Published in final edited form as:
Patient Educ Couns. 2018 October ; 101(10): 1741–1747. doi:10.1016/j.pec.2018.04.012.

The Complicated ‘Yes’: Decision -Making Processes and Receptivity to Lung Cancer Screening Among Head and Neck Cancer Survivors

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Abstract

Objective—Shared decision making (SDM) is recommended when offering lung cancer screening (LCS)—which presents challenges with tobacco-related cancer survivors because they were excluded from clinical trials. Our objective was to characterize head-and-neck cancer (HNC) survivors’ knowledge, attitudes, and beliefs toward LCS and SDM.

Methods—Between November 2017 and June 2018, we conducted semi-structured qualitative interviews with 19 HNC survivors, focusing on patients’ cancer and smoking history, receptivity to and perceptions of LCS, and decision-making preferences.

Results—Participants were receptive to LCS, referencing their successful HNC outcomes. They perceived that LCS might reduce uncertainty and emphasized the potential benefits of early diagnosis. Some expressed concern over costs or overdiagnosis, but most minimized potential

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Declarations of Interest: None

Personal Information of Patients: We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

harms, including false positives and radiation exposure. Participants preferred in-person LCS discussions, often ideally with their cancer specialist.

Conclusion and Practice Implications—HNC survivors may have overly optimistic expectations for LCS, and clinicians need to account for this in SDM discussions. Supporting these patients in making informed decisions will be challenging because we lack clinical data on the potential benefits and harms of LCS for cancer survivors. While some patients prefer discussing LCS with their cancer specialists, the ability of specialists to support high-quality decision making is uncertain.

Keywords

Head and neck neoplasms; Lung neoplasms; Early detection of cancer; Decision making; shared; Health knowledge; attitudes; practices; Qualitative research

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1. Introduction

Lung cancer is the leading cause of cancer-related deaths in the United States [1]. While 5-year survival is 65% for early-stage lung cancers, most lung cancers are diagnosed at advanced stage when survival is 16% [2]. The National Lung Screening Trial (NLST) found that lung cancer screening (LCS) with low-dose CT scans (LDCT) reduced lung cancer mortality by 20% compared to screening with chest radiographs [3]. Based in large part on the NLST results, in 2013 the US Preventive Services Task Force (USPSTF) issued a Grade B recommendation supporting LDCT screening of high-risk patients, including adults ages 55 to 80 years, with at least a 30-pack-year smoking history, who currently smoke or have quit within 15 years [4].

The National Comprehensive Cancer Network (NCCN) broadened eligibility criteria to include additional risk factors, including a history of head and neck cancer (HNC) [5]. The NCCN recommended considering screening these survivors beginning at age 50 if they had at least a 20-pack-year smoking history. Additionally, the Centers for Medicare & Medicaid Services (CMS) issued a national coverage determination for reimbursement, requiring clinicians to engage patients in shared decision making using a decision aid [6]. Survivorship guidelines from the American Cancer Society recommended that LCS discussions take place in the primary care setting [7].

However, there are multiple challenges to considering LCS discussions for HNC survivors. Little evidence exists that primary care providers can effectively hold LCS discussions with eligible patients without a cancer history [8], let alone among cancer survivors. Data suggest that primary care providers have limited awareness of lung cancer screening clinical trial results or professional society guidelines [9–14]. In the past, studies have shown that primary care providers often fail to present balanced information regarding cancer-screening decisions for breast, colorectal, and prostate cancer. While decision aids can greatly facilitate these discussions, the available decision aids present NLST data, which may not be applicable to HNC survivors because cancer survivors were not eligible for the study [15]. Epidemiologic data suggest that early stage lung cancer has a greater mortality impact on

HNC survivors than individuals with no prior cancer history, which might limit the mortality benefit of lung cancer screening for HNC survivors [16].

These issues call into question both how to conceptualize the overall benefits and risks of LCS for HNC survivors, and how and where to discuss LCS. Despite increased research into patient perceptions of LCS [10,17–21], little is known about cancer survivors' perceptions. We conducted a qualitative study to examine the knowledge, attitudes, and decision-making preferences about LCS among HNC survivors.

