Information needs of men regarding prostate cancer screening and the effect of a brief decision aid

Stacey L. Sheridan*, Kathryn Felix, Michael P. Pignone, Carmen L. Lewis
Division of General Medicine and Epidemiology, University of North Carolina at Chapel Hill, 3019 Old Clinic Building, CB #7110, Chapel Hill, NC 27599, USA

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Abstract

Background: Little is known about what information affects men’s decisions about prostate cancer screening. Methods: We developed a four-part decision aid about prostate cancer screening and tested it in men, ages 45-85, to determine how the information in each part—(1) the epidemiology of prostate cancer; (2) the PSA test; (3) prostate biopsy and treatment options for prostate cancer; and (4) balance sheets to aid decision-making—affect men’s interest in screening. Results: One hundred eighty-eight men from one general internal medicine clinic participated in our study (response rate 65%). Before the decision aid, 76% were interested in screening; 8% were not; and 16% were undecided. The decision aid increased the proportion of men who knew the advantages (+28%; 95% CI: 21–35) and disadvantages (+55%; 95% CI: 48–63%) of screening. It also increased the proportion who knew enough to make a decision (+24; 95% CI: 16–32%). It did not change men’s interest in screening (P = 0.134). Twenty percent of men, however, did change their interest category. Men who were undecided at baseline were more likely to change than those who were interested or not interested. There were no clinically meaningful changes in interest following each component part of the decision aid. Conclusion: Interest in prostate cancer screening is high and remained high after a 10 min decision aid. The decision aid increased the proportion of men with sufficient information to decide about screening. It also changed 20% of men’s interest in screening. Because no single piece of information was influential to decision-making in all men, clinicians may want to tailor information to men’s individual needs.

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1. Introduction

Several professional organizations now recommend that men participate in decision-making about prostate cancer screening [1–3] due to the unknown benefits of screening in the face of potential physical, psychological, and financial harms. Such recommendations are responsive to a call from decision-making experts to include patients in decisions that may be sensitive to individuals’ personal values and preferences based on the uncertainty of the evidence or a close balance between potential harms and benefits [4–10].

One way to encourage participation is through the use of decision aids, which are multi-media tools that provide balanced, evidence-based information and values clarification for a decision [11,12]. Decision aids on prostate cancer screening have been shown to increase knowledge about prostate cancer screening [13–16]. Additionally, some have been shown to decrease interest in screening and use of screening tests [13–17]. Little is known, however, about which information in these decision aids affects men’s decisions about prostate cancer screening. Such information could help clinicians better deliver information on prostate cancer screening and could lead to the development of more effective and efficient decision aids.

In this study, we developed a pamphlet-based decision aid on prostate cancer screening and used it to measure which information had an effect on men’s interest in screening and what proportion of men changed their interest in screening after viewing the decision aid.

2. Methods

2.1. Designing and developing the decision aid

We developed a four-part decision aid that included information about (1) the natural history and epidemiology of prostate cancer, (2) the prostate specific antigen
recently published decision aid development guidelines\[11\] , decision aid only on our consent forms. To conform with conflicts of interest, and our role in the development of our decision aid based on feedback from these interviews. We revised a wide range of prior education and included patients with participating in decision-making. We sampled individuals with and without a family history of prostate cancer. We revised our decision aid based on feedback from these interviews. We made full disclosure of our credentials, our potential conflicts of interest, and our role in the development of the decision aid only on our consent forms. To conform with recently published decision aid development guidelines [11], we have subsequently added these disclosures to the decision aid itself.

2.2. Testing the effects of the decision aid

2.2.1. Study population

We tested our decision aid in men, aged 45–85, who were presenting to a university internal medicine clinic for routine care. We identified potentially eligible men from daily appointment schedules and approached them about study participation in the waiting room or in the examination room prior to their scheduled visit. We excluded men if they were presenting for their first clinic visit, were unable to read, write, or speak English according to self-report or the assessment of our research assistant; had a prior history of prostate cancer; or were deemed poor candidates for participation by their providers. This study was approved by the university institutional review board.

