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The value of personalized risk information: a qualitative study of the perceptions of prostate cancer patients

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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of precise, personalized, risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending local prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. Participants most commonly reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but most expressed skepticism about its value. Most participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients have little experience using personalized risk information, favor heuristic- over risk-based decision making strategies, and perceive personalized risk

information as less valuable than other types of evidence. Patients' preferred approaches to decision-making and their perceptions of the relative value of different types of evidence are potential barriers to the clinical use of personalized risk information. Overcoming these barriers will require providing patients with greater exposure to risk information, environmental resources for deliberative decision making, and education about the nature and value of personalized risk information.

Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- Many prostate cancer patients favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having little value in clinical decision making
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

- The study sample was relatively small and homogeneous, and qualitative methods cannot definitively establish the prevalence, causes, or effects of the patients' experiences and perceptions.

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients[1]—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes[2]— have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.[3-8] Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,[9] and on patient values and preferences.[2] Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.[10]

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,[11-14] psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.[15-22] Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.[21-29] A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and "simpler, less precise representations" of risk are often more useful to patients.[30] In a similar vein, Reyna has

contended that people prefer to construe risk in qualitative terms representing its "gist" meaning, rather than in precise, quantitative terms representing its "verbatim" details.[31] Gigerenzer has gone further to challenge the conception of rationality underlying efforts to apply risk information to decision making. Extending an argument put forth by the economist Simon in the 1950s,[32] he emphasizes that rationality is "bounded" by limitations in the cognitive and environmental resources available to decision makers. Consequently, in real world decisions people do not "optimize"—i.e., they do not calculate and weigh probabilities and values in an exhaustive computational search for the best option. Instead, they use heuristics—"fast and frugal" rules of thumb that facilitate adaptive decisions.

These insights raise fundamental questions about the usefulness of precise, quantitative risk information in health care. Is such information really needed and desired by patients? Do patients—as opposed to health professionals—perceive personalized risk information as valuable, and how might their perceptions influence the success of efforts to use CPMs in clinical practice?

The aim of the current research was to explore these questions, focusing on personalized risk information in the treatment of prostate cancer—the most common and 2nd most common male cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer deaths.[33-35] Approximately 80% of newly diagnosed prostate cancer patients have clinically-localized disease for which there are multiple treatment options—surgery, radiation therapy, conservative treatment (active surveillance)—each with differing potential benefits and harms.[34] The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has

thus become a primary focus of predictive modeling activities, resulting in the development of over 100 CPMs[36-42] and growing efforts to disseminate and apply these models in clinical practice.[41-46]

Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and the information they produce. To this end, the current study explored prostate cancer patients' experiences with using risk information in treatment decisions, and their perceptions of the value of precise, personalized risk information produced by CPMs. The ultimate goal was to generate insights that might inform efforts to use CPMs to promote personalized, informed decision making in the treatment of prostate cancer and other conditions.

Methods

Study design, participants, and data collection. This qualitative study employed focus groups, a useful methodology for exploring people's perceptions, beliefs, and attitudes.[47,48] From September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 10 support groups throughout the entire state. Eligible participants were English-speaking prostate cancer survivors within 3 years of initial diagnosis. A purposive recruiting strategy was employed to select patients with varying treatment experiences and prognoses. To achieve sufficient within-group homogeneity to encourage open discussion,[49] participants were stratified into 3 groups (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as defined by U.S. National Comprehensive Cancer Network guidelines.[50] A total of 2 Low Risk, 3 Medium Risk,

and 2 High Risk focus groups were conducted at MCFPC support group sites in 3 rural and non-rural towns and cities (Brunswick, Lewiston, Portland). Participants received $50 compensation. Sessions lasted approximately 2 hours, were audiorecorded with prior consent of participants, and transcribed verbatim by a professional transcription service.

Interview content. Groups were led by PH and either a professional moderator or another study investigator (TK). Interviews were semi-structured and followed a moderator guide consisting of open-ended questions and close-ended probes designed to elicit patients' past experiences with risk information, preferences for personalized risk information, and attitudes towards CPMs. Interviews utilized visual aids consisting of screenshots of web-based CPMs for several different prostate cancer outcomes (e.g., risk of cancer recurrence, cancer-free survival, death) produced by the Cleveland Clinic (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)[42] and Memorial Sloan-Kettering Cancer Center (http://www.mskcc.org/mskcc/html/10088.cfm).[51] During the course of the study, minor revisions were made in the interview guide to clarify emergent themes.

Data analysis. In-depth analysis and line-by-line software-assisted coding of anonymized interview transcripts was conducted using the program NVivo (Version 8; QSR International). First, three investigators (PH, MN, BR) developed a preliminary conceptual schema and codebook by independently reading 3 transcripts, categorizing participants' verbatim statements according to thematic content, and organizing emergent themes—consistent with a "grounded theory" approach to the data.[52,53] Preliminary codebooks were reviewed by the team and areas of disagreement were resolved through further discussion. A single working codebook was then

produced, which two investigators (MN, BR) used to code the remaining transcripts, employing a "constant comparative" method to compare new data, concepts, and themes with ones previously identified.[52,54] The research team held periodic meetings to discuss coding decisions, identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH) conducted a secondary review of all coded text to organize dominant themes.

Results

Characteristics of participants are in **Table 2**. The primary interview domains consisted of participants' 1) past experiences with risk communication, and 2) perceptions of the value of personalized risk information produced by CPMs.

Past experiences with risk communication

Within these broad domains several dominant themes emerged; the first was the broad spectrum of risk communication experiences and practices reported by participants.

Absence of explicit risk communication. At one end of the spectrum were a small number of participants who reported having never received risk information of any kind during the decision making process:

> *I wasn't actually told about the numbers. I just went by what they were saying. I guess—they knew what the numbers were, what the odds were for me, and I went with that and yeah, I would've wanted to know what the numbers were. [Medium-Risk Participant]*

For these few participants treatment risks were implicitly understood rather than explicitly communicated:

> *I think the conversation that I had with my urologist was we each knew all of those possibilities. It was kind of like a given, and our conversation was based on the fact that*

we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a "histogram" and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with "average" risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication, was categorical and non-quantitative. A low-risk participated noted: "*he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low."* Other participants recalled the use of similarly broad categories—e.g., "good," "most likely," "very remote," "high," "very likely."

Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores. Illustrative quotations from men at different levels of risk for disease recurrence are in **Table 3**. For participants in all

groups, biomarker values served as an anchor point that helped them understand the magnitude of their risk and provided a basis for decision making; as one medium-risk participant related, referring to his PSA values: "*when you don't have any guidelines to go by, you gotta have some idea where that is, whether it's a four or six or ten or whatever*." The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

> *INTERVIEWER: So they gave you a sense of what those numbers meant …a four means you have an X percent chance of—*
> *PATIENT 3: No, they didn't.*
> *INTERVIEWER: But they just said—it was good—versus bad, right?*
> *PATIENT 3: Yeah.*
> *PATIENT 2: That's what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you're just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it's not a necessity, but they didn't recommend not doing anything about it all … So those numbers I think … kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]*

> *I really, you know, I read the books … And, I'm sure they had all sorts of graphs and stuff like that. But I've got to admit when I looked at my Gleason scores, this is gonna sound, you know it's all irrelevant. You know, my Gleason score is this. Stage 4. [High-Risk Participant]*

> *PATIENT 3: Well I think—if they're telling me my Gleason scale was under 4, I wouldn't have done anything.*
> *PATIENT 1: Yeah, that's what I would do.*
> *PATIENT 3: But when they said 6, that's when Dr. X said it's time to really think about it. But with me, I was upset for a little while, but once I made up my mind to do something, then I wasn't. The whole thing is wondering what you're gonna do and once you make up your mind—Yeah, then that's it. [Medium-Risk Participants]*

The usefulness of biomarker values appeared to stem from their apparently "hard," tangible nature, and their straightforward connection to a defined course of action:

> *PATIENT: My decision was based upon what we had for biopsies and stuff like that.*
> *INTERVIEWER: Okay. Alright.*
> *PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn't' really—that's irrelevant to me… but, based upon the information that I had, you know, hard information, I felt very comfortable.*

> *PATIENT 1: All that they've been giving me are the scores for my PSA … My doctor said, when your numbers double in four month spread, he said, we need to do something*

about it … he says, and I'll nip and tuck it just as soon as it gets up there, and my last time it was aggressive. It went from 0.12 to 5.5 in four months, and so, he encouraged me, and he told me what he was going to do …
INTERVIEWER: Okay.
PATIENT 2: They give you all kinds of information. And he'll tell you, you know, specifically we're talking about this spread, and this is where you are, and this is what we think … I totally felt like I was just as much in control of my life as he was. And it gave me, it gave me a lot of courage toward it. I had a bad two days when I found out about it. I haven't had a bad day since. [High-Risk Participants]

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]

Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]

Patient empowerment *vis a vis* their physicians was another perceived value of personalized risk information:

So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too … So, like, the doctor is not the god. [Low-Risk Participant]

Participants believed that such empowerment was necessary because of inherent biases of treating physicians:

> *I can see this being used to help people make a decision as to what course of treatment they should seek versus what side effect they can live with. Now, if you go to X and ask them what their percentage of incontinence is … they're gonna give you a skewed number because they don't want to make that million-dollar piece of equipment look bad. [High-Risk Participant]*

Some participants—particularly those who had chosen active treatment (surgery, radiation therapy) over active surveillance or watchful waiting—felt that personalized risk information produced by CPMs might have changed their treatment decisions:

> *PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would be based on what my diagnosis numbers were doing the various procedures, I, I probably would have looked at all those—and that may have strongly influenced me to do something other than what I did … in my case I think if I had a predictor like this which showed me the same result with watchful waiting or robot or radiation, I would, I would think real strongly about watchful waiting. [Medium-Risk Participant]*

Even if personalized risk information did not influence patients' actual decisions, furthermore, many valued such information as a means of simply being informed:

> *INTERVIEWER: Imagining that these kinds of tools were available when you were going through decision making, do you think this kind of information would have changed the decisions that you actually made about your own treatment?*
> *MULTIPLE PATIENTS (in unison): No.*
> *INTERVIEWER: Then what good is it?*
> *PATIENT 4: Like D. said, it's just a tool for you to go by, you know.*
> *PATIENT 5: Any information you can get adds to your knowledge of where you're gonna go with your treatment. [Medium-Risk Participants]*

Skepticism about the value of personalized risk information. Most participants, however, expressed skepticism about the value of personalized risk information. A primary source was the fundamental uncertainty inherent to all risk estimates. Several participants specifically

mentioned the uncertainty involved in applying probability estimates to the realm of single events experienced by individuals[14]:

> *You know, I don't care how much information you have, or how much the odds are, it can be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you looked at all the stats and it said they were gonna win. That ain't how it turned out! [Medium-Risk Participant]*

> *You don't know which percentage you're going to be in. I mean … the five-year number is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very high chance you won't spread, but you could be in the five percent. [Medium-Risk Participant]*

Another source of skepticism related to the reliability of statistical models and risk evidence itself. Several participants raised questions about the "*authenticity*" of CPMs, the qualifications and experience of CPM producers, and that the novel nature of CPMs. They also felt that different researchers and models should be "close to giving you the same type of prediction," and that conflicting estimates would lower their trust in CPMs. These concerns reflected "epistemic uncertainty" or the consciousness of what has been termed "ambiguity"—limitations in the reliability, credibility, or adequacy of risk information.[14]

Participants' uncertainties were manifest in skepticism about the value and influence of personalized risk information in decision making. Participants reported that at the most, they would use CPMs as a "second opinion" or "adjunct" that would augment—but not take precedence over—other types of evidence. As a medium-risk participant stated, "*I would consider the numbers very important, but it wouldn't drive the whole decision process*."