2. Methods

2.1 Subjects and Settings

We recruited participants through the Otolaryngology Clinic at The University of Iowa Hospitals and Clinics (UIHC), an academic tertiary facility. Eligibility criteria included 1) diagnosis of HNC, including oral cavity, oropharyngeal, or laryngeal cancers, 2) being free of any known persistent or recurrent upper aerodigestive tract cancer at least one year after completion of cancer-directed therapy, and 3) having at least a 20-pack-year smoking history. Once identified as eligible by treating clinicians through chart review, patients were approached during routine clinic appointments by the PI (NP) or research assistant (NK). Patients agreeing to participate were consented by the research assistant, using written informed consent, and interviewed by qualitative team members (KD, AS).

Between November 2016 and June 2017, we conducted interviews with 19 participants, of whom four were women and all identified as white, non-Hispanic. Most participants (n=18) met the NCCN's age eligibility criteria (50 to 74-years-old), and all reporting having completed their treatment at least one year prior to interview (years since treatment ranged from 1 to 21). We stopped recruitment once we reached consensus that we had achieved thematic saturation with our population of head and neck cancer survivors. The study was approved by the University of Iowa Institutional Review Board.

2.2 Data collection

We conducted one-on-one, in-depth interviews to elicit participants' unique experiences and perspectives. A semi-structured format allowed interviewers to focus on key domains while inviting participants to express what they felt was critical. The interview guide focused on five domains: 1) cancer history, 2) smoking and cessation history, 3) beliefs about and receptivity to screening, 4) perceived risks, benefits, and challenges of LCS, and 5) preferences about LCS decision making. Immediately after interviews concluded, we administered a questionnaire to obtain demographic data and smoking history. The interview process lasted between one and two hours, and all participants received a $75 gift card and a parking voucher.

2.3 Data Analysis

Through a content-driven, iterative analysis, we explored patients' understanding of LCS and their receptivity to screening given their previous experience with cancer. Interview transcripts were imported into MAXQDA 11 (VERBI GmbH), a qualitative data management software program. Qualitative team members (KD, AS, MVB) first reviewed a subset of transcripts to develop a codebook using *a priori* deductive codes, generated by the project's specific aims and research questions, and inductive codes that emerged during analysis. Team members iteratively adapted the codebook as analysis progressed. All qualitative team members reviewed interview transcripts independently, and then jointly coded for consensus on themes, or analytic categories. Differences were resolved by team consensus. Emergent findings were presented regularly to the study team, who also helped review individual transcripts, modify the codebook, and interpret findings. The primary results discussed in this article and representative quotations are presented in Table 1.

3. Results

3.1 Participant Characteristics

All 19 participants had been treated for HNC with surgical resection, radiation, and/or chemotherapy. Three patients were current smokers, and 16 reported having quit. Of the former smokers, three had quit longer than 15 years before, and six reported quitting as a result of their diagnosis. Table 2 presents sociodemographic information and smoking histories.

3.2 Knowledge of Screening and LCS

Many participants reported currently engaging in some screening, notably for prostate, colorectal, and/or breast cancer. However, most participants reported being unaware of LDCT screening. The few who were aware had received the information from their HNC specialist.

Overall, participants lacked a general understanding of screening's purpose as distinguished from other testing. When asked about screening tests, many offered examples of diagnostic testing recommended due to symptoms. Specifically discussing LCS, participants talked in terms of finding a cancer, rather than negative or suspicious findings despite the substantially higher prevalence of the latter. Most participants did not discuss distinguishing between surveillance monitoring for HNC metastases to the lungs and screening tests for a second primary lung cancer.

3.3 Receptivity to LCS and Decision-Making Considerations for HNC Survivors

Participants were overwhelmingly receptive to screening and specifically to LCS with LDCT. They had few concerns about LCS and the possible harms of screening, focusing on the potential for early detection and treatment. One person, when asked whether anything would dissuade him from screening, said: "[N]ot unless it involved acid and branding irons or something like that. No. … I wouldn't hesitate to do it" (P7). Even participants expressing ambivalence said they would screen if their provider recommended it. Most recognized their increased lung cancer risk, and felt LCS was appropriate for them. Participants' receptivity to LCS and assessment of screenings' potential benefits and harms did not differ by whether they were currently smoking, though we interviewed only 3 current smokers.

