

Use of a Web-Based Survey to Facilitate Shared Decision Making for Patients Eligible for Cancer Screening

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Abstract

Objective Our aim was to facilitate shared decision making (SDM) during preventive visits by utilizing a web-based survey system to offer colorectal cancer (CRC) and prostate cancer screening decision aids (DAs) to appropriately identified patients prior to the visit.

Methods Patients completed a web-based questionnaire before their preventive medicine appointment. Age- and gender-appropriate patients completed additional questions to determine eligibility for CRC or prostate-specific antigen (PSA) screening. Eligible patients were offered a choice of video or print DA, and completed questions assessing their knowledge, values, and preferences regarding the screening decision. Responses were summarized and fed forward to clinician and patient reports.

Results Overall, 11,493 CRC and 4,384 PSA questionnaires were completed. Patient responses were used to identify those eligible for cancer-screening DAs: 2,187 (19 %) for CRC and 2,962 (68 %) for PSA; 15 % of eligible patients requested a DA. Many patients declined a DA because they indicated they “already know enough to make their decision” (34 % for CRC, 46 % for PSA).

Conclusion A web-based questionnaire provides an efficient means to identify patients eligible for cancer screening decisions and to offer them DAs before an appointment. Pre-visit use of DAs along with reports

giving feedback to patients and clinicians provides an opportunity for SDM to occur at the visit.

Key Points for Decision Makers

A web-based survey can identify appropriate patients to receive decision aids (DAs) prior to a clinician visit

Pre-visit use of DAs and feed-forward of the patient’s decision quality and preferences can prepare both clinician and patient for an SDM discussion

A minority of patients chose to view the DA, with many declining because they felt they already knew enough to make the decision or they wanted their clinician to make the decision for them

1 Introduction

Whether or not to get screened for prostate cancer with the prostate-specific antigen (PSA) blood test, and which method to use for screening for colorectal cancer (CRC), are examples of preference-sensitive decisions. For such decisions there is no clear ‘right’ choice due to trade-offs between different options and incomplete scientific evidence regarding outcomes [1–3]. Preference-sensitive decisions are best made through shared decision making (SDM), a process in which an informed patient and their doctor reach a decision based on the patient’s specific

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characteristics and values [4]. Relevant professional organizations recommend SDM for these cancer-screening decisions [5, 6], but it is challenging to accomplish this process in the context of an office visit. Barriers include a lack of time for the discussions required to adequately address complex screening decisions, and patient difficulties with comprehending the relevant information [7].

Patient decision aids (DAs) can facilitate SDM by providing balanced, standardized, evidence-based information and helping clarify values and preferences [8]. A high-quality decision is defined as one in which the patient answers the knowledge questions correctly and whose stated values are concordant with their screening decision [9]. In addition to increasing knowledge and lowering decisional conflict [10], DAs have been shown to increase patient participation in decision making [11].

Our previous work demonstrated that clinicians prefer ‘pre-visit’ distribution of DAs because when the patient arrives at the visit having viewed the DA, the conversation with the clinician is richer, decision making is more efficient and effective, and the decision choice can be implemented at that time [12]. There are logistical challenges to identify appropriate patients before the visit as many patients considered appropriate by age and gender are not appropriate for SDM due to diagnoses mandating PSA or colonoscopic monitoring, or having already been screened within the appropriate interval.

Our goal was to utilize a web-based survey system to efficiently identify appropriate patients before a preventive visit, offer them a DA, correct patient misunderstandings of

screening facts, clarify values, and collect and feed-forward patient data to the clinician to facilitate SDM during the visit. We planned to use patient-entered data from the survey to examine preferences for viewing DAs (uptake and preferred format) and reasons for declining to view a DA.

2 Methods

Patients at an academic general internal medicine practice were asked to complete a web-based health history questionnaire before their preventive medicine appointment. Age- and gender-appropriate patients are asked questions to determine their eligibility for SDM regarding PSA or CRC screening. Men aged 50–75 years were deemed appropriate to consider PSA screening if they had not received a PSA test within the past 11 months nor had been diagnosed with prostate cancer, had a past elevated PSA or undergone a prostate biopsy. Men and women aged 50–75 years were deemed appropriate to consider CRC screening options if they did not have a history of colon cancer, polyp, or inflammatory bowel disease, did not have a first-degree relative with colon cancer, and had not had a colonoscopy in the past 10 years.