Participants viewed their own decision making processes as intuitive and based on non-statistical forms of evidence. Emotions were one prominent form, manifesting use of the "*affect heuristic*" in decision making[55,56]:

> *I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]*

For most participants the recommendations of trusted physicians constituted the primary form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the *"trust-the-doctor"*[57] *heuristic*:

> *… I'm a person who, who really respects and honors education … doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]*

Personal narrative was another form of evidence that took precedence over statistical evidence.[58-60] As one participant articulated: "*To me, you know, we can listen to the statistics from the physicians but it's also nice to hear from the patients and maybe even the wives."* Reliance on this "narrative heuristic" reflected a greater trust in information from the direct experiences of identifiable persons than from anonymous, population-based statistical information:

> *So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]*

> *Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience … It doesn't happen in a marketplace. [Medium-Risk Participant]*

Risk information vs. other types of evidence. More fundamentally, most participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of several types of evidence—all with equal legitimacy and weight in the decision-making process:

> *I think anything that you get anywhere is a guide … Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family.*
> *[Medium-Risk Participant]*

> *Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]*

The need for simplicity. Participants expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty[14] that could obscure the pertinent issues in decision making:

> *It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so boggled with all the information that you lose sight of the forest. [Medium-Risk Participant]*

> *But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery … I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]*

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process. As one participant reported, "*I think sometimes you can have too much information.*"

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): "*… what's simpler than if you have cancer here, what's simpler than taking it out?*" This cognitive strategy exemplified the use of another

simplifying heuristic: a conceptual equation of the cancer diagnosis itself with the necessity of active treatment:

> *PATIENT 2: There was no watchful waiting for me …Whether he told me that or not, I just—*
> *INTERVIEWER: There was no option.*
> *PATIENT 2: —no.*
> *PATIENT 1: I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]*

> *And, and you know, when I got those numbers of, you know, the, the biopsies and what not … I wanted to be done with it … I wanted it gone … Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]*

This "cancer heuristic" not only led many patients to perceive no real choice options, but diminished their interest in personalized risk information:

> *I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]*

> *PATIENT 1: I had to obviously make a decision, but it was very, for me it was such an easy decision.*
> *PATIENT 3: Yeah.*
> *PATIENT 2: A no-brainer.*
> *PATIENT 1: That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or … I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]*

Discussion

Our study provides new insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information patients currently receive is typically imprecise rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-

based), diagnostic rather than prognostic. To our knowledge, the current study provides the first empirical documentation of these phenomena in prostate cancer care; however, they are not unique to this disease. Indirect risk communication through biomarker values, for example, occurs in the treatment of common conditions such as hypercholesterolemia and hypertension,[9] and heuristics are employed in numerous types of decisions.[61,62] What the current study newly brings to light, however, is the critical role of patient values in reinforcing these processes. Although some prostate cancer patients in our study perceived personalized risk information as valuable, most viewed other types of evidence as more influential and expressed preferences for intuitive, heuristic-based rather than deliberative, risk-based approaches to decision making.

These findings should be interpreted cautiously given several study limitations. The sample was relatively small and homogeneous, and many participants had already made treatment decisions. The study assessed patient perceptions rather than behaviors, and used qualitative methods, a powerful approach for ascertaining the nature and breadth—but not the prevalence, causes, and effects—of people's beliefs and attitudes. Further research using larger, more diverse samples and quantitative methods is thus needed. Nevertheless, the validity of our findings is supported by their consistency with mounting evidence that precise, quantitative risk information is not always what patients need or want.[30,31] Our findings extend this evidence and have important implications for potential users of CPMs because they identify patient perceptions of the value of personalized risk information as an important barrier to the use of CPMs, and suggest potential modifiable reasons for these perceptions.

The most straightforward reason is lack of exposure to personalized risk information; most study participants reported having never received such information, and its value was thus simply beyond their imagination. This problem might be addressed by exposing patients to what they've been missing; as Steve Jobs famously quipped, "People don't know what they want until you show it to them."[63] Yet our study suggests that even if patients were provided with personalized risk information, they may not want it. Study participants expressed an overarching desire for simplicity in information and decision-making approach, manifested in preferences for heuristic- rather than risk-based decision making. This desire for simplicity is common,[30,64-66] and reflects fundamental limitations in human cognitive capacities (e.g., memory, literacy, numeracy) and available environmental resources (e.g., time, decision support)[32,67,68] that constrain people's ability to engage in effortful deliberation in decision making, and instead promote intuitive, heuristic-based decision making based on factors other than "estimations of probabilities, gains, costs, and the like."[61] Intuitive and deliberative decision-making approaches each have advantages and disadvantages;[69] however, if the goal is to increase the perceived value and clinical use of personalized risk information, then the limitations that reduce people's capacity for deliberation must somehow be overcome.

Another factor limiting the perceived value and use of personalized risk information among study participants was a perception that such information is less reliable than non-quantitative evidence. This perception raises a need that has not been addressed in efforts to apply risk information to patient care: to increase patients' *epistemological understanding*—i.e., their comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence at hand. Our study illustrates the two-fold challenge patients face in using personalized risk

information: they must weigh not only the magnitude of competing probabilities but the value of competing types of evidence, each with their own strengths and weaknesses. Personalized risk information represents the strongest form of evidence from the expert perspective; nevertheless, its clinical value is diminished by uncertainties arising from methodological problems in risk modeling[70,71] and the limited applicability of risk estimates to single events experienced by individuals.[72] On the other hand, non-quantitative forms of evidence (e.g., "gut feelings,"[73] physician recommendations, personal anecdotes) provide a means of mitigating irreducible uncertainties of risk estimates and are thus valuable from the lay perspective; however, such evidence is susceptible to numerous biases. Exactly how patients should weight these different types of evidence is a critical question for future research, but at the very least this task requires an understanding of their strengths and weaknesses. The lack of such understanding among study participants suggests that epistemological education should be a primary focus of efforts to apply personalized risk information to patient care.

Our study thus identifies several requisite tasks for enhancing the value and use of personalized risk information: 1) increasing patients' exposure to personalized risk information, 2) providing resources to support deliberative decision making, and 3) providing epistemological education on the nature of medical knowledge and evidence. The first task has been a primary focus of CPM proponents; however, more work is needed to effectively disseminate and implement CPMs in clinical practice. The second task has only begun to be addressed, but promising approaches include the delivery of personalized risk information through patient-centered decision support interventions (DeSIs) such as decision aids,[74,75] and the use of risk communication strategies such as visual representations to improve the evaluability of risk estimates.[30,31,76-83] A more

challenging task is to provide the environmental resources—e.g., clinical time, processes, and incentives—needed for deliberative and collaborative decision making.[74] The final task, the provision of epistemological education, is a new frontier that has yet to be explored but calls for efforts to expand the content of risk information communicated to patients—whether through DeSIs or larger-scale educational efforts delivered through other channels. It remains for further research to address these challenges, and to determine how best to help patients translate personalized risk information into better informed health care decisions.

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All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) PH, MN, BR, NH, TK, MD, and MH have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (2) spouses, partners, or

children of PH, MN, BR, NH, TK, MD, and MH have no financial relationships that may be relevant to the submitted work; and (3) PH, MN, BR, NH, TK, MD, and MH have no non-financial interests that may be relevant to the submitted work.

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Contributorship Statement

PH designed the study, obtained funding, conducted interviews and data analysis, drafted the manuscript, and edited the manuscript for important content.

MN, BR, and NH conducted data analysis and edited the manuscript for important content.

TK assisted in the design of the study, conducted interviews, and edited the manuscript for important content.

CG edited the manuscript for important content.

MD edited the manuscript for important content.

MH assisted in the design of the study and edited the manuscript for important content.

Data sharing statement

Data sharing: no additional data available; consent for data sharing was not obtained from study participants.

References

Table 1. Focus group categories

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6, Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, StageT3-T4,PSA >20)

Table 2. Characteristics of focus group participants

	N	%
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

I was told that with the Gleason score of 9 that that's frightening … That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

INTERVIEWER: And what was your understanding of what the Gleason score meant? PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]

… he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

My primary care physician, one of the things that she told me which made me feel good was, S, hey, it's low grade, low risk, stage 1. This is not going to get you, S. Something else is going to. [Low-Risk Participant]

My understanding is that, well, as I stated I'm going in for another biopsy in January. At this time I've met the criteria for active surveillance for the past year, and that's where I'm at at this time. In other words, the criteria for PSA testing and whether they've gone up or down in testing. [Low-Risk Participant]

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The value of personalized risk information: a qualitative study of the perceptions of prostate cancer patients

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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of personalized risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. Several participants reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but expressed skepticism about its value. Many participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients appear to have little experience using personalized risk information, may favor heuristic- over risk-based decision making strategies, and may perceive personalized risk information as less valuable than other types of evidence. These decision-

making approaches and perceptions represent potential barriers to the clinical use of personalized risk information. Overcoming these barriers will require providing patients with greater exposure to risk information, education about the nature and value of personalized risk information, and training in deliberative decision-making strategies. More research is needed to confirm these findings and address these needs.

Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients appear to have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- At least some prostate cancer patients favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having less value than other forms of evidence.
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence.

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

- The study sample was relatively small, geographically limited, and racially and ethnically homogeneous.
- Qualitative methods cannot definitively establish the prevalence, causes, or effects of patients' experiences and perceptions. Further research using quantitative methods is needed to confirm the study's findings.

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients[1]—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes[2]— have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.[3-8] Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,[9] and on patient values and preferences.[2] Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.[10]

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,[11-14] psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.[15-22] Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.[21-29] A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and "simpler, less precise representations" of risk are often more useful to patients.[30] In a similar vein, Reyna has

contended that people prefer to construe risk in qualitative terms representing its "gist" meaning, rather than in precise, quantitative terms representing its "verbatim" details.[31] Gigerenzer has gone further to challenge the conception of rationality underlying efforts to apply risk information to decision making. Extending an argument put forth by the economist Simon in the 1950s,[32] he emphasizes that rationality is "bounded" by limitations in the cognitive and environmental resources available to decision makers. Consequently, in real world decisions people do not "optimize"—i.e., they do not calculate and weigh probabilities and values in an exhaustive computational search for the best option. Instead, they use heuristics—"fast and frugal" rules of thumb that facilitate adaptive decisions.

These insights raise fundamental questions about the usefulness of precise, quantitative risk information in health care. Is such information really needed and desired by patients? Do patients—as opposed to health professionals—perceive personalized risk information as valuable, and how might their perceptions influence the success of efforts to use CPMs in clinical practice?

The aim of the current research was to explore these questions, focusing on personalized risk information in the treatment of prostate cancer—the most common and 2nd most common male cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer deaths.[33-35] Approximately 80% of newly diagnosed prostate cancer patients have clinically-localized disease for which there are multiple treatment options—surgery, radiation therapy, conservative treatment (active surveillance)—each with differing potential benefits and harms.[34] The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has

thus become a primary focus of predictive modeling activities, resulting in the development of over 100 CPMs[36-42] and growing efforts to disseminate and apply these models in clinical practice.[41-46]

Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and the information they produce. To this end, the current study explored prostate cancer patients' experiences with using risk information in treatment decisions, and their perceptions of the value of precise, personalized risk information produced by CPMs. The ultimate goal was to generate insights that might inform efforts to use CPMs to promote personalized, informed decision making in the treatment of prostate cancer and other conditions.

Methods

Study design, participants, and data collection. This qualitative study employed focus groups, a useful methodology for exploring people's perceptions, beliefs, and attitudes.[47,48] From September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 9 statewide support groups. Eligible participants were recruited by MCFPC and consisted of English-speaking prostate cancer survivors within 3 years of initial diagnosis. Purposive recruitment soliciting participation of men at various disease stages was conducted to obtain a study sample with diverse treatment experiences and prognoses; no volunteers were excluded. To achieve sufficient within-group homogeneity to encourage open discussion,[49] participants were stratified into 3 groups (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as

defined by U.S. National Comprehensive Cancer Network guidelines.[50] A total of 2 Low Risk, 3 Medium Risk, and 2 High Risk focus groups were conducted at MCFPC support group sites in 3 rural and non-rural towns and cities (Brunswick, Lewiston, Portland). Participants received $50 compensation. Sessions lasted approximately 2 hours, were audiorecorded with prior consent of participants, and transcribed verbatim by a professional transcription service.

Interview content. Groups were led by PH and either a professional moderator or another study investigator (TK). Interviews were semi-structured and followed a moderator guide consisting of open-ended questions and close-ended probes designed to elicit patients' past experiences with risk information, preferences for personalized risk information, and attitudes towards CPMs. To illustrate how CPMs work and what types of information they provide, participants were briefly shown visual aids consisting of screenshots of web-based CPMs (**Appendix A**) for several different prostate cancer outcomes (e.g., risk of cancer recurrence, cancer-free survival, death) produced by the Cleveland Clinic (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)[42] and Memorial Sloan-Kettering Cancer Center (http://www.mskcc.org/mskcc/html/10088.cfm).[51] During the course of the study, minor revisions were made in the interview guide to clarify emergent themes.

Data analysis. In-depth analysis and line-by-line software-assisted coding of anonymized interview transcripts was conducted using the program NVivo (Version 8; QSR International). First, three investigators (PH, MN, BR) developed a preliminary conceptual schema and codebook by independently reading 3 transcripts, categorizing participants' verbatim statements according to thematic content, and organizing emergent themes—consistent with a "grounded

theory" approach to the data.[52,53] Preliminary codebooks were reviewed by the team and areas of disagreement were resolved through further discussion. A single working codebook was then produced, which two investigators (MN, BR) used to code the remaining transcripts, employing a "constant comparative" method to compare new data, concepts, and themes with ones previously identified.[52,54] The research team held periodic meetings to discuss coding decisions, identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH) conducted a secondary review of all coded text to organize dominant themes. An outline of identified themes is in **Appendix B**.The current analysis focused on participants' perceptions of the value of personalized risk information; analyses of other themes will be reported separately.

Results

Characteristics of participants are in **Table 2**. The primary interview domains consisted of participants' 1) past experiences with risk communication, and 2) perceptions of the value of personalized risk information produced by CPMs.

1. Past experiences with risk communication

Within these two broad domains several dominant themes emerged; the first was the broad spectrum of risk communication experiences and practices reported by participants.

Absence of explicit risk communication. At one end of the spectrum were a small number of participants who reported having never received risk information of any kind during the decision making process:

> *I wasn't actually told about the numbers. I just went by what they were saying. I guess—they knew what the numbers were, what the odds were for me, and I went with that and yeah, I would've wanted to know what the numbers were. [Medium-Risk Participant]*

For these few participants treatment risks were implicitly understood rather than explicitly communicated:

> *I think the conversation that I had with my urologist was we each knew all of those possibilities. It was kind of like a given, and our conversation was based on the fact that we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]*

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a "histogram" and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with "average" risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication was categorical and non-quantitative. A low-risk participated noted: *"he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low."* Other participants recalled the use of similarly broad categories—e.g., "good," "most likely," "very remote," "high," "very likely."

Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores (**Table 3)**. Participants in all groups described using biomarker values *in lieu* of probability estimates to understand the magnitude of their risk:

> *I really, you know, I read the books … And, I'm sure they had all sorts of graphs and stuff like that. But I've got to admit when I looked at my Gleason scores, this is gonna sound, you know it's all irrelevant. [High-Risk Participant]*

This "biomarker heuristic"—which has not been previously described as such, to our knowledge—functioned as a shorthand rubric or guide to treatment decisions. As one medium-risk participant articulated, referring to his PSA values: "*when you don't have any guidelines to go by, you gotta have some idea where that is, whether it's a four or six or ten or whatever*."

The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

INTERVIEWER: So they gave you a sense of what those numbers meant …a four means you have an X percent chance of—
PATIENT 3: No, they didn't.
INTERVIEWER: But they just said—it was good—versus bad, right?
PATIENT 3: Yeah.
PATIENT 2: That's what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you're just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it's not a necessity, but they didn't recommend not doing anything about it all … So those numbers I think … kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]

The usefulness of biomarker values appeared to stem from their apparently "hard," tangible nature, and their straightforward connection to a defined course of action:

> *PATIENT: My decision was based upon what we had for biopsies and stuff like that.*

INTERVIEWER: Okay. Alright.
PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn't' really—that's irrelevant to me… but, based upon the information that I had, you know, hard information, I felt very comfortable.

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

> *I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]*

2. Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

> *You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]*

Patient empowerment *vis-a-vis* their physicians was another perceived value of personalized risk information:

> *So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too … So, like, the doctor is not the god. [Low-Risk Participant]*

Participants believed that such empowerment was necessary because of inherent biases of treating physicians:

> *I can see this being used to help people make a decision as to what course of treatment they should seek versus what side effect they can live with. Now, if you go to X and ask them what their percentage of incontinence is … they're gonna give you a skewed number because they don't want to make that million-dollar piece of equipment look bad. [High-Risk Participant]*

Some participants—particularly those who had chosen active treatment (surgery, radiation therapy) over active surveillance or watchful waiting—felt that personalized risk information produced by CPMs might have changed their treatment decisions:

> *PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would be based on what my diagnosis numbers were doing the various procedures, I, I probably would have looked at all those—and that may have strongly influenced me to do something other than what I did … in my case I think if I had a predictor like this which showed me the same result with watchful waiting or robot or radiation, I would, I would think real strongly about watchful waiting. [Medium-Risk Participant]*

Even if personalized risk information did not influence patients' actual decisions, furthermore, many valued such information as a means of simply being informed:

> *INTERVIEWER: Imagining that these kinds of tools were available when you were going through decision making, do you think this kind of information would have changed the decisions that you actually made about your own treatment?*
> *MULTIPLE PATIENTS (in unison): No.*
> *INTERVIEWER: Then what good is it?*
> *PATIENT 4: Like D. said, it's just a tool for you to go by, you know.*
> *PATIENT 5: Any information you can get adds to your knowledge of where you're gonna go with your treatment. [Medium-Risk Participants]*

Skepticism about the relative value of personalized risk information. Most participants, however, expressed skepticism about the value of personalized risk information. A primary source was the fundamental uncertainty inherent to all risk estimates. Several participants specifically mentioned the uncertainty involved in applying probability estimates to the realm of single events experienced by individuals[14]:

> *You know, I don't care how much information you have, or how much the odds are, it can be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you looked at all the stats and it said they were gonna win. That ain't how it turned out! [Medium-Risk Participant]*
>
> *You don't know which percentage you're going to be in. I mean … the five-year number is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very high chance you won't spread, but you could be in the five percent. [Medium-Risk Participant]*

Another source of skepticism related to the reliability of statistical models and risk evidence itself. Several participants raised questions about the "*authenticity*" of CPMs, the qualifications and experience of CPM producers, and the novel nature of CPMs. They also felt that different researchers and models should be "close to giving you the same type of prediction," and that conflicting estimates would lower their trust in CPMs. These concerns reflected "epistemic uncertainty" or the consciousness of what has been termed "ambiguity"—limitations in the reliability, credibility, or adequacy of risk information.[14]

Participants' uncertainties were manifest in skepticism about the value and influence of personalized risk information in decision making. Participants reported that at the most, they would use CPMs as a "second opinion" or "adjunct" that would augment—but not take precedence over—other types of evidence. As a medium-risk participant stated, "*I would consider the numbers very important, but it wouldn't drive the whole decision process*."

