Men's Theories About Benign Prostatic Hyperplasia and Prostate Cancer Following a Benign Prostatic Hyperplasia Decision Aid

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OBJECTIVE: To use qualitative methods to explore audiotape evidence of unanticipated confusion between benign prostatic hyperplasia (BPH) and prostate cancer in using a videotape BPH treatment decision aid (DA).

DESIGN: Qualitative analysis of semi-structured interviews and surveys originally collected to study men's interpretation of a DA.

SETTING AND PARTICIPANTS: Community sample of college and noncollege educated African American and white men (age ≥ 50 ; $n=188$).

MEASURES: Transcript analysis identified themes in men's comments about BPH and cancer. Surveys measured BPH general and prostate cancer-specific knowledge, literacy (Short Test of Functional Health Literacy in Adults), BPH symptoms, and demographics.

RESULTS: In transcript analysis, 18/188 men spontaneously talked about BPH and cancer as being related to each other, despite explicit statements to the contrary in the video. Survey data suggest that up to 126/188 men (67%) persisted in misconceptions even after viewing the DA video. Three themes were identified in the transcripts: (1) BPH and cancer are equated, (2) BPH surgery is for the purpose of removing cancer, and (3) BPH leads to cancer.

CONCLUSIONS: Overall knowledge increases with DA use may mask incorrect theories of disease process. Further research should identify decision support designs and clinical counseling strategies to address persistence of beliefs contrary to new information presented in evidence-based DAs.

KEY WORDS: decision aids; benign prostatic hyperplasia; prostate cancer; shared decision making.

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Shared decision making between health care providers and patients has become widely advocated over the last decade, particularly for medical problems where the benefit/risk ratio of treatment is uncertain, and patient values should influence choice.^{1,2} Patient decision aids (DAs), in multimedia and print formats, aim to inform patients about treatment alternatives. A Cochrane review showed beneficial effects of DAs on patient knowledge, and increases in realistic perceptions of

probabilities of benefits/harms.³⁻⁵ Central concerns in supporting informed shared decision making include providing accurate, balanced, complete, and accessible information and considering patients' personal values. However, this paradigm assumes a priori that patients uniformly accept information in DAs. Little in-depth study has investigated users' interpretations of the information presented in DAs, particularly among educationally and racially diverse audiences.

As part of a study of men's use and interpretation of information presented in a video DA for benign prostatic hyperplasia (BPH) treatment decision making, we performed semi-structured interviews using a "think aloud" technique.⁶ During the study, a critical incident suggested the need to analyze interview transcripts to understand an unanticipated association being made between the subject of the DA, BPH, and prostate cancer. The incident was the observation that a participant made inferences about the relationship between BPH and prostate cancer that were contrary to information presented in the video:

Interviewer: "Can you tell me why you would pick surgery?"

Participant: "Because I would not want any of the infection to come back into my body. And if they can remove the whole thing and say that you are free of the disease, I would feel total like that."

Later, the participant talked explicitly about cancer in relationship to information on surgically treating BPH. "So he can burn off some of the tissues. But he is not really saying that he is eliminating the prostate cancer. He is just getting some [it] out of there, right?" At the end of the interview, the interviewer dictated "interviewer comments" after the participant had left. An excerpt follows:

The interviewee's responses, I think, were very genuine . . . I do believe, however, that he was confused by much of the quantitative data . . . That was also clear in response to the presentation of the graphs . . . He clearly was confused most of the video between prostate cancer and BPH, even after I tried to distinguish the two for him.

This critical incident led us to systematically analyze the interview data to investigate the nature of patient associations between BPH and prostate cancer and the impact on interpreting the medical information presented in the DA.

METHODS

The overall objective of the Health Information for Patient Decision-Making project study was to examine how a racially and educationally diverse sample of men interprets and uses information in reaching informed decisions about BPH treat-

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ment. We used a previously developed and tested educational DA videotape to provide treatment information.⁷ A 2 (education level) $\times$ 2 (race) stratified sampling design was used to insure adequate participation of African-American men and men without a college education. Men with a history of prostate cancer were excluded. Men were recruited via community organizations, including retirement clubs, churches, homeless shelters, primary care clinics, barber shops, and union halls. The Michigan State University institutional review board for human research subjects reviewed and approved all study materials and procedures. Interviewers obtained verbal and written consent for participation before data collection. Subjects were paid \$25 after completing the interview.