Many participants drew upon their cancer experiences. One, when asked whether his HNC experience changed his feelings about screening, said he would be "more likely" to be screened after "the cancer that I had, what I've been through, I've seen other people going through. I've seen one of my roommates die…. It probably changed my outlook on it. I mean, I'd definitely need [to] be screened" (P11). Participants talked not only about their own HNC but also about others' cancer experiences.

When asked about helpful information for making a decision, participants discussed wanting to know about the screening test itself and the possible benefits and harms. While overall participants were not concerned about the procedure, citing a comfort that came from experience, some wanted to know what might happen in the event of a suspicious finding, "how we would decide if we see something…, what we should progress on, if we should, or if we should leave it alone" (P6).

Two benefits of LCS were noted: the possibility of early detection and the reduction of uncertainty. Most participants saw early detection as screening's primary benefit, stressing that it "gives you a fighting chance" (P1) to intervene and treat. Several discussed that the knowledge gained through screening would reduce their anxiety, either through the relief of a negative result or the opportunity to act upon a finding. As participants discussed how LCS would help to temper uncertainty about their health, they described a testing procedure that would produce clear results. Participant 12 said: "The screen is the opportunity to say, 'Hey, everything's good' or if there is a problem to catch it early. …And it's either you got nothing, or you got something we gotta deal with."

Participants also wanted to know the potential harms associated with LDCT screening and possible logistical challenges in having the test done. Many spoke generally of the "risks" or "pros and cons." Interviewers inquired specifically about false positives, overdiagnosis, and overtreatment, describing each in lay language—e.g., a false positive as when "the test may show something that looks suspicious, but ends up not being cancer", overdiagnosis as when "the test may reveal a cancer that otherwise would not have been found but that also would not necessarily have developed and caused you harm," and overtreatment as "possibly treating something that didn't need to be treated." When asked, most people recognized these as concerns, but not enough to deter them from screening. One participant (P15), bringing up false positives on his own, said, "It's a good idea, but it's qualified. …[T]he problem is the number of false positives. …[T]he discomfort of the biopsy, the number of false positives, where do we recommend, I don't know, I guess I think overall it's probably pretty good." While people noted radiation exposure, those who had undergone treatment radiation especially felt it was trivial compared to what they had already received. With few exceptions, participants who noted logistical concerns, including cost, insurance coverage, availability, and travel, did so in response to interviewers' questions and discussed them in terms of what other patients might encounter.

Considering possible harms and challenges, participants were influenced by their own diagnostic and treatment experiences. One person (P16) discussed overtreatment because he felt that his radiation treatment had been unnecessary, leading to protracted jaw problems. Another (P17) worried about the cost of screening and potential follow-up and treatment because his HNC treatment had been so financially burdensome: “I think [screening is] a good idea. Yes, I need this. Yes, I should do this. Whether I do it or not, honestly, I don’t know. …And it isn’t the fear of the test. It’s just simply--I put my family in too much now.”

A few participants discussed concerns about what the screening would find. They talked about “the way I lived my life” (P2), referencing a history of tobacco, alcohol, and/or drug use. One participant (P19) said she would be hesitant to screen because her poor health prevented follow up on any suspicious findings with invasive diagnostic or treatment procedures. Despite these concerns, participants said that they follow their provider’s recommendation.

3.4 Screening Decision-Making Process Preferences

Participants preferred an in-person LCS discussion with a provider they deemed credible. They evaluated credibility in terms of knowledge, medical authority, and trust in the patient-provider relationship. Several participants discussed the supporting role decision aid materials might play in LCS discussions.

All participants said they preferred a face-to-face consultation about LCS. Most participants thought that decision aid materials could also be useful for describing the screening process and the benefits and harms associated with it. Some participants thought a written decision aid tool would be best, while others preferred video or online formats, citing their visual nature, easy consumption, and in the case of online materials, perceived privacy. Preferences often correlated with general media comfort (e.g., written tools preferred by people who described themselves as not internet savvy). Even those expressing interest in decision aids saw those materials as complementary to a face-to-face discussion.