Risk information vs. other types of evidence. More fundamentally, many participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of several types of evidence—with at least equal legitimacy and weight in the decision-making process:

> *Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]*

> *I think anything that you get anywhere is a guide … Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family.*
> *[Medium-Risk Participant]*

Emotions were one prominent form of non-statistical evidence that participants utilized in decision making, manifesting use of the "*affect heuristic*"[55,56]:

> *I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]*

For other participants the recommendations of trusted physicians constituted the primary form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the *"trust-the-doctor"*[57] *heuristic*:

> *… I'm a person who, who really respects and honors education … doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]*

Personal narrative was another form of evidence that participants prioritized over statistical evidence.[58-60] As one participant articulated: *"To me, you know, we can listen to the statistics from the physicians but it's also nice to hear from the patients and maybe even the wives."* For some participants the use of narrative evidence appeared to function as a heuristic—a mental shortcut that obviated the need to rely on statistical evidence. Reliance on this "narrative heuristic"—well-described in the literature although not typically characterized as a heuristic—manifested a greater trust in the reported experiences of identifiable individuals than in statistical information:

> *Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience … It doesn't happen in a marketplace. [Medium-Risk Participant]*

> *So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]*

The need for simplicity. Several participants expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty[14] that could obscure the pertinent issues in decision making:

> *It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so boggled with all the information that you lose sight of the forest. [Medium-Risk Participant]*

> *But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery … I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]*

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process.

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): "… *what's simpler than if you have cancer here, what's simpler than taking it out?"* This cognitive strategy exemplified the use of what could be characterized as a simplifying "disease heuristic": a conceptual equation of the mere diagnosis of disease with the necessity of active treatment:

> *PATIENT 2: There was no watchful waiting for me …Whether he told me that or not, I just—*

INTERVIEWER: There was no option.
PATIENT 2: —no.
PATIENT 1: I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]

And, and you know, when I got those numbers of, you know, the, the biopsies and what not … I wanted to be done with it … I wanted it gone … Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]

Although the conceptual equation of disease diagnosis with treatment necessity has been previously recognized,[9] it has not been characterized as a decision-making heuristic. However, our data suggests that it have a heuristic function—obviating patients' need and desire to attend to outcome probabilities and leading many patients to perceive no real choice options:

I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]

PATIENT 1: I had to obviously make a decision, but it was very, for me it was such an easy decision.
PATIENT 3: Yeah.
PATIENT 2: A no-brainer.
PATIENT 1: That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or … I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]

Discussion

Our study provides preliminary insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information at least some patients currently receive is typically imprecise rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-based), diagnostic rather than prognostic. To our knowledge, the current study

provides the first empirical documentation of these phenomena in prostate cancer care; however, they are not unique to this disease. Indirect risk communication through biomarker values, for example, occurs in the treatment of common conditions such as hypercholesterolemia and hypertension,[9] and heuristics are employed in numerous types of decisions.[61,62] What the current study newly brings to light, however, is the critical role of patient values in reinforcing these processes. Although many prostate cancer patients in our study clearly perceived personalized risk information as valuable, they viewed other types of evidence as relatively more influential and expressed preferences for intuitive, heuristic-based rather than deliberative, risk-based approaches to decision making.

These findings should be interpreted cautiously, however, given several study limitations. The sample was relatively small, geographically limited, and homogeneous in race and ethnicity. Many participants had already made treatment decisions, and their negative attitudes towards personalized risk information may thus have been biased by a motivation to avoid regret or dissonance over not having used such information. Participants' negative attitudes could also have been influenced by the particular ways in which the information was represented by the websites shown in the interviews. It is conceivable that alternative representational methods—e.g., using visualizations or other patient-centered risk communication strategies aimed at improving comprehension—may have encouraged more favorable attitudes. This possibility remains to be explored and is an important focus for future research. Finally, the study assessed patient perceptions rather than behaviors and used qualitative methods, a powerful approach for ascertaining the nature and breadth—but not the prevalence, causes, and effects—of people's beliefs and attitudes. Further quantitative studies using larger, racially and ethnically diverse

samples are thus needed to confirm our preliminary findings. Nevertheless, the validity of these findings is supported by their consistency with mounting evidence that precise, quantitative risk information is not always what patients need or want.[30,31] Our findings have important implications for potential users of CPMs because they identify patient perceptions of the value of personalized risk information as a barrier to the use of CPMs, and suggest potential modifiable reasons for these perceptions.

The most straightforward reason is lack of exposure to personalized risk information; most study participants reported having never received such information, and its value was thus simply beyond their imagination. This problem might be addressed by exposing patients to what they've been missing; as Steve Jobs famously quipped, "People don't know what they want until you show it to them."[63] Yet our study suggests that even if patients were provided with personalized risk information, they may not always want it. Study participants expressed an overarching desire for simplicity in information and decision-making approach, manifested in preferences for heuristic- rather than risk-based decision making. This desire for simplicity is common,[30,64-66] and reflects fundamental limitations in human cognitive capacities (e.g., memory, literacy, numeracy) and available environmental resources (e.g., time, decision support)[32,67,68] that constrain people's ability to engage in effortful deliberation in decision making, and instead promote intuitive, heuristic-based decision making based on factors other than "estimations of probabilities, gains, costs, and the like."[61] Intuitive and deliberative decision-making approaches each have advantages and disadvantages;[69] however, if the goal is to increase the perceived value and clinical use of personalized risk information, then the limitations that reduce people's capacity for deliberation must somehow be overcome.

Another factor limiting the perceived value and use of personalized risk information among study participants was a perception that such information is less reliable than non-quantitative evidence. This perception raises a need that has not been addressed in efforts to apply risk information to patient care: to increase patients' *epistemological understanding*—i.e., their comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence at hand. Our study illustrates the two-fold challenge patients face in using personalized risk information: they must weigh not only the magnitude of competing probabilities but the value of competing types of evidence, each with their own strengths and weaknesses. Personalized risk information represents the strongest form of evidence from the expert perspective; nevertheless, its clinical value is diminished by uncertainties arising from methodological problems in risk modeling[70,71] and the limited applicability of risk estimates to single events experienced by individuals.[72] On the other hand, non-quantitative forms of evidence (e.g., "gut feelings,"[73] physician recommendations, personal anecdotes) provide a means of mitigating irreducible uncertainties of risk estimates and are thus valuable from the lay perspective; however, such evidence is susceptible to numerous biases. Exactly how patients should weight these different types of evidence is a critical question for future research, but at the very least this task requires an understanding of their strengths and weaknesses. The lack of such understanding among study participants suggests that epistemological education should be a primary focus of efforts to apply personalized risk information to patient care.

Our study thus identifies several potentially important tasks for enhancing the value and use of personalized risk information: 1) increasing patients' exposure to personalized risk information,

2) providing resources to support deliberative decision making, and 3) providing epistemological education on the nature of medical knowledge and evidence. The first task has been a primary focus of CPM proponents; however, more work is needed to effectively disseminate and implement CPMs in clinical practice. The second task has only begun to be addressed, but promising approaches include the delivery of personalized risk information through patient-centered decision support interventions (DeSIs) such as decision aids,[74,75] and the use of risk communication strategies such as visual representations to improve the evaluability of risk estimates.[30,31,76-83] A more challenging task is to provide the environmental resources—e.g., clinical time, processes, and incentives—needed for deliberative and collaborative decision making.[74] The final task, the provision of epistemological education, is a new frontier that has yet to be explored but calls for efforts to expand the content of risk information communicated to patients—whether through DeSIs or larger-scale educational efforts delivered through other channels. It remains for further research to address these challenges, and to determine how best to help patients translate personalized risk information into better informed health care decisions.

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All authors had full access to all of the data (including statistical reports and tables) in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The

study was approved by the Maine Medical Center Institutional Review Board (IRB#3805X), and granted a waiver of informed consent.

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) PH, MN, BR, NH, TK, CG, MD, and MH have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (2) spouses, partners, or children of PH, MN, BR, NH, TK, CG, MD, and MH have no financial relationships that may be relevant to the submitted work; and (3) PH, MN, BR, NH, TK, CG, MD, and MH have no non-financial interests that may be relevant to the submitted work.

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Contributorship Statement

PH designed the study, obtained funding, conducted interviews and data analysis, drafted the manuscript, and edited the manuscript for important content.

MN, BR, and NH conducted data analysis and edited the manuscript for important content.

TK assisted in the design of the study, conducted interviews, and edited the manuscript for important content.

CG edited the manuscript for important content.

MD edited the manuscript for important content.

MH assisted in the design of the study and edited the manuscript for important content.

Data sharing statement

Data sharing: no additional data available; consent for data sharing was not obtained from study participants.