We stratified by race because race has been shown in the screening literature to affect health care utilization.^{8–11} Differences in risk perceptions and levels of psychologic distress associated with screening have been attributed to African-American values on interpersonal relationships, spirituality, and time orientation.¹²

Procedure

The study protocol was divided into 3 parts: (1) survey, (2) semi-structured interview while watching the video, and (3) postvideo debriefing. During part 2, men viewed the shared decision-making-BPH program (SDP-BPH) videotape, and were asked to “think aloud” about treatment decision making after defined segments for a semi-structured interview. Interviewers were matched with study participants by race and age ≥ 50 . Ten male interviewers conducted 15 to 20 interviews a piece, each lasting between 2 and 3 hours. The interviews were tape-recorded, transcribed, and coded using QSR N5 qualitative analysis software.¹³ Survey analyses were performed using SPSS, version 11.¹⁴

Stimulus Material

The 47 minute SDP-BPH was developed by the Foundation for Informed Medical Decision-Making/Health Dialog. Surveys have shown the program to be highly valued by patients and balanced in presenting the risks and benefits of treatment options.^{7,15,16} A prior randomized clinical trial and a large pre-post study found the SDP-BPH acceptable to both patients and family physicians.^{17,18}

We used the verbatim script of the videotape to identify the language used to describe the relationship of BPH to cancer. Cancer is discussed in 2 places in the 43-page video script: (1) in the concluding remark of the introduction (p. 4), and (2) in the description of surgery (p. 22). The text of each passage follows.

Remember: the “B” in BPH stands for *benign* which means that BPH is *not* cancer. BPH can be annoying, but it is not a life-threatening condition. . . .

Throughout the tape, the benefits of treatment were always stated in terms of symptom relief. The cancer discussion in the surgery passage stated:

First, some men who are concerned about prostate cancer assume that surgically removing the prostate will prevent them from ever getting prostate cancer. However, in the prostate surgeries used most often for BPH, *not all* the prostate is removed, so the possibility of cancer remains. If you choose surgery for BPH, do it to reduce problems urinating, *not* to prevent cancer.

The source of all cancer information in the video was voice narration, sometimes reinforced with added text. The video patient testimonials did not mention cancer.

Interview Transcript Coding and Analyses

The issue of potential misinterpretation of information because of associating BPH and cancer had not occurred to us at the outset, and was not systematically assessed as part of the study design. To investigate the nature and extent of this association in the transcripts, the 2 principal coders (K.K.B., J.L.) used N5 software to code evidence of this association in the set of 188 transcripts of semi-structured interviews and interviewer debriefing notes. To check for errors of omission, coders performed a text search in N5 for the word “cancer.” These text passages were analyzed by the principal data analyst (C.P.) for preliminary characterization of themes. Draft thematic analysis was submitted to all authors and a consensus process was used to characterize the themes. Independent coding of text passages into the themes was performed by 2 authors (C.P., M.H.R.), with 100% agreement. The unit of analysis was the person. Coders noted where an individual expressed 2 different counterfactual ideas, but assigned a predominant category to represent the person.

Survey Measures and Analysis

Symptom level was assessed by the American Urologic Association BPH symptom scale, a 35-point scale where 0 to 7=mild, 8 to 19=moderate, 20 to 35=severe.¹⁹ Symptom bother, previously shown to predict treatment decision making, was assessed on a scale ranging from 0 to 12, modified from Barry et al.¹ To document interaction with providers about prostate health, participants were asked if they had ever been diagnosed with a prostate problem. Functional health literacy was measured by the standardized Short Test of Functional Health Literacy in Adults (S-TOFHLA).^{20,21} College educated was defined as having completed at least 1 year of a 4-year college education. Trade school was considered equivalent to a high school education. A 20-item BPH knowledge scale, administered before and after video viewing, was specific to the DA. The knowledge scale, developed by the authors of the DA, assessed knowledge of treatment side effects, cancer relationship to BPH, and some aspects of physiology (F.J. Fowler, PhD, Prostate cancer knowledge test—20 items, 12-4-2000, personal written communication). A 3-item cancer-specific subscale was identified for this analysis. It includes only cancer-specific items, whose answers were given in the video (see online Appendix).