Patients meeting eligibility criteria were presented with a brief description of the screening decision to be made and asked their baseline screening preference. They were then offered the choice of a video or print DA (Fig. 1). The video DAs were titled “Is a PSA Test Right for You” and

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Would you like more information about the PSA blood test?
Please click on one of the choices below or press the Next button.

- ☒ **Yes, I would like to watch a 30-minute video on my computer now (web streaming)**
- ☐ **Yes, I would like to get a video at my appointment**
- ☐ **Yes, I would like to view more detailed written information on my computer now**
- ☐ **No, I already know enough to make the decision**
- ☐ **No, I prefer for my doctor to make this decision for me**
- ☐ **No, I'm not interested (other reason)**

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Fig. 1 Screenshot from the web-based questionnaire. *PSA* prostate-specific antigen

Table 1 Frequency and percentage of patients completing surveys for colorectal cancer and prostate cancer screening

	Colorectal cancer		Prostate cancer	
	<i>N</i>	%	<i>N</i>	%
Self-reported eligibility criteria				
Gender/age eligible (50–75 years)	11,493	100	4,384	100
No Polyp Ca IBD FH*/no PSA in last 11 months	8,723	76	3,274	75
No colonoscopy in last 10 years/no biopsy PrCa	2,187	19	2,962	68
Clinically eligible for screening decision aid	2,187		2,962	
Had previous decision aid loan	347	16	1,215	41
Decision aid uptake (no previous DA loan)	1,840		1,747	
I already know enough	620	34	807	46
I prefer my doctor to make this decision	213	12	378	22
I'm not interested (other reason)	348	19	190	11
Requested more information				
Written information	188	10	219	13
30-min video DA	80	4	65	4
Answer missing	391	21	88	5

DA decision aid

* CRC eligibility criteria: no history of colon cancer, polyp, or inflammatory bowel disease (IBD), did not have a first degree relative with colon cancer (FH), and had not had a colonoscopy in the past 10 years. Prostate-specific antigen (PSA) screening criteria: no PSA test within the past 11 months nor had been diagnosed with prostate cancer (PrCa), had a past elevated PSA or undergone a prostate biopsy

Advance Directives

We encourage everyone to:

- complete an advanced directive
- choose a durable power of attorney (DPOA) for health care decisions
- discuss your health care preferences with your DPOA

Ask your doctor for a slip to bring to the Center for Shared Decision Making, where you can get a tape or DVD (free of charge, return mailer included).

Shared Decision Making

You got 1 out of 5 of the prostate questions correct.

Below are the correct answers to the ones you missed:

3 out of 100 men will die of prostate cancer.

An elevated PSA does NOT always mean you have prostate cancer.

The PSA test and biopsy may miss a prostate cancer that is really there.

Most men with prostate cancer found by PSA will die of something else.

For more information on PSA screening, visit <http://www.cancer.gov/cancertopics/factsheet/Detection/PSA>

You got 0 out of 4 of the colon cancer screening questions correct.

Below are the correct answers to the ones you missed:

Colon cancer screening should start at age 50.

6% of adults will develop colon cancer in their lifetime.

1-2% fewer people will die from colon cancer if they get screening.

5-14% of FOBT tests are positive, leading to a colonoscopy.

Ask your doctor for the Colon screening video, or pick one up at the Center for Shared Decision Making

For more information on colon cancer screening options, visit <http://www.cdc.gov/cancer/colorectal/pdf/fs-patient.pdf>

Please email comments or suggestions about this report to reportfeedback@hitchcock.org

Fig. 2 Sample patient report. *PSA* prostate-specific antigen, *FOBT* fecal occult blood test