References

Table 1. **Focus group categories**

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6, Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, StageT3-T4,PSA >20)

Table 2. Characteristics of focus group participants

	N	%
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

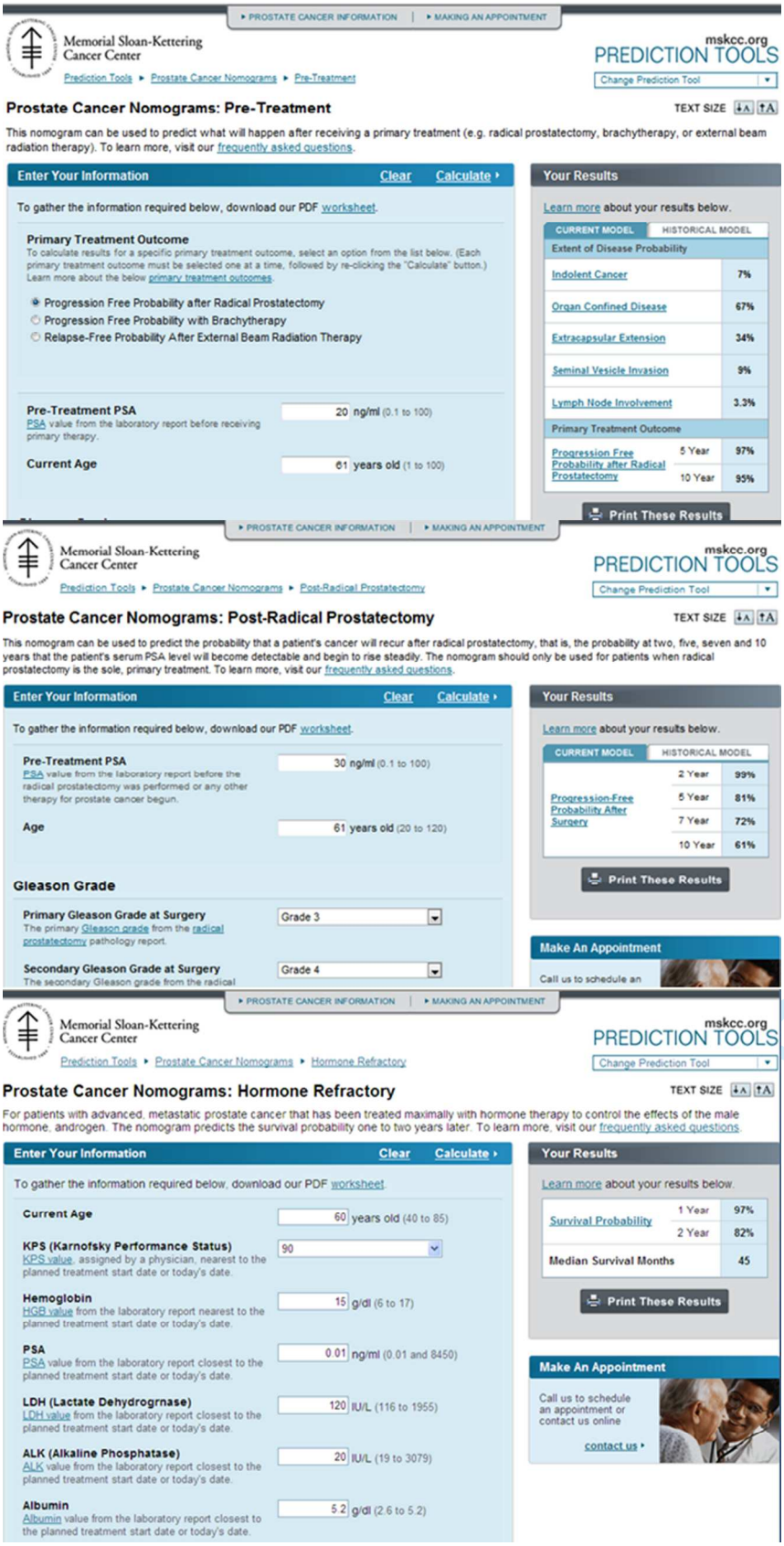
I was told that with the Gleason score of 9 that that's frightening ... That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

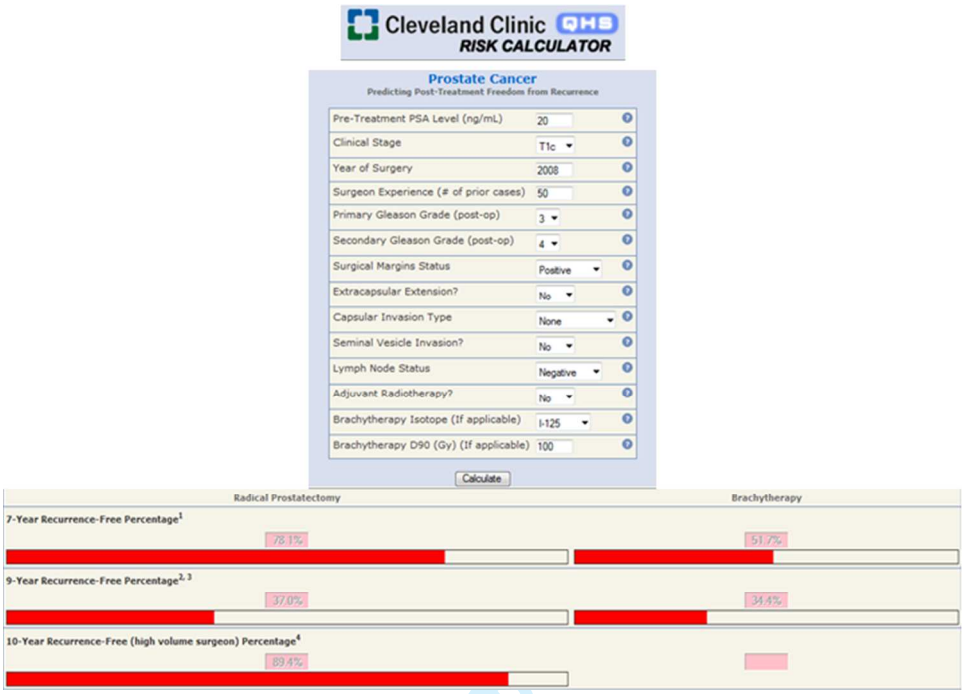
INTERVIEWER: And what was your understanding of what the Gleason score meant? PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]

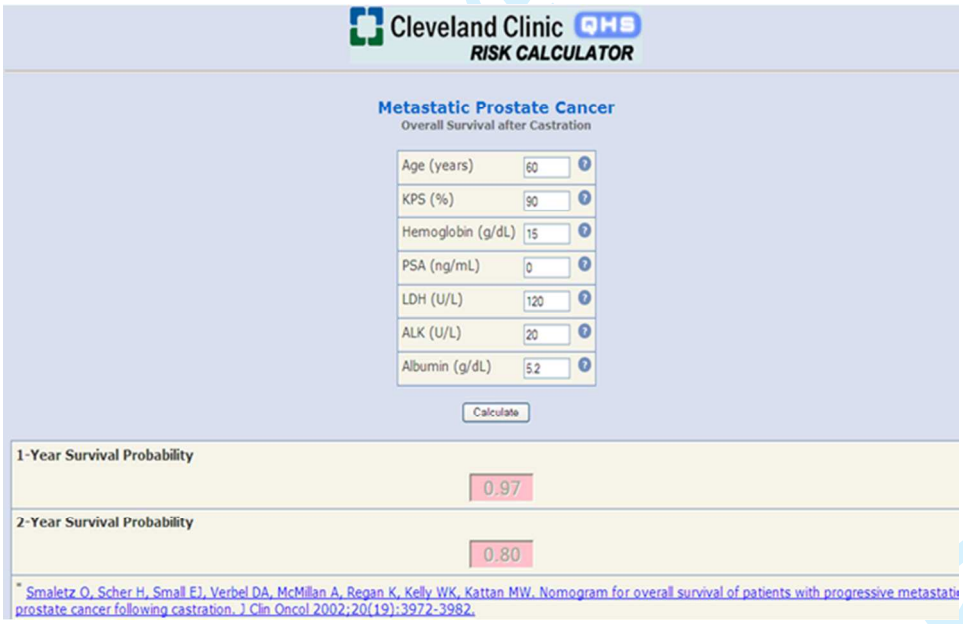
... he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

Appendix A. Clinical prediction model screenshots used as interview aids







Appendix B. Theme outline – Focus group study

A. PAST EXPERIENCES WITH RISK COMMUNICATION

1. Extent of communication
    a. No risk communication
    b. Detailed communication of individualized, quantitative risk information
    c. Non-individualized quantitative risk communication
    d. Imprecise quantitative risk communication
    e. Categorical risk communication: qualitative categories
    f. Indirect risk communication: biomarker heuristic
2. Sources of risk information
    a. Doctor: urologist, radiation oncologist, PCP, other
    b. Other health professionals: nurse navigators, etc.
    c. Friends, family
    d. Internet, books

B. PERCEIVED VALUE OF PERSONALIZED RISK INFORMATION

1. Promote SDM
2. Provide insight into physician thinking
3. Provide second opinion / counter physician bias
4. Confirmatory
5. Facilitate advance care planning
6. Justify decisions

C. PERCEIVED CHALLENGES IN USE OF PERSONALIZED RISK INFORMATION

1. Lack of self-efficacy in understanding risk information
2. Logistic barriers: lack of time
3. Physician bias/self-interest
4. Preference for simplicity
5. Low perceived need for information
    a. Low preference for information and participation in decision making
    b. Trust the doctor heuristic
    c. Cancer heuristic (removal heuristic: "cut it out"): perceived lack of decision
    d. Reliance on intuitive vs. rational decision-making approaches
6. Distrust of statistical information: "anti-statistics" viewpoint
    a. Preference for anecdotal/narrative vs. statistical information: "unreality" of numbers vs. narrative information
    b. Questionable relevance to individual: reference class problem
    c. Uncertainty: epistemic (ambiguity)
        i. Imprecision
        ii. Conflicting data
        iii. Missing data, multiple/unknown/unaccounted risks
        iv. Source credibility

d. Uncertainty: aleatory (randomness)

7. Motivated reasoning: desire for good news/fear of bad news

D. VALUE OF INDIRECT RISK COMMUNICATION (BIOMARKER HEURISTIC)

1. Provide sense of control
2. Communicate the bottom-line/gist
3. Represent "hard information"
4. Facilitate decision resolution
5. Simplify decision making

E. INTERPRETATION OF PERSONALIZED RISK ESTIMATES

1. Understanding of risk estimate: frequency or confidence statement
2. Perceived difficulty

F. COMMUNICATION OF UNCERTAINTY (AMBIGUITY)

1. Preferences for/against
2. Reactions to use of range/confidence interval

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The value of personalized risk information: a qualitative study of the perceptions of prostate cancer patients

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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of ~~precise,~~ personalized~~,~~ risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending ~~local~~ prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. Several p~~P~~articipants ~~most commonly~~ reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but ~~most~~ expressed skepticism about its value. ~~Most~~ Many participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients appear to have little experience using personalized risk information, may favor heuristic- over risk-based decision making strategies, and may perceive

personalized risk information as less valuable than other types of evidence. These decision-making approaches and~~Patients' preferred decision-making approaches to decision-making and their~~ perceptions ~~may be~~represent potential barriers to the clinical use of personalized risk information. Overcoming these barriers will require ~~providing patients with greater~~providing patients with greater exposure to risk information, education about the nature and value of personalized risk information, and training in deliberative decision-making strategies~~, environmental resources for deliberative decision-making, and education about the nature and value of personalized risk information~~. More research is needed to confirm ~~and address~~ these findings and address these needs.

Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients appear to have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- At least some p~~Many p~~Prostate cancer patients ~~may~~ favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having ~~little~~ less value ~~in clinical decision making~~than other forms of evidence.
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence.

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

- The study sample was relatively small, geographically limited, and racially and ethnically homogeneous.
- ~~q~~Qualitative methods cannot definitively establish the prevalence, causes, or effects of ~~the~~ patients' experiences and perceptions. Further research using quantitative methods is needed to confirm the study's findings.

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients[1]—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes[2]— have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.[3-8] Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,[9] and on patient values and preferences.[2] Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.[10]

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,[11-14] psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.[15-22] Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.[21-29] A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and "simpler, less precise representations" of risk are often more useful to patients.[30] In a similar vein, Reyna has

contended that people prefer to construe risk in qualitative terms representing its "gist" meaning, rather than in precise, quantitative terms representing its "verbatim" details.[31] Gigerenzer has gone further to challenge the conception of rationality underlying efforts to apply risk information to decision making. Extending an argument put forth by the economist Simon in the 1950s,[32] he emphasizes that rationality is "bounded" by limitations in the cognitive and environmental resources available to decision makers. Consequently, in real world decisions people do not "optimize"—i.e., they do not calculate and weigh probabilities and values in an exhaustive computational search for the best option. Instead, they use heuristics—"fast and frugal" rules of thumb that facilitate adaptive decisions.

These insights raise fundamental questions about the usefulness of precise, quantitative risk information in health care. Is such information really needed and desired by patients? Do patients—as opposed to health professionals—perceive personalized risk information as valuable, and how might their perceptions influence the success of efforts to use CPMs in clinical practice?

The aim of the current research was to explore these questions, focusing on personalized risk information in the treatment of prostate cancer—the most common and 2nd most common male cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer deaths.[33-35] Approximately 80% of newly diagnosed prostate cancer patients have clinically-localized disease for which there are multiple treatment options—surgery, radiation therapy, conservative treatment (active surveillance)—each with differing potential benefits and harms.[34] The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has

thus become a primary focus of predictive modeling activities, resulting in the development of over 100 CPMs[36-42] and growing efforts to disseminate and apply these models in clinical practice.[41-46]

Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and the information they produce. To this end, the current study explored prostate cancer patients' experiences with using risk information in treatment decisions, and their perceptions of the value of precise, personalized risk information produced by CPMs. The ultimate goal was to generate insights that might inform efforts to use CPMs to promote personalized, informed decision making in the treatment of prostate cancer and other conditions.

Methods

Study design, participants, and data collection. This qualitative study employed focus groups, a useful methodology for exploring people's perceptions, beliefs, and attitudes.[47,48] From September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 9 statewide support groups ~~throughout the entire state~~. Eligible participants were recruited by MCFPC and consisted of English-speaking prostate cancer survivors within 3 years of initial diagnosis. Purposive recruitment soliciting participation of men at various disease stages ~~. A purposive recruiting strategy was employed to select~~was conducted to obtain a study sample with ~~varying~~ diverse treatment experiences and prognoses; no volunteers were excluded. ~~-~~ To achieve sufficient within-group homogeneity to encourage open discussion,[49] participants were stratified

into 3 groups (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as defined by U.S. National Comprehensive Cancer Network guidelines.[50] A total of 2 Low Risk, 3 Medium Risk, and 2 High Risk focus groups were conducted at MCFPC support group sites in 3 rural and non-rural towns and cities (Brunswick, Lewiston, Portland). Participants received $50 compensation. Sessions lasted approximately 2 hours, were audiorecorded with prior consent of participants, and transcribed verbatim by a professional transcription service.

Interview content. Groups were led by PH and either a professional moderator or another study investigator (TK). Interviews were semi-structured and followed a moderator guide consisting of open-ended questions and close-ended probes designed to elicit patients' past experiences with risk information, preferences for personalized risk information, and attitudes towards CPMs. To illustrate how CPMs work and what types of information they provide, participants were~~Interviews~~ briefly~~utilized~~ shown visual aids consisting of screenshots of web-based CPMs (**Appendix A**) for several different prostate cancer outcomes (e.g., risk of cancer recurrence, cancer-free survival, death) produced by the Cleveland Clinic (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)[42] and Memorial Sloan-Kettering Cancer Center (http://www.mskcc.org/mskcc/html/10088.cfm).[51] During the course of the study, minor revisions were made in the interview guide to clarify emergent themes.

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Data analysis. In-depth analysis and line-by-line software-assisted coding of anonymized interview transcripts was conducted using the program NVivo (Version 8; QSR International). First, three investigators (PH, MN, BR) developed a preliminary conceptual schema and codebook by independently reading 3 transcripts, categorizing participants' verbatim statements

according to thematic content, and organizing emergent themes—consistent with a "grounded theory" approach to the data.[52,53] Preliminary codebooks were reviewed by the team and areas of disagreement were resolved through further discussion. A single working codebook was then produced, which two investigators (MN, BR) used to code the remaining transcripts, employing a "constant comparative" method to compare new data, concepts, and themes with ones previously identified.[52,54] The research team held periodic meetings to discuss coding decisions, identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH) conducted a secondary review of all coded text to organize dominant themes. An outline of identified themes is in **Appendix B**.The current analysis focused on participants' perceptions of the value of personalized risk information; analyses of other themes will be reported separately.

Results

Characteristics of participants are in **Table 2**. The primary interview domains consisted of participants' 1) past experiences with risk communication, and 2) perceptions of the value of personalized risk information produced by CPMs.

1. Past experiences with risk communication

Within these two broad domains several dominant themes emerged; the first was the broad spectrum of risk communication experiences and practices reported by participants.

Absence of explicit risk communication. At one end of the spectrum were a small number of participants who reported having never received risk information of any kind during the decision making process:

> *I wasn't actually told about the numbers. I just went by what they were saying. I guess—they knew what the numbers were, what the odds were for me, and I went with that and yeah, I would've wanted to know what the numbers were. [Medium-Risk Participant]*

For these few participants treatment risks were implicitly understood rather than explicitly communicated:

> *I think the conversation that I had with my urologist was we each knew all of those possibilities. It was kind of like a given, and our conversation was based on the fact that we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]*

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a "histogram" and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with "average" risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication was categorical and non-quantitative. A low-risk participated noted: *"he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low."* Other participants recalled the use of similarly broad categories—e.g., "good," "most likely," "very remote," "high," "very likely."

Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores~~.~~ ~~(Illustrative quotations from men at different levels of risk for disease recurrence are in~~ **Table 3**~~)~~. ~~For p~~ Participants in all groups ~~, biomarker~~ described using biomarker values *in lieu* of probability estimates to understand the magnitude of their risk:

> *I really, you know, I read the books … And, I'm sure they had all sorts of graphs and stuff like that. But I've got to admit when I looked at my Gleason scores, this is gonna sound, you know it's all irrelevant. [High-Risk Participant]*

This "biomarker heuristic"—which has not been previously described as such, to our knowledge—~~provided a basis for decision making~~functioned as a shorthand rubric or guide to treatment decisions. ~~, a~~As ~~values served as an anchor point that helped them understand the magnitude of their risk and provided a basis for decision making; as~~ one medium-risk participant ~~related~~articulated, referring to his PSA values: "*when you don't have any guidelines to go by, you gotta have some idea where that is, whether it's a four or six or ten or whatever*." The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

INTERVIEWER: So they gave you a sense of what those numbers meant …a four means you have an X percent chance of—
PATIENT 3: No, they didn't.
INTERVIEWER: But they just said—it was good—versus bad, right?
PATIENT 3: Yeah.
PATIENT 2: That's what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you're just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it's not a necessity, but they didn't recommend not doing anything about it all … So those numbers I think … kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]

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~~*PATIENT 3: Well I think – if they're telling me my Gleason scale was under 4, I wouldn't have done anything.*~~

~~*PATIENT 1: Yeah, that's what I would do.*~~

~~*PATIENT 3: But when they said 6, that's when Dr. X said it's time to really think about it. But with me, I was upset for a little while, but once I made up my mind to do something, then I wasn't. The whole thing is wondering what you're gonna do and once you make up your mind – Yeah, then that's it. [Medium-Risk Participants]*~~

The usefulness of biomarker values appeared to stem from their apparently "hard," tangible nature, and their straightforward connection to a defined course of action:

PATIENT: My decision was based upon what we had for biopsies and stuff like that.
INTERVIEWER: Okay. Alright.
PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn't' really—that's irrelevant to me… but, based upon the information that I had, you know, hard information, I felt very comfortable.

~~*PATIENT 1: All that they've been giving me are the scores for my PSA … My doctor said, when your numbers double in four month spread, he said, we need to do something about it … he says, and I'll nip and tuck it just as soon as it gets up there, and my last time it was aggressive. It went from 0.12 to 5.5 in four months, and so, he encouraged me, and he told me what he was going to do …*~~

~~*INTERVIEWER: Okay.*~~

~~*PATIENT 2: They give you all kinds of information. And he'll tell you, you know, specifically we're talking about this spread, and this is where you are, and this is what we think … I totally felt like I was just as much in control of my life as he was. And it*~~

~~*gave me, it gave me a lot of courage toward it. I had a bad two days when I found out about it. I haven't had a bad day since. [High-Risk Participants]*~~

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

> *I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]*

2. Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

> *You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]*

Patient empowerment *vis-a-vis* their physicians was another perceived value of personalized risk information:

> *So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too … So, like, the doctor is not the god. [Low-Risk Participant]*

Participants believed that such empowerment was necessary because of inherent biases of treating physicians:

> *I can see this being used to help people make a decision as to what course of treatment they should seek versus what side effect they can live with. Now, if you go to X and ask them what their percentage of incontinence is … they're gonna give you a skewed number because they don't want to make that million-dollar piece of equipment look bad. [High-Risk Participant]*

Some participants—particularly those who had chosen active treatment (surgery, radiation therapy) over active surveillance or watchful waiting—felt that personalized risk information produced by CPMs might have changed their treatment decisions:

> *PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would be based on what my diagnosis numbers were doing the various procedures, I, I probably would have looked at all those—and that may have strongly influenced me to do something other than what I did … in my case I think if I had a predictor like this which showed me the same result with watchful waiting or robot or radiation, I would, I would think real strongly about watchful waiting. [Medium-Risk Participant]*

