the Icelandic men received little information about the pros and cons of PSA testing prior to undergoing the testing and that in rare cases did the men receive the information in a written format (1.8%) or in both written and verbal format (7.3%), are in line with the only other Nordic study, a study conducted by Fridriksson et al. in Sweden (2012). The Swedish study reported that around 27% of the men received no information about pros and cons of PSA testing, and 14% recalled that they had received written or both written and verbal information about the pros and cons of PSA testing. This is a slightly higher proportions than among the Icelandic men, where 9.1% recalled receiving written or both verbal and written information. This lack of written information is concerning as written information improves retention of information (Macfarlane et al., 2002), increases information satisfaction (Angioli et al., 2014) and knowledge (Cheema et al., 2018). Most worrying is the fact that 22.2% of the Icelandic men reported that they were not aware that their PSA levels were being tested, that being more than twice as high as in Sweden, where the reported rate was 10.2%. Other non-Nordic studies have yielded similar results, too many men do not get information about pros and cons of PSA testing prior to testing (Federman et al., 1999; Han et al., 2013; Hoffman et al., 2009; Volk et al., 2013) and many are not aware that their PSA levels are being tested (Federman et al., 1999; Volk et al., 2013). The findings from this study are likely to generalize to North American men, as a recent U.S. study using data from 2015 demonstrated that majority of men or 72.0% did not receive information about both pros and cons of PSA testing (Cooper et al., 2019).

The two studies, from Iceland and Sweden, identified that information about pros and cons of PSA testing and the delivery form of the information remained relatively stable over the years. The Swedish study included men that underwent PSA testing in 2006 through 2008 while this study included men who underwent testing from 2015 through 2020. The similar findings in these two Nordic studies are somewhat worrisome as they suggest that information about pros and cons of PSA testing from health care providers prior to testing has not changed much in the past decade and is still deficient despite the emphasis that has been placed on shared decision-making for more than a decade. Consistent with the lack of information, the results demonstrated that Icelandic men have

a low level of knowledge of the pros and cons of PSA testing prior to testing with 81.8% reporting no, little or very little knowledge. This is in line with other non-Nordic studies reporting that knowledge about pros and cons is generally low (Hoffman et al., 2009; Lamplugh et al., 2006). These findings further emphasize the importance of informing men about the pros and cons of PSA testing prior to making the decisions to undergo PSA testing.

The results also indicated that the information participants received prior to PSA testing was similar for both symptomatic and asymptomatic men. This was somewhat surprising because the majority of participants were asymptomatic and shared decision-making is especially advised for asymptomatic men before making a decision on PSA testing, and there is perpetually increasing focus on involving patients in their own health care decisions (Carter et al., 2013; US Preventive Services Task Force et al., 2018).

The limitations of this study are that the response rate was low (47.0%) and only men who had been diagnosed with prostate cancer were included in the study. Future research should focus on including men that have both considered getting their PSA levels tested and those that have already gotten their PSA levels tested (and have or have not been diagnosed with prostate cancer). In addition, we did not identify if the information that patients received was balanced, so even though we know that around half of the men that underwent PSA testing did get some information about PSA testing we do not know if that information was balanced and led to shared decision-making. In addition, since the results demonstrate that at least half of the men who underwent PSA testing did not get the opportunity to make a shared decision with their health care providers prior to PSA testing, future studies should focus on identifying obstacles for shared decision-making and how to overcome them. One solution to this would be to increase the use of decision aids (DAs). DAs are evidence-based and provide the patient with information about available options together with the pros and cons of each option in a balanced way. They prepare the patients to take part in their own health decisions and to reach a shared decision with a health care provider who is in line with the patients' values and goals (O'Connor et al., 1999, 2001). DAs improve patients knowledge and decisional satisfaction as well as decrease decisional regret and decisional conflict (Stacey et al., 2011; Taylor et al., 2010; Volk et al., 2007). By using DAs, the number of men who are involved in shared decision-making prior to PSA testing could be increased. In Iceland, a DA to assist with PSA testing has been developed and is currently being tested, but to the best of our knowledge, there are no DAs designed to assist men with their PSA testing decision available in the other Nordic countries.

The strength of this study is that it adds to the limited knowledge about how men in the Nordic countries receive information about the pros and cons of PSA testing from their health care providers. It also demonstrates that the patient–provider communication about pros and cons of PSA testing continues to be deficient even though greater emphasis has been placed on shared decision-making for more than a decade. The findings indicate that there is a pressing need to develop and test new interventions, particularly in the Nordic countries, to educate men about the benefits and limitations of PSA testing before men undergo medical procedures that can have adverse effects on their quality of life.

Conclusion

Most studies on how much information men received about the pros and cons of PSA testing prior to testing were conducted more than a decade ago (e.g., Fridriksson et al., 2012; Han et al., 2013; Hoffman et al., 2009; Lamplugh et al., 2006; Leyva et al., 2016); however, two major trials of PSA screening emerged more than 10 years ago, reporting that the benefit of prostate cancer screening is minor and controversial (Andriole et al., 2012; Schröder et al., 2014). Following these studies, the importance of shared decision-making prior to PSA testing has been further emphasized (Carter et al., 2013; Moyer, 2012; US Preventive Services Task Force et al., 2018; Wolf et al., 2010). Given the increased emphasis over the years, on shared decision-making prior to PSA testing, it is important to examine if there have been improvements in patient–provider communications about the pros and cons of PSA testing. This study is one of the first studies using recent data (2015–2020) to demonstrate that, despite this controversy of PSA testing and strong emphasis on patient–provider communication in the last decade, the information men receive prior to PSA testing is still deficient. Most of the men in this study (81.8%) reported having no or little knowledge about the pros and cons of PSA testing prior to testing and only 6.4% of men reported having much or very much knowledge. A majority of participants (63.3%) did not have symptoms of prostate cancer prior to the PSA testing and the information that participants received prior to the PSA testing was very similar for both symptomatic and asymptomatic men, even though shared decision-making is especially encouraged for asymptomatic men. Furthermore, only half of the men (49.8%) received information about the pros and cons of PSA testing prior to testing, either verbal, written or both and a third (27.9%) did not receive any information. In addition, 22.2% reported that they were not aware that their PSA levels were being tested. This means that, at least half of the men in this study were not invited to participate in

shared decision-making with their health care providers because they either did not get any information on pros and cons of PSA testing prior to testing or were not aware of being tested. This indicates that there is room for improvement when it comes to shared decision-making prior to PSA testing. The findings have major public health relevance as they indicate that men are not getting enough information prior to PSA testing and that there is a pressing need for interventions that educate men about the benefits and limitations of PSA testing before men undergo medical procedures that can seriously affect their quality of life.

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Authors' contributions

V.K.E., B.B., J.O.F., and H.B.V. designed the research. V.K.E. conducted the study and analyzed the data; drafted the manuscript; and incorporated comments and finalized the manuscript. B.B., J.O.F., and H.B.V. discussed the results and commented on the manuscript. All the authors read and approved the final manuscript.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: V.K.E., B.B., J.O.F., and H.B.V. declare that they have no competing interests.

Ethics approval (include appropriate approvals or waivers)

The study received ethical approval from the Icelandic Cancer Registry and The National Bioethics Committee (Reference number: VSN-21-050). Informed consent was obtained from all participants in the study.

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ORCID iDs

Valgerdur Kristin Eiriksdottir  <https://orcid.org/0000-0003-0110-1877>

Birna Baldursdottir  <https://orcid.org/0000-0001-8702-3173>

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