Participants expressed less consensus about the ideal person for leading those conversations. Some named specific otolaryngology specialists, describing the provider’s perceived cancer expertise, their role in what patients felt were positive treatment outcomes, or the physician-patient relationship. Others more generally discussed people in health care roles: specialists (e.g., oncologists, pulmonologists, cardiologists), primary care physicians, and physician assistants or registered nurses. A third group focused on the potential person’s LCS knowledge, rather than their medical role.

For many, their HNC experience affected these discussion preferences: “When you are in a position where people saved your life and you darn sure know that their knowledge saved your life, it changes that” (P2). After advocating for the possibility of a “liaison,” the participant (P12), above, continued that a primary care physician could have the conversation for “a basic general level screening for lung cancer for high risk people.” Given his HNC history, though, he said he would prefer to have the conversation with his specialists: “It would be only natural to be here…because these are the people that you’re associating with and being impacted with.” Participants focused primarily on the treatment discussion, and their preferences reflected that.

Some participants wanted the input of treating providers and valued their authority, believing providers had the specialized knowledge to guide their decisions. Many reported their confidence and trust in specific providers or the group of providers who treated their HNC, discussing that this trust reduced their concerns about overdiagnosis or overtreatment. These participants felt that their specialists would protect them as much as possible, and provider expertise could minimize potential harms.

4. Discussion and Conclusion

4.1 Discussion

We addressed the broader screening recommendations for HNC survivors by conducting in-depth interviews regarding their cancer experiences and views about LCS. We found that survivors' cancer experiences shaped LCS decision-making processes, including their health care priorities and their preferences for receiving and working through information about LCS. Given CMS' reimbursement requirement for shared decision making, our findings have important implications for how health care providers conduct LCS discussions with patients.

We found that cancer survivors had a heightened preference for screening, a desire to reduce uncertainty, and a belief that early detection would lead to successful treatment outcomes. Although HNC survivors had some awareness of surveillance imaging for lung metastases, they had limited knowledge of LCS, similar to other populations [14,17,19]. Prior literature has demonstrated variation in patient attitudes and receptivity toward LCS based on characteristics such as smoking status, age, socioeconomic status, race and ethnicity, and education level [10,14,17–22]. In our study, people drew upon their own history of HNC and the experience of friends and family when discussing their LCS receptivity and information needs. People recognized that smoking increased their lung cancer risk and felt that their prior cancer put them at risk for future occurrences. They indicated that their receptivity to screening and preventive care had shifted after their HNC. Many also discussed others' cancer experiences as influencing their willingness to engage in preventive care. While most felt more receptive, a few expressed ambivalences about screening due to their experiences with cancer. The individualized nature of these experiences indicates, building on what others have found [17], that decision-making conversations about LCS should be personalized and account for these contextual factors of people's personal and health history.

Our study findings suggest that, when discussing LCS with people who have a cancer history, it may be necessary to frame the potential benefits and harms in a way that reflects that history and how it might affect their screening priorities. It seems likely that participants' LCS views are influenced by their extensive medical experience, both diagnostic and treatment-oriented. Prior research has examined how people perceive the risks of LCS [18], and guidelines and decision aid materials have focused on providing this information. While previous research has shown that people overestimate the benefits and underestimate the harms of screening [23], participants in our study provide evidence that cancer survivors evaluate, especially, the potential of early detection to result in successful intervention differently than heavy smokers in the general population. Participants frequently presupposed a positive finding, rather than considering what would happen in the case of negative or suspicious but unclear finding. They saw the treatment decision as the critical decision point, expressing more concerns with the treatment potential in the case of finding a cancer than with the potential harms of screening. Given their successful HNC treatment and the trust they placed in their treating providers, they expressed that risks from screening would be mitigated by their providers and that the benefits of reduced uncertainty and possible early detection outweighed any risks. Many minimized the possibility of anxiety or harm from false positives, overdiagnosis, and overtreatment. They viewed LCS as providing a greater level of certainty than warranted given the high frequency of false positive results [3]. For these patients, our data suggest that they might be most comfortable discussing LCS with their cancer care provider. Depending on where patients receive that care, one possible solution might be to house an LCS program within a specialized survivorship clinic managed by a physician or advanced practice provider.