Even if personalized risk information did not influence patients' actual decisions, furthermore, many valued such information as a means of simply being informed:

> *INTERVIEWER: Imagining that these kinds of tools were available when you were going through decision making, do you think this kind of information would have changed the decisions that you actually made about your own treatment?*
> *MULTIPLE PATIENTS (in unison): No.*
> *INTERVIEWER: Then what good is it?*
> *PATIENT 4: Like D. said, it's just a tool for you to go by, you know.*
> *PATIENT 5: Any information you can get adds to your knowledge of where you're gonna go with your treatment. [Medium-Risk Participants]*

Skepticism about the relative value of personalized risk information. Most participants, however, expressed skepticism about the value of personalized risk information. A primary source was the fundamental uncertainty inherent to all risk estimates. Several participants

specifically mentioned the uncertainty involved in applying probability estimates to the realm of single events experienced by individuals[14]:

> *You know, I don't care how much information you have, or how much the odds are, it can be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you looked at all the stats and it said they were gonna win. That ain't how it turned out! [Medium-Risk Participant]*
>
> *You don't know which percentage you're going to be in. I mean … the five-year number is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very high chance you won't spread, but you could be in the five percent. [Medium-Risk Participant]*

Another source of skepticism related to the reliability of statistical models and risk evidence itself. Several participants raised questions about the "*authenticity*" of CPMs, the qualifications and experience of CPM producers, and ~~that~~ the novel nature of CPMs. They also felt that different researchers and models should be "close to giving you the same type of prediction," and that conflicting estimates would lower their trust in CPMs. These concerns reflected "epistemic uncertainty" or the consciousness of what has been termed "ambiguity"—limitations in the reliability, credibility, or adequacy of risk information.[14]

Participants' uncertainties were manifest in skepticism about the value and influence of personalized risk information in decision making. Participants reported that at the most, they would use CPMs as a "second opinion" or "adjunct" that would augment—but not take precedence over—other types of evidence. As a medium-risk participant stated, "*I would consider the numbers very important, but it wouldn't drive the whole decision process*."

Risk information vs. other types of evidence. More fundamentally, many participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of

several types of evidence—with at least equal legitimacy and weight in the decision-making process:

> *Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]*

> *I think anything that you get anywhere is a guide … Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family. [Medium-Risk Participant]*

~~Participants viewed their own decision making processes as intuitive and based on non-statistical forms of evidence.~~ Emotions were one prominent form of non-statistical evidence that participants utilized in decision making, manifesting use of the "*affect heuristic*" ~~in decision making~~[55,56]:

> *I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]*

For ~~most~~ other participants the recommendations of trusted physicians constituted the primary form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the *"trust-the-doctor"*[57] *heuristic*:

> *… I'm a person who, who really respects and honors education … doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]*

Personal narrative was another form of evidence that ~~took precedence~~participants prioritized over statistical evidence.[58-60] As one participant articulated: "*To me, you know, we can listen to the statistics from the physicians but it's also nice to hear from the patients and maybe even the*

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wives." For some participants the use of narrative evidence appeared to function as a heuristic—a mental shortcut that obviated the need to rely on statistical evidence. Reliance on this "narrative heuristic"—well-described in the literature although not typically characterized as a heuristic—manifested a greater trust in the reported experiences of identifiableable ~~persons~~ individuals ~~than from~~than in statistical information ~~anonymous, population-based statistical information~~:

> *Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience … It doesn't happen in a marketplace. [Medium-Risk Participant]*

> *So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]*

> ~~*Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience … It doesn't happen in a marketplace. [Medium-Risk Participant]*~~

~~***Risk information vs. other types of evidence.*** More fundamentally, most many participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of several types of evidence—all with equal legitimacy and weight in the decision-making process:~~

> ~~*I think anything that you get anywhere is a guide … Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family. [Medium-Risk Participant]*~~

> ~~*Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]*~~

The need for simplicity. ~~Participants~~ Several participants expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty[14] that could obscure the pertinent issues in decision making:

> *It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so boggled with all the information that you lose sight of the forest. [Medium-Risk Participant]*
>
> *But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery … I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]*

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process. ~~As one participant reported, "*I think sometimes you can have too much information.*"~~

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): "… *what's simpler than if you have cancer here, what's simpler than taking it out?*" This cognitive strategy exemplified the use of ~~another simplifying :~~ what could be characterized as a simplifying "~~cancer~~disease heuristic": ~~characterized by~~a conceptual equation of the mere diagnosis of~~cancer diagnosis itself~~ disease with the necessity of active treatment:

> *PATIENT 2: There was no watchful waiting for me …Whether he told me that or not, I just—*
> *INTERVIEWER: There was no option.*
> *PATIENT 2: —no.*

PATIENT 1: I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]

And, and you know, when I got those numbers of, you know, the, the biopsies and what not … I wanted to be done with it … I wanted it gone … Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]

Although t~~This T~~he conceptual equation of disease diagnosis with treatment necessity ~~is a~~has been previously recognized ~~phenomenon~~,[9] ~~this type of categorical thinking~~it has not been ~~previously described~~characterized as a decision-making heuristic. However, our data suggests that it have a heuristic function—obviating patients' need and desire to attend to outcome probabilities and~~suggests that such thinking has the heuristic function of "cancer heuristic" not only~~ le~~d~~ading many patients to perceive no real choice options~~, but diminisheding their interest in personalized risk information~~:

I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]

PATIENT 1: I had to obviously make a decision, but it was very, for me it was such an easy decision.
PATIENT 3: Yeah.
PATIENT 2: A no-brainer.
PATIENT 1: That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or … I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]

Discussion

Our study provides ~~new~~ preliminary insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information at least some patients currently receive is typically imprecise

rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-based), diagnostic rather than prognostic. To our knowledge, the current study provides the first empirical documentation of these phenomena in prostate cancer care; however, they are not unique to this disease. Indirect risk communication through biomarker values, for example, occurs in the treatment of common conditions such as hypercholesterolemia and hypertension,[9] and heuristics are employed in numerous types of decisions.[61,62] What the current study newly brings to light, however, is the critical role of patient values in reinforcing these processes. Although many prostate cancer patients in our study clearly perceived personalized risk information as valuable, ~~most~~ they viewed other types of evidence as relatively more influential and expressed preferences for intuitive, heuristic-based rather than deliberative, risk-based approaches to decision making.

These findings should be interpreted cautiously, however, given several study limitations. The sample was relatively small, geographically limited, and homogeneous in race and ethnicity~~,~~. ~~m~~Many participants had already made treatment decisions, and their negative attitudes towards personalized risk information may thus have been biased by a motivation to avoid regret or dissonance over not having used such information. Participants' negative attitudes could also have been influenced by the particular ways in which the information was represented by the websites shown in the interviews. It is conceivable that~~although not a focus of the interviews,~~ alternative representational methods—e.g., using visualizations or other patient-centered risk communication strategies aimed at improving comprehension—may have encouraged more favorable attitudes. This possibility remains to be explored and is an important focus for future research. Finally, t~~T~~he study assessed patient perceptions rather than behaviors~~,~~ and used

qualitative methods, a powerful approach for ascertaining the nature and breadth—but not the prevalence, causes, and effects—of people's beliefs and attitudes. Further ~~research~~ quantitative studies using larger, racially and ethnically diverse samples ~~and quantitative methods is~~are thus needed to confirm our preliminary findings. Nevertheless, the validity of ~~our~~ these findings is supported by their consistency with mounting evidence that precise, quantitative risk information is not always what patients need or want.[30,31] Our findings ~~extend this evidence and~~ have important implications for potential users of CPMs because they identify patient perceptions of the value of personalized risk information as a~~n important~~ barrier to the use of CPMs, and suggest potential modifiable reasons for these perceptions.

The most straightforward reason is lack of exposure to personalized risk information; most study participants reported having never received such information, and its value was thus simply beyond their imagination. This problem might be addressed by exposing patients to what they've been missing; as Steve Jobs famously quipped, "People don't know what they want until you show it to them."[63] Yet our study suggests that even if patients were provided with personalized risk information, they may not always want it. Study participants expressed an overarching desire for simplicity in information and decision-making approach, manifested in preferences for heuristic- rather than risk-based decision making. This desire for simplicity is common,[30,64-66] and reflects fundamental limitations in human cognitive capacities (e.g., memory, literacy, numeracy) and available environmental resources (e.g., time, decision support)[32,67,68] that constrain people's ability to engage in effortful deliberation in decision making, and instead promote intuitive, heuristic-based decision making based on factors other than "estimations of probabilities, gains, costs, and the like."[61] Intuitive and deliberative

decision-making approaches each have advantages and disadvantages;[69] however, if the goal is to increase the perceived value and clinical use of personalized risk information, then the limitations that reduce people's capacity for deliberation must somehow be overcome.

Another factor limiting the perceived value and use of personalized risk information among study participants was a perception that such information is less reliable than non-quantitative evidence. This perception raises a need that has not been addressed in efforts to apply risk information to patient care: to increase patients' *epistemological understanding*—i.e., their comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence at hand. Our study illustrates the two-fold challenge patients face in using personalized risk information: they must weigh not only the magnitude of competing probabilities but the value of competing types of evidence, each with their own strengths and weaknesses. Personalized risk information represents the strongest form of evidence from the expert perspective; nevertheless, its clinical value is diminished by uncertainties arising from methodological problems in risk modeling[70,71] and the limited applicability of risk estimates to single events experienced by individuals.[72] On the other hand, non-quantitative forms of evidence (e.g., "gut feelings,"[73] physician recommendations, personal anecdotes) provide a means of mitigating irreducible uncertainties of risk estimates and are thus valuable from the lay perspective; however, such evidence is susceptible to numerous biases. Exactly how patients should weight these different types of evidence is a critical question for future research, but at the very least this task requires an understanding of their strengths and weaknesses. The lack of such understanding among study participants suggests that epistemological education should be a primary focus of efforts to apply personalized risk information to patient care.