2.2.2. Administration of the decision aid and survey

Men completed a baseline questionnaire detailing their personal history of prostate cancer and prostate cancer screening, their family history of prostate cancer, their knowledge about prostate cancer screening, their concern about prostate cancer, and their feelings regarding decision-making for prostate cancer screening. They then viewed the decision aid. The decision aid was delivered as a scripted pamphlet and was orally administered in 10 min by a trained health educator. Men read along on a flip chart during the presentation. We chose to use oral administration in order to make the information available to participants with low literacy. Previous studies in our clinic have found that two-thirds read below the ninth grade level and one-third read below the sixth grade level [21].

To determine the effects of the different parts of the decision aid on men’s interest in screening, we measured interest in screening by written survey at five points in time (see Fig. 1): first, at baseline and then following each component of a four-part decision aid.

2.2.3. Sample size calculation

We used STATA (College Station, TX) to determine that we would need a sample size of 210 patients to detect a 20% difference in the proportion of patients interested in screening before and after the decision aid, accepting 80% power and a two-sided alpha of 0.05. We estimated that 65% would be interested in screening at baseline based on the number of patients in a general medicine clinic who reported a high likelihood of being tested for prostate cancer during another decision aid trial [14]. After calculation, we inflated our sample size by 10% to allow for a 10% non-completion rate of our questionnaire.

2.2.4. Statistical analysis

Because interest in screening was skewed in our population, we examined change in interest in screening using both parametric and non-parametric testing. Our results varied with these testing strategies. We, therefore, report the results of non-parametric testing here.

Fig. 1. Study design. Men’s interest in screening was measured at five points in time, at baseline and after each component of a four-part decision aid.
tests, reporting interest on a five-point Likert scale (1: definitely not interested in screening to 5: definitely interested in screening). We also used Wilcoxon signed rank tests to assess change in interest in screening across each informational component of the decision aid.

To assess the effect of the decision aid on men’s decision-making process, we collapsed interest into two categories and used McNemar $\chi^2$-tests to compare the proportion of men interested (versus not interested/undecided), undecided (versus interested/not interested), and not interested (versus interested/undecided) before and after the entire decision aid.

Because variables other than interest in screening were normally distributed in our sample, we assessed which characteristics of men were associated with baseline and post-decision aid interest in screening using t-tests for continuous variables and $\chi^2$-tests for categorical variables. To assess whether certain characteristics of men were associated with any change in interest across the decision aid, we created a variable for any change in interest across three interest categories (interested, undecided, and not interested) and used $\chi^2$-tests to look for associations with change in interest. Fischer’s exact tests were used when comparisons involved a small number of subjects.

2.3. The role of funding

The funding sources had no role in the design, conduct, or reporting of this study.

3. Results

We approached 313 men about participation in our study. Ninety-eight (31%) refused and 23 (7%) were ineligible because they had a prior history of prostate cancer ($n = 6$), could not read, write, or speak English ($n = 8$), or did not complete the decision aid and survey ($n = 9$). One hundred eighty-eight men were determined to be eligible and agreed to participate in our study for a response rate of 65%.

Table 1 provides information about the study participants. Mean age was 60. Seventy percent were white and 26% were African–American. Sixty-seven percent had at least some college education. Twenty percent had any family history of prostate cancer and 70% had been previously screened for prostate cancer. Eighty-eight percent of men reported that they had received prior information about prostate cancer screening; 86% of these men said it came from their doctor. Significant numbers also reported other information sources including the news (35%), magazines (29%), friends (20%), and the internet (6%).

Despite the high report of prior information, only 70% (95% CI: 63–77%) of participants reported they knew the advantages of screening and only 40% (95% CI: 33–47%) reported they knew the disadvantages of screening (see Table 2). Although 63% (95% CI: 55–70%) reported that they already knew enough information to decide about screening, 86% (80–91%) wanted some or a lot of additional information. When asked about their level of interest in screening, 76% (95% CI: 69–81%) said they were interested

![Fig. 2. Effect of the decision aid on men’s self-reported knowledge and interest in screening.](image-url)
in screening within the next year, 16% (95% CI: 11–23%) reported they were still undecided about screening, and 8% (95% CI: 5–13%) reported they were not interested.

3.1. Overall effect of the decision aid on self-reported knowledge and interest in screening

Fig. 2 shows the overall effects of the decision aid on men’s self-reported knowledge and interest in screening. The proportion of men reporting they knew the advantages of screening increased by 28 (95% CI: 21–35) percentage points after viewing the decision aid; the proportion of men reporting they knew the disadvantages of screening increased by 55 (95% CI: 48–63) percentage points; and the proportion of men reporting that they knew enough information to make a decision about screening increased by 24 (95% CI: 16–32) percentage points.

