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Measuring decisional control preferences in men newly diagnosed with prostate cancer

Nora B. Henrikson, PhD, MPH[Research Associate],
Group Health Research Institute, Group Health Cooperative, 1730 Minor Ave. Suite 1600, Seattle, WA 98101, PHONE 206-287-4675, FAX 206-287-2871

B. Joyce Davison, RN, PhD[Associate Professor], and
College of Nursing, University of Saskatchewan, St. Andrew's College Bldg., Room 310, 1121 College Drive, Saskatoon, SK S7N 0W3, Phone: 306-966-8379, Fax: 306-966-1745

Donna L. Berry, PhD, RN, AOCN®, FAAN[Director]
Phyllis F. Cantor Center for Research in Nursing & Patient Care Services, Dana-Farber Cancer Institute, 44 Binney Street, CP 305, Boston, Massachusetts 02115-6084, Phone 617.632.1909 tel, 617.582.8550 fax

Nora B. Henrikson: henrikson.n@ghc.org; B. Joyce Davison: joyce.davison@usask.ca; Donna L. Berry: donna_berry@dfci.harvard.edu

Abstract

The Control Preferences Scale is widely used in decision research to measure patient preferences for participation in treatment decision making with health care providers. Following anecdotal reports of confusion with the scale we conducted an exploratory interview study to examine perceptions of the meaning and applicability of the Control Preferences Scale for men with localized prostate cancer seeking treatment in a multidisciplinary urology clinic. Our preliminary data suggest potential validity challenges when the CPS is used in a multidisciplinary prostate cancer care setting, including the clinical context of localized prostate cancer and the meaning of shared decision making.

Keywords

prostate cancer; qualitative; measurement; multidisciplinary care; measurement interview

Introduction

The Control Preferences Scale (CPS) is a widely used instrument in decision research designed to measure a patient's preferred level of their own versus their doctor's control over a treatment decision (Degner, Sloan, & Venkatesh, 1997). The CPS was developed for use in research with people facing life-threatening medical decisions and has been used in research with newly diagnosed breast and prostate cancer patients (Beaver, et al., 1996; Bilodeau & Degner, 1996; Davison & Degner, 1997; Davison, Degner, & Morgan, 1995; Davison, et al., 2002; Davison, Goldenberg, Wiens, & Gleave, 2007; Degner, Kristjanson, et al., 1997; Hack, Degner, & Dyck, 1994). Administration methods have shifted over time from the original card-sorting method (Davison & Degner, 1997; Davison, et al., 1995) to a pick-one-option method (Davison & Degner, 1997; Davison, et al., 2002; Davison, et al., 2007), and from analytic groupings of the original five response options into three categories

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Correspondence to: Nora B. Henrikson, `henrikson.n@ghc.org`.

consistent with Charles's model of decision-making styles: active, passive and shared (Charles, Gafni, & Whelan, 1999).

The CPS was developed based on qualitative data collected in the 1970s when surgery was the primary treatment choice. Since then we have seen significant shifts in the management of prostate cancer (Table 1). Men with localized prostate cancer (LPC) now have substantially more treatment choices and subsequently numerous health care professionals to interact when making a treatment decision., As a result there also has been an emergence of multidisciplinary clinics where patients simultaneously or sequentially consult with surgeons, radiation therapists and medical oncologists rather than solely with the urologist (Kurpad, et al., 2009; Montagut, Albanell, & Bellmunt, 2008). As there is little evidence for survival benefit with any one treatment option, patient preferences and opportunities for participation in the decision making process has increased (Charles, et al., 1999; Godolphin, 2009; Siminoff & Step, 2005; Stacey, Samant, & Bennett, 2008). Since the evolution of the internet, patients now have access to a variety of information resources, so the specialist is typically no longer the only source of patient information (Berry, et al., 2003).