Our findings have uncertain generalizability, because we drew our sample from a single otolaryngology clinic in a tertiary care center. While we attempted to oversample minority and women participants, everyone in our sample identified as white, non-Hispanic. However, we interviewed four women (21%), which approximates the overall percentage of people with HNC who are women (26.3%, 18). The study also has strengths. The findings are the first examining how HNC survivors, identified to be at higher risk for lung cancer by the NCCN, conceptualize LCS. Our in-depth, one-on-one interviews allowed for a rich exploration of the complex, individualized decision-making processes people undergo as they consider LCS.

4.2 Conclusion

As institutions work to implement LCS with LDCT, it is important to consider how the varying recommendations guiding these initiatives will translate into practice. A critical piece of implementation is how providers undertake the shared decision-making process around screening. Engaging patients who were not represented in the NLST [15], such as HNC survivors, is challenging because there are no clinical outcome data—for either benefits or harms--to guide screening decisions. Screening discussions should account for how patients’ prior cancer experiences may have influenced their understanding and receptivity regarding LCS. Given that successful treatment experiences may increase patient receptivity towards LCS, providers need to thoughtfully engage patients to consider both the potential benefits and harms of LCS for their own unique situation.

4.3 Practice Implications

Through this qualitative inquiry, we have provided evidence indicating that, especially within a shared decision-making framework, providers must work to clarify HNC survivors’ understanding and values for LCS. Providers should acknowledge the influence of patients’ cancer histories on screening decisions, particularly their potentially heightened receptivity to screening and high expectations for cancer treatment benefit, as well as their limited familiarity with LCS. At the same time, they must offer comprehensive, accurate, and balanced information about LCS’s actual potential to relieve patients’ uncertainty given the high rate of false positive results and potential diagnostic and treatment harms. Providers also need to inform patients that there are no clinical trial data regarding the benefits and harms of LCS among cancer survivors.

Although guidelines suggest that primary care providers should hold LCS discussions, they might lack both the time and expertise to address cancer survivors' complex needs [9,10,12–14]. And while our participants overall expressed a preference for discussing screening with their cancer specialists, little is known about specialists' attitudes toward and knowledge of LCS and shared decision making (see, however, 22). For these reasons, further study is required before making a definitive recommendation about the ideal context for shared decision making around LCS for cancer survivors.

Acknowledgments

We thank the patients and providers who participated in the study for sharing their time, experiences, and expertise with us.

Funding: Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under the Award Number UG1CA189823 (Alliance for Clinical Trials in Oncology NCORP Grant), U10CA180858, and by the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number U54TR001356. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Highlights

- Qualitatively examines head and neck cancer survivors' perspectives on lung cancer screening
- Survivors were receptive to lung cancer screening, minimizing potential harms
- They drew upon their head and neck cancer experiences as they considered screening
- Lung cancer screening discussions are complicated by head and neck cancer survivors' history
- Specialty care settings might be more appropriate for screening discussions with this population

Table 1

Head and Neck Cancer (HNC) Survivors' Knowledge of and Preferences for Lung Cancer Screening (LCS) with Low-Dose Computed Tomography (LDCT)