RESULTS

Recruitment of equal groups by race (white=53%) and education (no college=43%) was largely successful ($n=188$). Twenty men linked BPH and cancer together in their comments. Two of these discussed the 2 conditions in the context of new information gained by watching the video. For example, one said, “I really thought some of the symptoms would have indicated that you did have prostate cancer. But then I seen that it wasn’t true.” Eighteen men remained in a sample of men who incorrectly associated BPH and cancer. The characteristics of this subsample (whom we call the persistent sub-

Table 1. Health and Literacy Characteristics[†]

Demographic and Literacy Characteristics	Mean (SD)	
	Original Sample Minus Persistent (n=170)	Persistent Group (n=18)
Age (y)	61.5 (7.7)	60.6 (7.4)
African American (%)	47	44
College educated (%)	58	44
Income	\$33,909 (\$24,811)	\$30,278 (\$21,572)
Blue collar occupation (%)*	42	33
Health insurance (any type) (%)	92	94
S-TOFHLA no. correct	31.7 (5.4)	30.1 (7.4)
Health status		
Diagnosed prostate problem (%)	22	0 [‡]
AUA symptom total	8.0 (5.9)	6.3 (4.4)
Symptom bother total	1.6 (2.2)	1.1 (1.3)

*Blue collar occupations included: service workers, unskilled labor, laborer. White collar included skilled labor, professional, health professional, administrator.

[†]Results are expressed as mean (SD) except where noted.

[‡]Difference in values significant $P = .03$.

S-TOFHLA, Short Test of Functional Health Literacy in Adults.

sample), and the full sample (minus the 18) are described in Table 1.

Thematic analysis identified 3 categories of statements indicating association of BPH and cancer: (1) equates BPH with cancer, (2) talks about BPH surgery as treating cancer, and (3) suggests that BPH leads to cancer. One participant who discussed cancer in the context of BPH surgery also indicated that surgery prevents cancer. "My percentage for . . . not getting cancer would be better if I had the surgery." However, his predominant discussion was about the purpose of surgery being to treat cancer. Several men mentioned that the media and experiences of friends or relatives with cancer contributed to their concerns about BPH. Several mentioned that they had

relatives who had died or suffered from prostate cancer. Table 2 shows the frequency of themes among the 18 participants making spontaneous comments about cancer associations with BPH.

As the men who explicitly discussed BPH and cancer did so spontaneously, we explored the presence of similar understandings in the whole sample by means of the cancer-specific items in the BPH knowledge survey. Among all the knowledge items, 2 of the 3 cancer-specific knowledge items were the most frequently missed questions on the knowledge test following the video. To explore the impact of the video on preexisting beliefs, we analyzed each of the items by rates of concordant and discordant pairs of responses to each of the 3 items before and after the video. Table 3 shows that before viewing the videotape, two thirds of the sample thought that men with BPH have a higher risk of cancer. This is consistent with the idea that BPH leads to cancer.

Mean overall knowledge scores increased by 25%, from 6.1 to 10.4. The noncancer items included BPH treatment, side effects, and physiologic information.⁶

DISCUSSION

The survey and qualitative data, taken together, suggest that a substantial proportion of the men (67%) came to the DA believing that BPH and cancer were associated and continued to believe so even after reviewing the videotape. Among the spontaneous comments about associations between BPH and cancer, most showed a general lumping of BPH with cancer, or an assumption that the purpose of BPH surgery was to remove cancer. These misperceptions may have influenced their interpretation of the DA and their thinking about treatment decisions. For some, it appeared that new information in the video was incorporated into conceptual schemas based on the idea that any abnormal cells would lead to cancer. BPH, in this interpretive framework, was the beginning of cancer, in spite of statements by the narrator of the video explicitly to the contrary. Men may have heard the information in the videotape

Table 2. Thematic Analysis Results

Theme	N (%)	Examples
Equates prostate cancer with BPH	10 (56)	"This benign prostatic hyperplasia, I never heard them say it's not cancer. It is cancer." " . . . to control the system of prostate cancer . . . if it's any infection the medicine can cure it before you go to surgery." "I wish they would have went in to more of the procedures, like the freezing and the radiation pellets that they put in . . ." " . . . infection for cancer in the penis." " . . . PSA or some other kind of index of prostate health . . . the rectal exam thing . . . I suspect that it is related."
Surgery is to remove cancer	4 (22)	"I feel that it gives me more insight as to prostate cancer and treatments, side effects." "If it wasn't cancerous, then I wouldn't choose surgery." "I choose it over death. It would be better to have it to rid oneself of it, of cancer if it is a cancerous tumor." "So when I said they took it out then you wouldn't be able to get cancer. So now they say that they don't take it all." "One of the first things we begun thinking about is cancer . . . try the medication . . . once the surgery, it's not gonna get any better no matter what."
BPH leads to cancer	4 (22)	"if you don't do anything to it, you could get cancer." "I have learned if you don't treat . . . there is a better possibility of cancer starting in the prostate." " . . . even though the term is benign hyperplasia . . . nonetheless the real concern underlying this is the big C, that's cancer . . . maybe it's going to happen here later on." "Some people like myself didn't know nothing about it . . . Just that it leads to cancer or something."