It would not be surprising, then, that interpretations of the statements in the CPS may have shifted over time. Based on anecdotal comments and feedback from participants with prostate cancer in multiple studies conducted by two investigators (DLB, BJD), we hypothesized that participants may be interpreting the CPS responses differently than originally intended when the scale was validated. The purpose of this exploratory cognitive interview study was to examine men's views of the meaning and fit of the CPS in a multidisciplinary urologic oncology setting.

Methods

We conducted an interview study as a sub-study of a multi-site, randomized controlled trial assessing a web-based treatment decision aid for men with newly diagnosed localized prostate cancer (Berry, et al., 2010). Consecutive trial participants in the United States Pacific Northwest were recruited by telephone to participate in this study during the summer of 2008. All eligible men had received a diagnosis of localized prostate cancer, were in the process of treatment decision making, and could read and communicate in English. Each participant gave verbal and written informed consent, and the study was approved by the Fred Hutchinson Cancer Research Center, Cancer Consortium Internal Review Board during all phases of recruitment, data collection and analyses.

We conducted telephone interviews with 20 men participating in the Personal Patient Profile-Prostate (P3P) randomized trial. Interviews were conducted by one investigator (NBH) within three weeks of the participant's one-month follow-up contact for the larger trial, intentionally timed to be one month after the treatment options consultation appointment. Study participants had completed the CPS scale, reporting decisional control preference at that time as part of the larger study data collection a few days prior to the telephone interview.

Before the telephone interview, a copy of the CPS scale (Table 2) was e-mailed or mailed with a request for the participant to have it on hand for the interview. We provided the scale on the study website for men who preferred to access it directly for the interview. During each interview, we asked a series of questions using a think-aloud cognitive interviewing technique (Collins, 2003; Fonteyn, Kuipers, & Grobe, 1993; Jaspers, 2009) asking the men to describe (1) what each response item meant in their own words and (2) what other response would better explain their own preference. We used spontaneous verbal cues to explore ideas mentioned or non-verbal behavior such as hesitations, uncertainty, or confusion. In accordance with IRB approval, we did not record or transcribe the calls but made extensive written notes during and immediately after each interview. Interview data was connected to study identifiers only and contained no personal identifiers.

We conducted content and thematic analysis of the interview data consistent with cognitive interviewing methods (Ahmed, Bestall, Payne, Noble, & Ahmedzai, 2009; Rebok, et al., 2001; Yorkston, et al., 2008). Two investigators (NBH, DLB) read through a sample of five interview notes, and created a coding system modeled on the probes used in the interviews. Any disagreements were resolved by consensus. After coding was complete, the author team collaboratively analyzed the themes and selection of exemplar quotations for reporting what actions the men described for each response option and any areas of ambiguity.

Results

Of the consecutively-contacted trial participants, two men declined and three consenting participants could not be reached for interview within the desired time frame when 20 interviews were completed. All of the sub-study participants were white, educated to at least high school level and earning at least $50,000/year. Three quarters were married or partnered, and about half had private health insurance (Table 3). Seventeen of the twenty had decided on treatment by the time of the one month interview. Prostatectomy was the most common treatment choice, followed by radiation therapy (primarily brachytherapy). Nine of twenty men endorsed option B in the control preferences scale; six endorsed C, and five endorsed A (Table 2).

Active role (responses A and B): “They give you options and expect you to make the decision”

Descriptions of options A and B were most likely to describe scenarios where doctors supported the patient’s decision process while the patient role was the primary one—seeking the doctor’s expertise, making the decision, and wanting to maintain control over one’s own body. A and B were most likely to be described together but several men described option A as a patient making a decision either without consulting a doctor or actively going against a doctor’s recommendation. Some phrases mentioned when describing A and B were *listening to the doctor part of the way* and *considering the doctor’s opinions*.

Shared role (response C) “Both are happy with the decision”

Descriptions of response C tended to describe a more collaborative process, though fewer specific actions were described here than in descriptions of active or passive roles. Men described processes where the patient did his own research but a more shared process was described: *working together*, *sharing equally in the decision*, *coming to common ground*. In this response, patient research was described as key or what the patient “brings to the table.” One man described C as a “50-50 situation”, whereas A and B were “80-20” situations where the patient contributes more to the decision. Additional exemplar quotes are in Table 4.