1. Knowledge of screening and LCS	
Awareness of LCS with LDCT	"I have my chest x-ray once a year because of the radiation. That's all they pushed too hard. But, no, I haven't heard anything." (P2, male, age 44) "[T]hey recommended it here. …So they set it up, and I had a CAT scan." (P5, male, age 72)
Understandings and misperceptions about the purpose of LCS with LDCT purpose (i.e., to screen asymptomatic patients for a second primary lung cancer)	"I mean, if I had a cough or something, the other doctor would say, we want to take your, your lungs X-rayed" (P3, male, age 72) "…if they had symptoms, like coughing up blood or something like that" (P14, female, age 68) "[W]ithin the five-year period is kind of that concern about cancer recurring. Anything outside of that five, the way it's been explained to me is that, if you get cancer again, it's probably a new type of current cancer, not a recurrence." (P12, male, age 63)
2. Receptivity to LCS and Decision-Making Considerations for HNC Survivors	
Receptivity to LCS	"I think it's a wise thing to do, you know?" (P1, male, age 68) "We got to nip it in the bud as soon as we possibly can. The only way is through screening, whether it's mammograms or having your lungs checked or whatever it might be. It needs to be part of a yearly thing." (P3, male, age 72) "Sounds pretty simple to me…I'd be more than glad to do one of them scans." (P11, male, age 56) "I just feel that if they screen--if they do more screenings they're gonna find things faster. And even if it doesn't come up with cancer, they might find other things too, you know, so that's how they find stuff is test." (P18, female, age 59) "But if they recommend it, yeah, then I'll do it, but let's don't go lookin' for trouble. Unless there's some reason you really think that I should do this, then certainly I'll do it. I won't, you know, I won't jump up and down. …As general goes, I do whatever they want me to do, or recommend, I should say." (P6, male, age 65)
Influence from cancer experiences	"I think anybody with a cancer history should do all they can do to detect any more cancer in the body because, you know, I've had in the throat, I can have it in my lungs." (P9, male, age 71) "My mom and her brother both died of lung cancer, small cell lung cancer…[O]f course you'd do some screening…if you're high risk, which I would classify myself as a high risk, uh, case. Wouldn't you? With my family history, and my personal history, and that same--yeah, you're probably in that higher risk." (P12, male, age 63) "If…they would've tested the lung earlier, he [her relative] might still have been, you know, there, so I think they should do that." (P18, female, age 59)
Perceived potential benefits of screening	"I'd hate to find out that I had it. I wouldn't wanna go through that again, but I guess I'd wanna know, you know, even though if it did--would scare the heck outta you, you'd still, you know, it's just preventive, you know? … You'd want a fighting chance about it, I guess you'd say." (P1, male, age 68) "End result. End result is what we're after. I don't care what avenue we get there by. If it doesn't hurt me and it gets us answers, we're goin'… Bein' on the topside of the dirt lookin' down, instead of the downside lookin' up … 'Cause that day's comin' for all of us. No need to hurryin' it." (P2, male, age 44) "…you're not gonna cure it by not knowin' you have it… it might be cancer, it might be a cold. Well, let's find out what it is, you know. Can't treat it 'til you know what you're treating." (P7, male, age 66) "…if there's a way that they can screen it beforehand, you know, it would be preventable." (P14, female, age 68) "It's either you want to find out if there's something the matter with you or not. I mean, you know you could question, 'Well, I don't know if I want to.' Well, why not? Get it done. Find out. Then you know. You don't get it done, you ain't ever gonna know." (P4, male, age 56) "I'd rather err on the side of safe…and cautious…than to say, 'Nah, I'll just let it go and see what happens.' 'Cause maybe something might be there that's not anything, but it could turn into something. So, at least you know it's there. If they find it and they know it's there, it's something that the doctor can keep an eye on." (P13, female, age 58)
Perceived potential harms of screening	"Let's don't go lookin' for trouble 'cause they can probably find plenty on me if they really go to lookin'. …I think that I've been through enough of this that I think we'll just leave it alone. That's my feeling." (P6, male, age 65) "Well, treating something that doesn't need to be treated? It's always a concern to me. 'Cause like I say, we're all human, …[t]here's a lot of gray areas, and you're trusting people to make judgments that don't necessarily always make the right decision." (P16, male, age 63) "[S]ay you got over a cold two weeks ago. It's gonna show up on there that you had an infection. Or it might show up as cancer, but it might only have been an infection." (P19, female, age 58) "[I]t depends upon the cost…if I got to have a screening, and it's gonna cost me $5,000.00, I'm not gonna have it. I can't afford it." (P3, male, age 72)
3. Screening Decision-Making Process Preferences	
Preference for LCS discussion with provider	"I'd rather talk face-to-face with the doctor. I don't like all the paperwork and videos and stuff. Just have him tell me what it is and, and how he can take care of it." (P1, male, age 68)