Interest in screening was not affected by the decision aid ($P = 0.134$, Wilcoxon signed rank). After viewing the entire decision aid, the total proportion of men interested in screening did not change significantly (+2%; 95% CI: −4 to +7%; McNemar $\chi^2$). The proportion of men who were undecided about screening was reduced by 7 (95% CI: 2–14; McNemar $\chi^2$) percentage points, while the proportion who were not interested increased by 6 (95% CI: 1–12; McNemar $\chi^2$) percentage points. While the previous analysis indicates the proportion of men at a given level of interest, it does not account for influx and efflux from these interest categories. Overall, 37 out of 188 men, or 20% of men in the study, changed their interest category after viewing the decision aid; 80% of men reported no change in their interest category.

3.2. Change in interest for prostate cancer screening across informational components

The effects of each piece of information in the decision aid are depicted in Fig. 3. Mean interest in prostate cancer decision aid, the total proportion of men interested in screening did not change significantly (+2%; 95% CI: −4 to +7%; McNemar $\chi^2$). The proportion of men who were undecided about screening was reduced by 7 (95% CI: 2–14; McNemar $\chi^2$) percentage points, while the proportion who were not interested increased by 6 (95% CI: 1–12; McNemar $\chi^2$) percentage points. While the previous analysis indicates the proportion of men at a given level of interest, it does not account for influx and efflux from these interest categories. Overall, 37 out of 188 men, or 20% of men in the study, changed their interest category after viewing the decision aid; 80% of men reported no change in their interest category.

3.2. Change in interest for prostate cancer screening across informational components

The effects of each piece of information in the decision aid are depicted in Fig. 3. Mean interest in prostate cancer
remained the same after each piece of information. Although the biopsy and treatment information did produce a sharper downward trend in interest (−0.13 Likert points, \( P = 0.001 \)), this trend was not clinically significant. We found similar results when interest was examined in three categories (interested, undecided, not interested) across the decision aid.

### 3.3. Information that men reported was new and influential

Each component of the decision aid provided information that men reported was both new and influential. Although slightly more than two-thirds of men thought they received new information from each component, only 10–15% of men reported that the information in each of these components was influential. Additionally, reporting receipt of influential information was only mildly correlated with change in interest in screening across any decision aid component.

Fig. 4 shows the proportion of answering men reporting that various pieces of information were new to them. Corroborating this sample's self-reported knowledge, 50% of answering men reported they were previously unaware of the disadvantages of screening. Additionally, nearly a quarter were unaware that they had a decision to make regarding prostate cancer screening or that individual patient preference regarding screening may vary.

### 3.4. Predictors of change in interest in screening following the decision aid

The strongest predictor of change in interest in screening following the decision aid was baseline interest in screening (see Fig. 5). Of the 142 men interested in screening at baseline, 92% (95% CI: 87–96%) remained interested after viewing the decision aid. Similarly, of the 15 men who were not interested at baseline, 66% (95% CI: 38–88%) remained uninterested. For those men who were undecided \( (n = 31) \), only 32% (95% CI: 17–51%) remained undecided. Thirty-two percent (95% CI: 17–51%) of undecided men became interested in screening and 36% (95% CI: 19–55%) became not interested in screening.

We found no association between change in interest in screening following the decision aid and age, race, or prior screening history.

### 4. Discussion

Interest in prostate cancer screening among patients in a university internal medicine clinic was high and remained high even after a brief decision aid. The decision aid increased the proportion of men who knew the advantages and disadvantages of screening and increased the proportion who knew enough to make a decision. It did not affect mean interest in screening, although 20% of men changed their interest category after viewing the decision aid. Men who were undecided at baseline were more likely to change than others. There were no clinically meaningful changes in interest following each component part of the decision aid. Additionally, we found no association between change in interest and age, race, or prior screening history.

These findings are consistent with those of other investigators, who have shown that decision aids about prostate cancer screening increase knowledge about prostate cancer screening [13–17]. Our study, however, suggests that many men may have already decided about prostate cancer screening prior to receiving information in the clinical encounter and that no single piece of information is influential in interest in screening in all men.