Active role (responses D and E): “Just tell me what to do and I’ll do it”

D and E were often described together with little differentiation. Men described a more doctor-driven decision process in which the patient “leaves” the treatment decision to the doctor or the doctor “makes” the final decision. Many men mentioned that the doctor would not elicit patient wishes or be more likely to offer a strong opinion on treatment. A few men described a doctor going against a patient’s wishes as fitting under D. Men who mentioned having faith/trust in the doctor were more likely to mention them during a description of D or E. Compared to D, E was sometimes described as being even more paternalistic, as with one man who described it as, “in D, the doctor considers patient wishes, but in E he does not.” (Table 4)

Contextual fit with localized prostate cancer setting

Few men provided an explicit answer to our second question (statement that would better describe their preferred process) but many offered feedback on how the response options could be changed or identified sources of confusion experienced during the course of the interview (Table 5). Several men suggested that the nature of localized prostate cancer—slow progression allowing ample time for decision-making and the lack of evidence about treatment outcomes—made D or E incompatible with their decision. One man said he might choose D or E (passive role) if he “had a different kind of cancer”; another said E would only happen “if you really didn’t have choices.”

One common source of confusion was the word “doctor”—men nearly always indicated they had consulted with several doctors and did not know which doctor the question referred to. Men variously interpreted it to mean the treating physician; the primary care physician; or the urologist. Several men suggested that the wording of the question be changed to reflect multiple doctors or to clarify which doctor the question refers to.

The perceived tendency of different specialists to recommend treatment in their own specialty was another common contextual theme. Many men reported getting multiple opinions as a matter of course, given the bias they expected within each specialty. In one man’s words: “you sort of know what each doctor is going to say.”

At least one man mentioned that each of response options A, C, D, or E was unrealistic (B was the only response option not critiqued in this way). Response A was likely to be called unrealistic by those who interpreted it to mean that it did not involve talking with doctors at all—”ludicrous”—C for the perceived difficulty of true decision-sharing, and D and E for contextual issues.

Pressure to assume active role (A or B) “My surgeons were adamant that I make the final decision”

All the men mentioned expectation of a significant patient role in the treatment decision. Many men mentioned that they would prefer that the doctor have a more active role than was available, as with one man who said that if the doctor had made a firm recommendation he would have followed it, “but [the doctor] did not.” (Table 5)

Who does what in shared role (option C)? “Either I give him authority or I don’t”

Several men described ambiguity in the concept of sharing responsibility that appears in option C, either thinking that was practically unlikely or surmising that the word “responsibility” had more to do with malpractice liability. One man described C as “just in the middle of A and E.” Although at least one man described C as “very clear”, others called it “wishy-washy”, “ambiguous,” or said that it “doesn’t make sense,” or “didn’t resonate.”

Discussion

We conducted a cognitive interview study with men with newly diagnosed prostate cancer participating in a trial of a treatment decision aid that included the Control Preference Scale (CPS) one month after study enrollment. We describe men’s descriptions of what each CPS response option meant in their own words and identified several areas of confusion relating to the clinical/cultural contexts of multidisciplinary urologic oncology.

Understanding patient preferences for control in treatment decision-making is crucial to furthering shared decision-making and patient-centered care. The CPS was rated as one of the few outcome measures used in shared decision-making (SDM) studies that met high appraisal standards of quality (Kryworuchko, Stacey, Bennett, & Graham, 2008). Although the actions described by the men for each response option were generally consistent with our understanding of active, shared, and passive roles, they also identified several points of confusion with the CPS in a multidisciplinary urologic oncology clinic context.