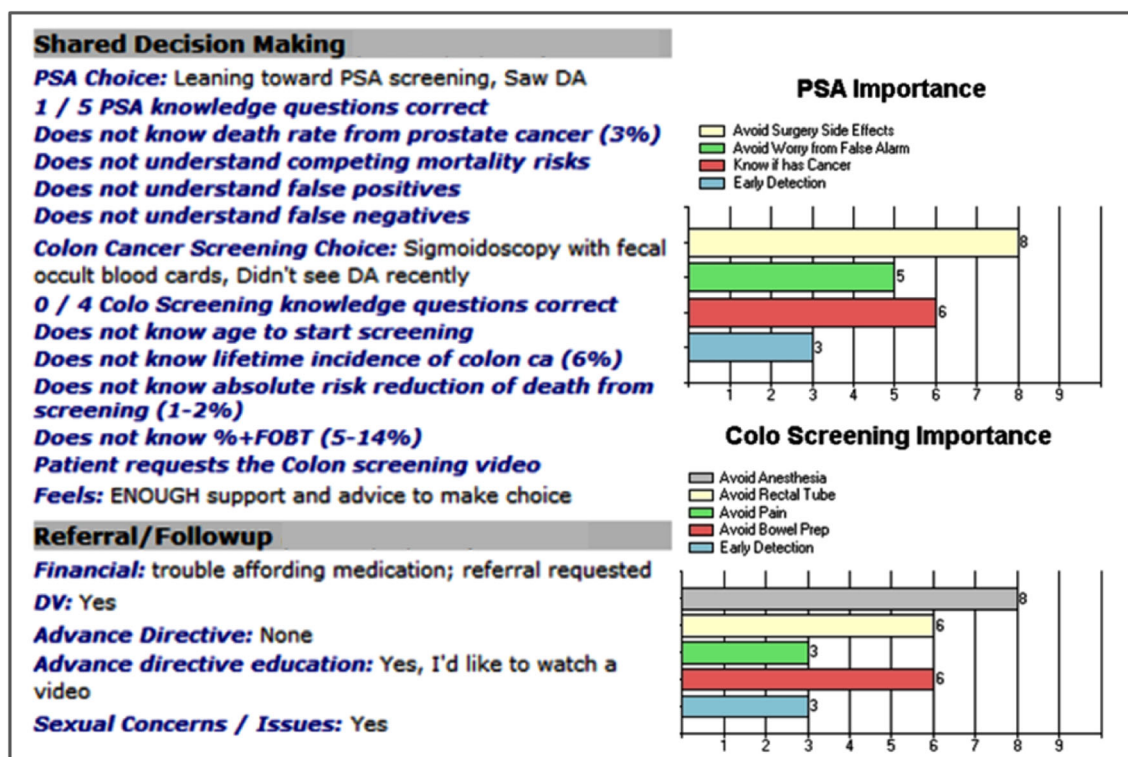


Fig. 3 Sample clinician report. PSA prostate-specific antigen, DA decision aid, FOBT fecal occult blood test

“Colon Cancer Screening: Deciding What’s Right for You”, produced by the Informed Medical Decisions Foundation. The print DAs were titled “Prostate Cancer Screening: A Decision Guide” and “Colorectal Cancer Screening: Basic Fact Sheet”, both from the Centers for Disease Control and Prevention [13, 14]. Patients were also offered three options to decline a DA: “I already know enough to make a decision”, “I want my doctor to make this decision for me”, or “I’m not interested/other reason”.

All patients, including those not viewing DAs, were then asked to complete questions assessing their knowledge and personal values regarding the screening decision and re-asked their screening preference. Knowledge items consisted of multiple-choice questions (disease natural history, risk factors, potential benefits and limitations of screening tests—see “Appendix”). Patient-value items were rated on an importance scale from 1 (not at all important) to 10 (extremely important).

Feedback on incorrect answers to knowledge questions and another offer of further information were displayed on a written report given to the patient (Fig. 2). Patients’ screening preference and responses to knowledge and values questions were fed forward to a clinician report available at the visit (Fig. 3). This report allowed the clinician to start the screening conversation already knowing the patient’s preference, certainty, and decision quality.

Together, the patient and provider could reach a final screening decision and implement it.

Descriptive summary statistics, including means and standard deviation for continuous variables and frequencies for categorical variables, were calculated. Differences in mean scores for the total knowledge were calculated using two-sided *t*-tests. Statistical analysis was conducted with SAS software, version 9.2 (SAS Institute, Cary, NC, USA).

3 Results

From January 2008 to March 2011, a total of 11,493 CRC and 4,384 PSA questionnaires were completed. Patient responses were used to identify the subset of patients who met the eligibility criteria for a DA (age, gender, history, no recent screening test): 2,187 (19 %) for CRC and 2,962 (68 %) for PSA. Fifteen percent of eligible patients requested a DA, with the majority (74 %) of those preferring the written format over video (Table 1).

A subset of patients had received a DA during a previous intervention (16 % of CRC and 41 % of PSA patients previously received the video-screening DA). Excluding those who had previously received a DA, many patients declined a DA because they “already know enough to make their decision” (34 % for CRC and 46 % for PSA);

16 % of patients declined a DA because they preferred the doctor make the decision (12 % for CRC and 22 % for PSA); and 15 % of patients declined a DA due to lack of interest or an unspecified ‘other’ reason (Table 1).