In our study, the strongest predictor of men’s interest in screening after viewing the decision aid was men’s interest in screening prior to the decision aid. This finding has many potential explanations. First, men may have made up their minds about screening prior to viewing the decision aid and would perceive changing their mind as admitting a flaw in their prior decision. To look for support for this hypothesis in other studies, we used prior interest and screening rates as an estimate of “making up one’s mind” and graphed the proportion of men previously screened with PSA against the change...
or whether they had previously received a recommendation anticipated in decision-making about prostate cancer screening, doctor or other sources, whether they had previously participated in decision-making about prostate cancer screening, or whether they had previously received a recommendation for or against screening. However, we can infer much of this information from men’s reports of what information was new to them in our study.

We are concerned about men’s lack of awareness that there is a decision to be made about whether to be screened or not, and their lack of knowledge about the potential harms of screening. In this context, clinicians’ recommendations for screening in the absence of explanations about the potential benefits and harms is problematic because physician recommendations significantly influence patients’ decisions even when they are inconsistent with the decision that patients feel would optimize their health [23]. Fortunately, the medical community is increasingly recognizing these issues and several organizations [1–3] are recommending that clinicians inform patients and share the decision about prostate screening.

We set out to determine the identity of information on prostate cancer screening that would allow clinicians and patients to engage in brief, but meaningful, discussions. Our study suggests that it may be difficult to do so. No one piece of information is influential to decision-making in all men and men differ in their baseline knowledge. Additionally, although the dominant effect of men’s baseline interest in screening may have obscured our ability to detect what information is influential to decision-making and examination of the effects of information in men who are undecided about prostate cancer screening may show certain pieces of information to be more influential than others, our study suggests that men react differently to each piece of information. To ensure good decision-making, we therefore believe all men should receive information that there is a decision to be made regarding prostate cancer screening, that decisions may vary depending on individual preferences, and that screening can be both helpful and harmful. A similar approach has been proposed by others [4].

### 4.1. Limitations

Our study does have several potential limitations. First, although our study design was optimal for measuring changes in men’s interest in screening in response to various pieces of information, it was not optimal for measuring the overall effect of the decision aid. For this purpose, a randomized trial would be better. Second, our study population may not be representative of the general population eligible for screening in a university internal medicine clinic because clinician referral was necessary for enrollment in the study. Clinicians may have selectively enrolled only those patients whom they felt were capable of participating in the decision for prostate cancer screening or, alternatively, only those who they felt were not already informed. Third, because a research assistant administered the decision aid and survey, patients may have responded to survey questions differently from how they would have responded in a real-world setting.

In our study, 86% of men reported they received prior information about prostate cancer screening from their doctor, while smaller numbers reported receiving information from the news, magazines, friends, and the Internet. We did not ask men what information they had received from their doctor or other sources, whether they had previously participated in decision-making about prostate cancer screening, or whether they had previously received a recommendation.
References


was new to men by self-report. This may not correlate with an objective comparison of knowledge before and after the decision aid. Fifth, interest in screening may not translate to actual screening practices. We continue to feel, however, that interest in screening is a more appropriate measure of the impact of information because multiple additional confounding factors contribute to actual screening rates. Sixth, our study included a limited number of undecided patients, limiting our ability to draw conclusions about the impact of information in the group where most of the change in interest was occurring. Future studies that examine similar issues should consider examining the impact of information in a stratified sample where each stratum has sufficient power to detect changes in the impact of information. Alternately, studies could target only individuals who are undecided.

This later strategy has the additional benefit of allowing researchers to examine information impact while avoiding the confounding effects of prior recommendations. Measuring prior exposure to clinician recommendations and controlling for these in multivariate analysis would accomplish the same effects. Finally, our decision aid slightly understated the mortality rates in men with prostate cancer. This information may have reduced men’s perceived severity of the disease and thus reduced their interest in screening.

5. Practice implications

Despite the limitations, we believe our study has important implications for clinical practice. Because no one piece of information is influential to decision-making in all men, clinicians may want to tailor information to men’s individual needs. In deciding what information is necessary to present, clinicians should consider that a substantial portion of men do not know that whether to be screened or not is a decision and they do not feel they know the harms of screening. Decision aids can increase the proportion of men who know these facts and have sufficient information to decide about prostate cancer screening.

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