Our evaluation of the CPS is consistent with a methodological priority to establish whether measures are valid and reliable in different clinical settings (Rothman, et al., 2009). A systematic review found the CPS was frequently used in informed decision making studies of cancer screening decisions with little discussion of the validity or reliability of the measure in that setting (Mullen, et al., 2006). Others have suggested that special attention is required to support shared decision making in different clinical contexts since control preferences may differ according to the situation (Gattellari & Ward, 2005; O’Donnell & Hunskaar, 2007). Gender differences in control preferences and decision making style are not well understood, though there is some evidence that men are less likely to desire participation or to seek a second opinion (Hamann, et al., 2007; Tattersall, et al., 2009). A few recent studies have examined the validity of the CPS for use in research in various health states and suggest that the CPS may conflate several concepts like the complexity of preferred patient involvement, information seeking preferences, and doctor’s ability to engage in shared decision making (Davey, Lim, Butow, Barratt, & Redman, 2004; Entwistle, Skea, & O’Donnell, 2001; Gattellari & Ward, 2005).

Our data suggest several contextual issues that might affect responses to the CPS in a multidisciplinary oncology setting. The nature of localized prostate cancer itself, a cultural expectation of patient involvement, mentioned by every man in our study, or a sense of bias along specialty lines may lead some men to conclude that one or more of the response options are unrealistic or do not apply to their situation. Confusion with the referent of the word “doctor” and of the operational meaning of the words “shared” and “responsibility” may also leave gaps in interpretation that might affect the validity of responses. It is also worth noting that many men thought option A described men who had either not spoken to a doctor at all or who had make their treatment decision before choosing a doctor, a problem also encountered in the original development of the CPS (Degner, Sloan, et al., 1997). This point may take on increasing importance in an era of patient-controlled treatment decisions.

There has been thoughtful research into the operational meaning of shared decision-making, suggesting that doctors and patients may have differing definitions, such as the meeting of informed consent requirements versus active patient engagement (Charles, Gafni, & Whelan, 1997; Edwards & Elwyn, 2006; Pieterse, Baas-Thijssen, Marijnen, & Stiggelbout, 2008). It has been suggested that truly shared decision-making rarely happens (Godolphin, 2009), and that the process of involvement may be more important than who actually makes the decision (Edwards & Elwyn, 2006). Our findings confirm that when asked to reflect on the meaning of “shared responsibility,” many men have difficulty describing a specific set of actions.

We acknowledge several limitations of this study. First and most importantly, our sample was an educated, white sample of men in the Pacific Northwest whose endorsements of the CPS did not cover the range of responses (A, B, and C only). Since the larger trial participants included the range of responses, including D and E, we know that our study did not capture men who endorsed those two options. However, several men mentioned that they would prefer to endorse D or E if it were possible, so it is likely that we captured a larger range of opinions than the distribution of CPS responses in our sample might suggest.

Second, we conducted the interviews in the first weeks after diagnosis and for many participants, before the final treatment choice; this single data collection point could not capture sshifts in control preference may occur over the course of disease (Davison & Degner, 1997; Davison, Goldenberg, Gleave, & Degner, 2003; Davison, et al., 2007; Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). Also, in accordance with our IRB approval, we did not have fully transcribed recordings of the interviews. Although we took detailed notes during and after each interview, some data may have been missed in this process.

These data present intriguing preliminary data suggest ambiguity with the use of the CPS in a multidisciplinary urologic oncology setting. Further study is required to determine how to best measure the concept of decision control with prostate cancer patients. Understanding the views of a more socioeconomically diverse group of men will be crucial in understanding the full range of interpretations of the CPS. Such work could lead to the development of a model of decisional control preference that fits the current clinical culture of this patient population.

Conclusions

The Control Preferences Scale may not fully capture decisional control preferences in a multidisciplinary setting or under conditions of uncertainty in outcome. Further research can inform response options that would more fully capture control preferences in a multidisciplinary clinical environment where there is a culture of patient information-seeking.