	“Personally I like to hear it first hand from the person instead of watching or reading. I mean, yes the reading is nice and the watching the videos, some of that is ok. But the best to me is still talking.” (P8, male, age 67)
Preferred providers for LCS discussion	“I’d ask Dr. A… if Dr. A said to me, ‘You know, you might want to consider this.’…Somebody that’s got a lot of experience doing these kinds of things now. I know Dr. A well enough now that if he didn’t feel comfortable talking about it, he would tell me and he would point me in the right direction.” (P15, male, age 65) “I would say the person that’s dealing with the problem. I mean if it’s your prostate, your urologist, …If it’s my general surgeon for my hernia I deal with him. I don’t go to my heart doctor to deal with my hernia.” (P5, male, age 72) “I wanna hear it right directly from the doctor because he is the guy that ultimately is the one that’s gotta treat you each and every day.” (P10, male, age 55) “[I]f they know what they’re…talking about. I’m willing to listen to anybody that knows something” (P8, male, age 67) “[I]t wouldn’t have to be a doctor. It could be a liaison person that sits down with you, that understands all this stuff. …I don’t know how you’d have that many people or just someone with that much knowledge, but I guess that’s the challenge, but even a person like that could sit down…in a setting like this would be extremely beneficial.” (P12, male, age 63)
Use of decision aids	“But as long as the conversation’s there, he shows you the tools, shows you the diagram, shows you procedures, and tells you what’s gonna happen. That’s the main thing. What’s gonna happen. What your recovery time is or whatever. And, you know, I’m comfortable with it. But I think conversation is the most important thing.” (P5, male, age 72) “Anything that your, your physician can steer you to or…anything that he either gives you or recommends for you to read or recommends for you to look up. As long as it’s got his blessing, yeah, go with it.” (P7, male, age 66) “Well, I think that there should be pamphlets out there. I’m a firm believer word-of-mouth is the best way to get things out to people…. I think some people wanna just maybe look at that…a doctor could present it to them, maybe, and say something to them, and then say, ‘Ok, here’s a pamphlet. Here’s, here’s a website where you can go and you can do some more research on this of your own.’” (P13, female, age 58) “Personal contact first. Then perhaps audio video, because we’re in an audio video society” (P17, male, age 56)
Trust and authority	“When you are in a position where people saved your life and you darn sure know that their knowledge saved your life, it changes that. So, for me, I would have to hear it from one of them. I wouldn’t want even my little local doctor to tell me that. I would want these people because they’ve truly had my life in the palm of their hand. And they were wonderful enough to take care of that.” (P2, male, age 44) “When you bring your car to me and I got it all tore apart, do you come in there and ask me, ‘Is it gonna run?’ Do you? You just expect me to know what I’m doin’. Right? Why wouldn’t I expect that from my doctor? Why would I not? That’s his profession. That’s his field. Right? That’s actually puttin’ trust in him because you know that you got the best…All the information.” (P10, male, age 55) “I would trust ‘em not to [treat something that’s benign]. ‘[C]ause I know up here that they have that…tumor board or whatever they call it. And, there’s some pretty good heads on that I think that knows what they’re talking about. I would trust them, what they say.” (P9, male, age 71) “[W]e’re supposed to be in charge of our health, but we don’t have the knowledge all the times to be in charge of our health. We have to have somebody who knows it. It’s kind of like a parent and a kid. You know? The kid’s supposed to be in charge of his life, not all the time. A parent knows better most of the time, most parents. …I would think the doctor would say, ‘Yes, we found this, but we, we think the likelihood is so low,’ or ‘We found this and we really should do this,’ and then you become a layman, and you listen to your parent, and you go, ‘Ok.’ Doctors carry a lot of weight, which they should, and they should never take that power lightly.” (P12, male, age 63)

Table 2

Study Participant Characteristics[a]

Age	Mean (SD)	61.7 (6.9)
Sex	Male	15 (79%)
	Female	4 (21%)
Race/Ethnicity	White/Non-Hispanic	19 (100%)
Marital Status	Single	4 (21%)
	Married	13 (68%)
	Other	2 (11%)
Years Smoking [b, c]	Mean (SD)	35.5 (8.4)
Maximum packs per day [c]	.5	1 (5%)
	1	9 (47%)
	2	7 (37%)
	3	1 (5%)
Years Since Treatment	Mean (SD)	4.2 (4.4)

[a] All data were self-reported.

[b] Three (3) participants were still smoking at the time of the interview.

[c] One (1) participant did not respond.