Patients in the PSA group who indicated they ‘knew enough’ had higher scores on the knowledge quiz [mean (SD) 76 (21)] compared with those requesting DAs [mean (SD) 60 (32); $p < 0.001$]. However, those in the CRC group who indicated they ‘knew enough’ showed lower scores on the knowledge quiz [mean (SD) 44 (23)] compared with those requesting a DA [mean (SD) 50 (27); $p = 0.14$].

4 Discussion

A minority (15 %) of eligible patients requested a DA, but it was unclear what the optimal uptake should be. The most common reason to decline a DA was the patient’s sense that they already knew enough to make the decision. Some patients made an appropriate self-assessment (suggested by the higher knowledge scores among patients declining the PSA DA because they ‘knew enough’), while other patients (some of those declining the CRC DA) ‘don’t know what they don’t know’, and may come to the decision with unrealistic expectations of the benefits or inadequate awareness of the risks of screening [15].

A significant number of patients declined a DA due to preferring the doctor to make the screening decision for them. Although this role preference in decision making should be respected when it is clearly stated, it is malleable. Watching the PSA DA used in this study has been shown in our previous work to be associated with only 2 % of patients wanting the physician to decide (while taking the patient’s opinion into account), with the vast majority of patients who used the DA preferring to take the lead role or to share the decision [16]. A recent focus group study [17] found that although participants voiced a strong desire to engage in SDM, even the relatively affluent and well-educated felt compelled to conform to socialized roles and defer to physicians, for fear of being labeled as ‘difficult’ patients.

The large majority of patients desiring a DA preferred the shorter written version to the longer video version. One barrier to widespread implementation of DAs may be offering more than patients want or need. Different patients and different decisions will require different levels of decision support, ranging from a brief chart of pros and cons to a 40 min video supplemented by decision coaching [18]. A randomized control trial of PSA DAs suggests that a printed worksheet was comparable to an interactive web-

based DA at conveying information and reducing patient uncertainty [10]. Offering patients a choice of DAs of varying lengths and formats will likely increase the likelihood that a DA will be used and result in more informed patients choosing the screening option that is right for them.

5 Practical Implications

A web-based survey can be used to identify appropriate patients to receive a cancer screening DA before an upcoming clinic visit, and to collect data from the patient. Having the patient’s preference for screening, certainty about that preference, and decision quality (a combination of knowledge and concordance of stated values with preference) available in a report viewable by the clinician at the time of the visit can allow the clinician to quickly assess where the patient is at in their decision-making process. This can lead to a more efficient and richer discussion where misunderstandings can be addressed and patient preferences clarified in order to arrive at a quality decision and implement that choice during the visit.

6 Conclusion

This web-based patient survey instrument offers an efficient solution to the logistical problem of how to get the right information (DA) to the right patients (meeting eligibility criteria for shared decisions about screening) at the right time (before a preventive visit).

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Authors’ contributions Both authors contributed substantially to the study including (i) the conception and design of the study, analysis and interpretation of data; (ii) drafting the article or revising it critically for important intellectual content; (iii) final approval of the version to be submitted (all authors). The corresponding author, Charles D. Brackett (cdb@hitchcock.org) is responsible for the integrity of the work as a whole.

Appendix

See Appendix Table 2.

Table 2 Prostate cancer and colorectal cancer knowledge questions (correct answer in bold)

Prostate cancer knowledge questions

Out of 100 men, about how many will eventually die of prostate cancer?	Between 0 and 5 Between 6 and 10 Between 11 and 20 More than 20 I am not sure
Does having an elevated PSA test always mean you have prostate cancer?	Yes No I am not sure
Both the PSA test and prostate biopsy:	Will always find a prostate cancer that is really there May miss a prostate cancer that is really there I am not sure
Many men with prostate cancers found by PSA tests will die of something else before the prostate cancer causes any problems, especially if they are older	True False I am not sure
PSA tests:	May not help a man live longer, even if prostate cancer is found May find slow-growing cancers that would not have caused problems Both of the above are true I am not sure

Colorectal cancer knowledge questions

At what age should people at average risk who want to be screened start getting regular screening tests for colon cancer?	35 40 50 55
Out of 100 adults, about how many will develop colon cancer in their lifetime?	Fewer than 10 10–19 20–29 30 or more
How many fewer people out of 100 will die of colon cancer if they get the recommended screenings over their lifetime, compared to those who don't get screening?	1–2 3–9 10–20 Greater than 20
If 100 people have an FOBT, how many will have a result that will lead to a follow-up colonoscopy?	Less than 5 5–14 15–25 26 or more

PSA prostate-specific antigen, FOBT fecal occult blood test

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