References

Ahmed N, Bestall JC, Payne SA, Noble B, Ahmedzai SH. The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs. Supportive care in cancer. 2009; 17(6):665–673. [PubMed: 18982363]

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nursing. 1996; 19(1):8–19. [PubMed: 8904382]

Berry DL, Ellis WJ, Woods NF, Schwien C, Mullen KH, Yang C. Treatment decision-making by men with localized prostate cancer: the influence of personal factors. Urologic oncology. 2003; 21(2): 93–100. [PubMed: 12856636]

Berry DL, Halpenny B, Wolpin S, Davison BJ, Ellis WJ, Lober WB, et al. Development and evaluation of the personal patient profile-prostate (P3P), a Web-based decision support system for men newly diagnosed with localized prostate cancer. Journal of Medical Internet Research. 2010; 12(4):e67. [PubMed: 21169159]

Bilodeau BA, Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. Oncology nursing forum. 1996; 23(4):691–696. [PubMed: 8735327]

Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Social science & medicine. 1997; 44(5):681–692. [PubMed: 9032835]

Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Social science & medicine. 1999; 49(5):651–661. [PubMed: 10452420]

Collins D. Pretesting survey instruments: an overview of cognitive methods. Quality of life research. 2003; 12(3):229–238. [PubMed: 12769135]

Davey HM, Lim J, Butow PN, Barratt AL, Redman S. Women's preferences for and views on decision-making for diagnostic tests. Social science & medicine. 2004; 58(9):1699–1707. [PubMed: 14990371]

Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. Cancer Nursing. 1997; 20(3):187–196. [PubMed: 9190093]

Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. Oncology nursing forum. 1995; 22(9):1401–1408. [PubMed: 8539181]

Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. Cancer Nursing. 2002; 25(1):42–49. [PubMed: 11838719]

Davison BJ, Goldenberg SL, Gleave ME, Degner LF. Provision of individualized information to men and their partners to facilitate treatment decision making in prostate cancer. Oncology nursing forum. 2003; 30(1):107–114. [PubMed: 12515988]

Davison BJ, Goldenberg SL, Wiens KP, Gleave ME. Comparing a generic and individualized information decision support intervention for men newly diagnosed with localized prostate cancer. Cancer Nursing. 2007; 30(5):E7–15. [PubMed: 17876177]

Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, et al. Information needs and decisional preferences in women with breast cancer. JAMA: Journal of the American Medical Association. 1997; 277(18):1485–1492.

Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. The Canadian journal of nursing research. 1997; 29(3):21–43. [PubMed: 9505581]

Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expectations. 2006; 9(4):307–320. [PubMed: 17083558]

Entwistle VA, Skea ZC, O'Donnell MT. Decisions about treatment: interpretations of two measures of control by women having a hysterectomy. Social science & medicine. 2001; 53(6):721–732. [PubMed: 11511048]

Fonteyn M, Kuipers B, Grobe SJ. A description of the use of think aloud method and protocol analysis. Qualitative Health Research. 1993; 3:430–441.

Gattellari M, Ward JE. Measuring men's preferences for involvement in medical care: getting the question right. Journal of evaluation in clinical practice. 2005; 11(3):237–246. [PubMed: 15869554]

Godolphin W. Shared decision-making. Healthcare Quarterly, 12 Spec No Patient. 2009:e186–190.

Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. Social science & medicine. 1994; 39(2):279–289. [PubMed: 8066506]

Hamann J, Neuner B, Kasper J, Vodermaier A, Loh A, Deinzer A, et al. Participation preferences of patients with acute and chronic conditions. [Health]. Health Expectations. 2007; 10(4):358–363. [PubMed: 17986072]

Jaspers MW. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. International journal of medical informatics. 2009; 78(5):340–353. [PubMed: 19046928]

Kryworuchko J, Stacey D, Bennett C, Graham ID. Appraisal of primary outcome measures used in trials of patient decision support. Patient education and counseling. 2008; 73(3):497–503. [PubMed: 18701235]