Our study thus identifies several ~~requisite~~ potentially important tasks for enhancing the value and use of personalized risk information: 1) increasing patients' exposure to personalized risk information, 2) providing resources to support deliberative decision making, and 3) providing epistemological education on the nature of medical knowledge and evidence. The first task has been a primary focus of CPM proponents; however, more work is needed to effectively disseminate and implement CPMs in clinical practice. The second task has only begun to be addressed, but promising approaches include the delivery of personalized risk information through patient-centered decision support interventions (DeSIs) such as decision aids,[74,75] and the use of risk communication strategies such as visual representations to improve the evaluability of risk estimates.[30,31,76-83] A more challenging task is to provide the environmental resources—e.g., clinical time, processes, and incentives—needed for deliberative and collaborative decision making.[74] The final task, the provision of epistemological education, is a new frontier that has yet to be explored but calls for efforts to expand the content of risk information communicated to patients—whether through DeSIs or larger-scale educational efforts delivered through other channels. It remains for further research to address these challenges, and to determine how best to help patients translate personalized risk information into better informed health care decisions.

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All authors had full access to all of the data (including statistical reports and tables) in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The study was approved by the Maine Medical Center Institutional Review Board (IRB#3805X), and granted a waiver of informed consent.

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) PH, MN, BR, NH, TK, CG, MD, and MH have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (2) spouses, partners, or children of PH, MN, BR, NH, TK, CG, MD, and MH have no financial relationships that may be relevant to the submitted work; and (3) PH, MN, BR, NH, TK, CG, MD, and MH have no non-financial interests that may be relevant to the submitted work.

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Contributorship Statement

PH designed the study, obtained funding, conducted interviews and data analysis, drafted the manuscript, and edited the manuscript for important content.

MN, BR, and NH conducted data analysis and edited the manuscript for important content.

TK assisted in the design of the study, conducted interviews, and edited the manuscript for important content.

CG edited the manuscript for important content.

MD edited the manuscript for important content.

MH assisted in the design of the study and edited the manuscript for important content.

Data sharing statement

Data sharing: no additional data available; consent for data sharing was not obtained from study participants.

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Table 1. **Focus group categories**

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6, Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, StageT3-T4,PSA >20)

Table 2. Characteristics of focus group participants

	N	%
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

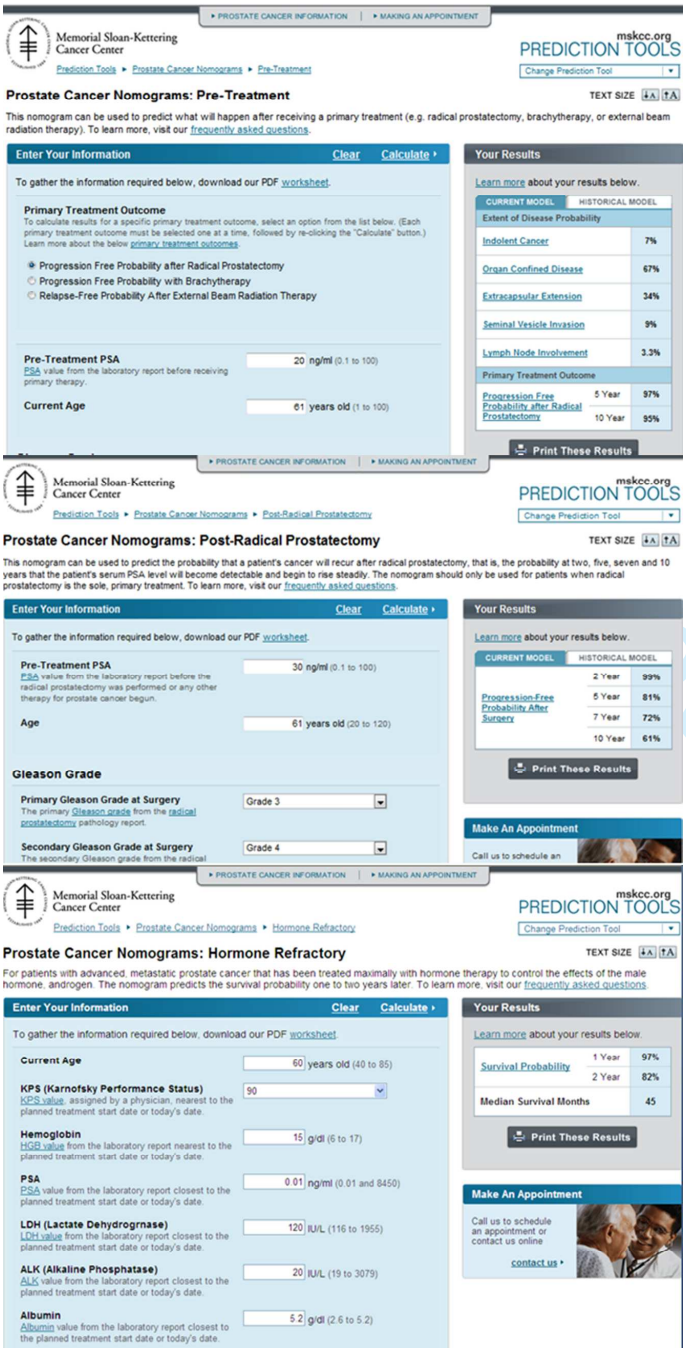
I was told that with the Gleason score of 9 that that's frightening … That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

INTERVIEWER: And what was your understanding of what the Gleason score meant? PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]

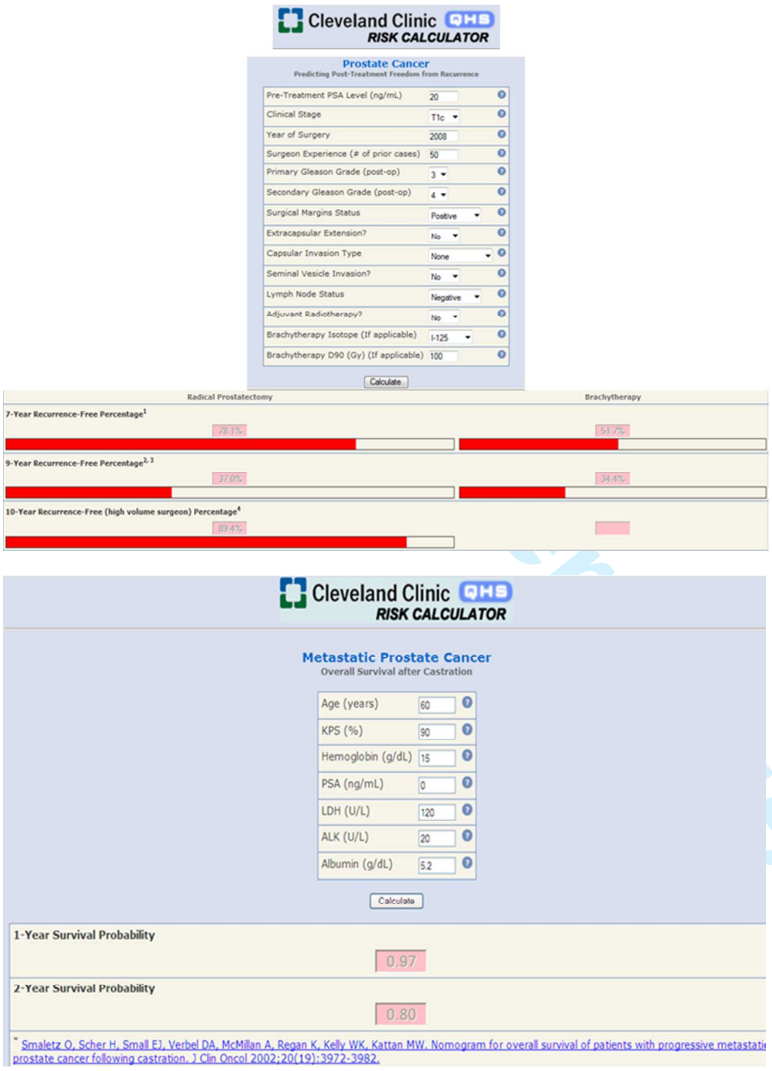
… he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

Appendix A. Clinical prediction model screenshots used as interview aids



30



Appendix B. Theme outline – Focus group study

A. PAST EXPERIENCES WITH RISK COMMUNICATION

1. Extent of communication
    a. No risk communication
    b. Detailed communication of individualized, quantitative risk information
    c. Non-individualized quantitative risk communication
    d. Imprecise quantitative risk communication
    e. Categorical risk communication: qualitative categories
    f. Indirect risk communication: biomarker heuristic
2. Sources of risk information
    a. Doctor: urologist, radiation oncologist, PCP, other
    b. Other health professionals: nurse navigators, etc.
    c. Friends, family
    d. Internet, books

B. PERCEIVED VALUE OF PERSONALIZED RISK INFORMATION

1. Promote SDM
2. Provide insight into physician thinking
3. Provide second opinion / counter physician bias
4. Confirmatory
5. Facilitate advance care planning
6. Justify decisions

C. PERCEIVED CHALLENGES IN USE OF PERSONALIZED RISK INFORMATION

1. Lack of self-efficacy in understanding risk information
2. Logistic barriers: lack of time
3. Physician bias/self-interest
4. Preference for simplicity
5. Low perceived need for information
    a. Low preference for information and participation in decision making
    b. Trust the doctor heuristic
    c. Cancer heuristic (removal heuristic: "cut it out"): perceived lack of decision
    d. Reliance on intuitive vs. rational decision-making approaches
6. Distrust of statistical information: "anti-statistics" viewpoint
    a. Preference for anecdotal/narrative vs. statistical information: "unreality" of numbers vs. narrative information
    b. Questionable relevance to individual: reference class problem
    c. Uncertainty: epistemic (ambiguity)
        i. Imprecision
        ii. Conflicting data
        iii. Missing data, multiple/unknown/unaccounted risks
        iv. Source credibility

d. Uncertainty: aleatory (randomness)

7. Motivated reasoning: desire for good news/fear of bad news

D. VALUE OF INDIRECT RISK COMMUNICATION (BIOMARKER HEURISTIC)

1. Provide sense of control
2. Communicate the bottom-line/gist
3. Represent "hard information"
4. Facilitate decision resolution
5. Simplify decision making

E. INTERPRETATION OF PERSONALIZED RISK ESTIMATES

1. Understanding of risk estimate: frequency or confidence statement
2. Perceived difficulty

F. COMMUNICATION OF UNCERTAINTY (AMBIGUITY)

1. Preferences for/against
2. Reactions to use of range/confidence interval

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