BPH, benign prostatic hyperplasia.

Table 3. Cancer-Specific Survey Questions: Incorrect Answers Before and After Video

Survey Question: Concordant/Discordant Pairs	N (%)
<i>Q: Men with BPH have higher risk of prostate Cancer</i>	
Incorrect before and incorrect after video	126 (67)
Incorrect before and correct after video	53 (28)
Correct before and incorrect after video	9 (05)
Correct before and correct after video	0
<i>Q: Incidental cancers found on surgery for BPH do not usually lead to death</i>	
Incorrect before and incorrect after video	27 (14)
Incorrect before and correct after video	124 (66)
Correct before and incorrect after video	2 (01)
Correct before and correct after video	35 (19)
<i>Q: BPH surgery (TURP) lowers the risk of future cancer</i>	
Incorrect before and incorrect after video	66 (36)
Incorrect before and correct after video	87 (46)
Correct before and incorrect after video	5 (03)
Correct before and correct after video	28 (15)

BPH, benign prostatic hyperplasia.

about BPH not being precancerous, but not believed it. Alternatively, they may have forgotten or been unable to absorb the information because it was hard to incorporate into their schemas.

As discussed previously, the DA was modestly successful, overall, at improving knowledge, and in conveying that the purpose of treating BPH was symptom relief, not cancer prevention.¹¹ Neither level of education nor race was associated with the increase in general or cancer-specific knowledge gain. The effect of prior beliefs, and public awareness of prostate cancer may influence what men hear, even in a lengthy video. For instance, 64% of men still believed, postvideo, that BPH increases the risk of prostate cancer.

Interestingly, significantly fewer men with a prior prostate diagnosis were in the persistent subsample. Quite possibly, men who previously saw their physicians for prostate problems gained knowledge effectively in those discussions. For men just learning about BPH, many may resist messages that counter their personal theories of causation. This is consistent with previous findings that the perceived personal risk for getting cancer is widely exaggerated.²²⁻²⁴ High levels of patient satisfaction with DAs and enthusiasm for shared decision making should not mask the potential for such resistance to and/or misinterpretation of information presented.

Of note, subjects had more time for viewing and reviewing information in this study than would be possible in most clinical settings. This worked in favor of our participants' absorbing the information presented. Under normal use of the DA in practice, the rates of misunderstanding may be higher, particularly as the presence of a pretest may have cued men that they would be tested again. The video was designed to explain BPH and describe treatment choices. For some, it appeared that strongly held beliefs about a natural progression of disease from any abnormal cell to cancer might be resistant to change through information alone. Persistent misconception is common in contemporary scientific teaching. A growing field of discipline-based science research is assessing student scientific misconceptions in order to develop formative diagnostic assessment tools to identify and address them directly.^{25,26} Further research should explore ways to address common dis-

ease-specific and general etiologic misconceptions, and develop ways to address them successfully.

While the high increase in overall knowledge was consistent with previous findings in DA research,⁴⁻⁶ our results suggest that clinicians should not assume that patients accept or remember everything they hear or read in a DA. Clinicians who use DAs should check patient understanding and interpretation of information before discussing treatment or screening preferences. For using this particular DA, the potential need for clarification is probably best pursued by alert clinicians at the very outset of the treatment discussion. It may be important to review what the patient thinks can be accomplished by treatment. It should be assessed with an explicit question about the patient's understanding of how treatment might affect the chance of getting prostate cancer. The implication for DA design, in general, is to pay attention in the design process to known areas of potential misconceptions. Raising the sensitivity of DA designers to this area may increase the extent to which DAs can address patients' concerns as well as providing the evidence necessary to make an informed decision.

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Supplementary Material

The following supplementary material is available for this article online at www.blackwell-synergy.com:

Appendix. Knowledge survey: cancer subscale.

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