Kurpad R, Kim W, Kim Rathmell W, Godley P, Whang Y, Fielding J, et al. A multidisciplinary approach to the management of urologic malignancies: Does it influence diagnostic and treatment decisions? Urologic oncology. 2009

Montagut C, Albanell J, Bellmunt J. Prostate cancer. Multidisciplinary approach: a key to success. Critical reviews in oncology/hematology. 2008; 68(Suppl 1):S32–36. [PubMed: 18723370]

Mullen PD, Allen JD, Glanz K, Fernandez ME, Bowen DJ, Pruitt SL, et al. Measures used in studies of informed decision making about cancer screening: a systematic review. Annals of behavioral medicine. 2006; 32(3):188–201. [PubMed: 17107291]

O'Donnell M, Hunskaar S. Preferences for involvement in treatment decision-making generally and in hormone replacement and urinary incontinence treatment decision-making specifically. Patient education and counseling. 2007; 68(3):243–251. [PubMed: 17904327]

Pieterse AH, Baas-Thijssen MC, Marijnen CA, Stiggelbout AM. Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration. British Journal of Cancer. 2008; 99(6):875–882. [PubMed: 18781148]

Rebok G, Riley A, Forrest C, Starfield B, Green B, Robertson J, et al. Elementary school-aged children's reports of their health: a cognitive interviewing study. Quality of life research. 2001; 10(1):59–70. [PubMed: 11508476]

Rothman M, Burke L, Erickson P, Leidy NK, Patrick DL, Petrie CD. Use of existing patient-reported outcome (PRO) instruments and their modification: the ISPOR Good Research Practices for Evaluating and Documenting Content Validity for the Use of Existing Instruments and Their Modification PRO Task Force Report. Value in Health. 2009; 12(8):1075–1083. [PubMed: 19804437]

Siminoff LA, Step MM. A communication model of shared decision making: accounting for cancer treatment decisions. Health psychology. 2005; 24(4 Suppl):S99–S105. [PubMed: 16045427]

Stacey D, Samant R, Bennett C. Decision making in oncology: a review of patient decision aids to support patient participation. CA: a cancer journal for clinicians. 2008; 58(5):293–304. [PubMed: 18755939]

Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp K. Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. Annals of Oncology. 2010; 21(6):1145–1151. [PubMed: 19940010]

Tattersall MH, Dear RF, Jansen J, Shepherd HL, Devine RJ, Horvath LG, et al. Second opinions in oncology: the experiences of patients attending the Sydney Cancer Centre. The Medical journal of Australia. 2009; 191(4):209–212. [PubMed: 19705981]

Yorkston KM, Baylor CR, Dietz J, Dudgeon BJ, Eadie T, Miller RM, et al. Developing a scale of communicative participation: a cognitive interviewing study. Disability and rehabilitation. 2008; 30(6):425–433. [PubMed: 17943516]

Table 1

Contextual issues that may influence content validity

Original CPS context	**Current multidisciplinary oncology context**
Few treatment choices	Many treatment choices with no clear survival advantage
Urgency for treatment decision	Men with slowly progressing cancers may extend decision-making time
Patient had single doctor	Not unusual for patients to consult several specialists
Doctor main source of information	Wide access to internet and other cancer information sources
Little consumer participation in health care	Norm of patient involvement; doctor may refuse control of decision

Table 2

Control preference scale (Degner, Sloan, et al., 1997)

The role you play in the treatment option you choose is important. The next question will tell us how you would like the treatment decision to be made.

Please choose one of the following statements that best describes how you would like the decision to be made:

A. I prefer to make the final treatment decision.

B. I prefer to make the final treatment decision after seriously considering my doctor’s opinion.

C. I prefer that my doctor and I share responsibility for deciding which treatment is best.

D. I prefer that my doctor makes the final treatment decision, but seriously considers my opinion.

E. I prefer to leave all treatment decisions to my doctor.

Table 3

Sample demographics (N=20)

	n	%
Age <60	7	35.0
Age 60–64	5	25.0
Age 65+	8	40.0
Education		
HS graduate	3	15.0
College graduate	11	55.0
Post-graduate	6	30.0
Married or partnered	15	75.0
Income <$50k (2008 USD)	3	15.0
$55k–$85k	6	30.0
$85k+	10	50.0
White/Caucasian	20	100
Medicare	7	35.0
Private insurance	11	55.0
State insurance	2	10.0
CPS response A	5	25.0
CPS response B	9	45.0
CPS response C	6	30.0
Treatment choice*		
Radiation therapy (brachytherapy and/or EBRT)	4	20.0
Surgery	11	55.0
High intensity focus ultrasound	1	5.0
Other (Proton therapy)	1	5.0
Undecided	3	15.0

*Participants had not begun treatment at the time of interview

Table 4

Actions described for each CPS response option

Actions described by men	Exemplar quotes
Responses A & B (active role)	
Patient does own research Patient wants control over own body	*It's my body, my decision. I'm going to make the final choice.*
Patient may or may not seek doctor's expertise Patient offers preferences to the doctor	*A is when a patient thinks it is irrelevant what doctor thinks, does what he wants because "I know what's best for me and don't care what anyone else thinks.*
Patient makes the treatment decision (possibly against doctor's recommendation; possibly choosing doctor after making decision)	*Obviously I have to get a doctor to do the procedure, I can't do it myself.*
Doctor offers options, not opinions Doctor agrees after patient decides	*In B the patient says "doc, what do you think? what is my best shot?" then combines with the other research (books etc) and makes own decision but "puts a lot of weight or emphasis on doc's opinion" [field note]*
Response C (shared role)	
Patient does own research Doctor offers options, possibly opinions Patient offers preferences, wishes to doctor	*The doctor has opinions, the patient does research and "brings that to the table," the doctor considers patient preferences around side effects, etc, the two "come to common ground." [field note]*
Doctor/patient shared action	*This is kind of what I did. I read, brought myself up to speed, so he and I understand each other and we share equally in the decision.* *Doctor says, "We'll work together."*
Responses D & E (passive role)	
Patient leaves choice to doctor	*[Patient says,] "Just tell me what you're going to do to me and I'll do it."*
Patient has trust/faith in doctor	*[Doctor says,] "this is what we're going to do."*
Patient offers preferences to doctor Doctor may or may not elicit patient preferences Doctor offers a strong opinion Doctor makes treatment decision (possibly rejecting patient's preference)	*I ran into two doctors like this. They were like, here's what you've got, here's what we're going to do, and would have been more than happy to operate on me right there. In fact, if I had listened to them I would have had surgery weeks ago. They did not ask my opinion.*

Table 5

Potential validity challenges

Context fit with localized prostate cancer decision
Nature of disease:
Maybe if I had a different kind of cancer I would choose D or E.
Maybe D or E [passive role] would be acceptable if there was an imminent threat or immediate need to make a decision, but that's not my situation.
E would only happen "if you really didn't have choices."
Multiple doctors:
I try to interpret words as they are written, and the question here is which doctor?
[Specialists are] like housepainters, each one wants you to do business with them--you can brush paint your house or spray paint your house.
Pressure to assume "active" role (response A or B)
C [shared role] is not relevant because the docs didn't try to share the decision with me.
It would be a perfect world if D were possible, but D and E [passive role] would never occur.
I would have had to go out of my way to find a doctor who would make the decision for me.
"My surgeons were adamant that I make the final decision."
Unclear who does what in "shared" role (response C)
C is the same as B.
[C] is just in the middle of [A and E] but I wouldn't pick it. Someone has to make the final decision or you're just hanging out in limbo.
I can't see how you could share responsibility. Either I give him authority or I don't. What would that look like? The doctor can't take half the responsibility if the treatment goes wrong. [C] is not a realistic scenario.
Where does the responsibility lie if it's the wrong decision?
Either I give him authority or I don't.