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Patients' perceptions and attitudes on recurrent prostate cancer and hormone therapy: Qualitative comparison between decision-aid and control groups

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ABSTRACT

Objective: To compare patients' attitudes towards recurrent prostate cancer (PCa) and starting hormone therapy (HT) treatment in two groups—Decision-Aid (DA) (intervention) and Standard-of-care (SoC) (Control).
Methods: The present research was conducted at three academic clinics—two in the Midwest and one in the Northeast U.S. Patients with biochemical recurrence of PCa (n = 26) and follow-up oncology visits meeting inclusion criteria were randomized to either the SoC or DA intervention group prior to their consultation. Analysts were blinded to group assignment. Semi-structured phone interviews with patients were conducted 1-week post consultation. Interviews were audio-taped and transcribed. Qualitative analytic techniques were used to extract salient themes and conduct a comparative analysis of the two groups.
Results: Four salient themes emerged—1) knowledge acquisition, 2) decision-making style, 3) decision-making about timing of HT, and 4) anxiety-coping mechanisms. A comparative analysis showed that patients receiving the DA intervention had a better comprehension of Prostate-specific antigen (PSA), an improved understanding of HT treatment implications, an external locus-of-control, participation in shared decision-making and, support-seeking for anxiety reduction. In contrast, SoC patients displayed worse comprehension of PSA testing and HT treatment implications, internal locus-of-control, unilateral involvement in knowledge-seeking and decision-making, and no support-seeking for anxiety-coping.
Conclusions: The DA was more effective than the SoC group in helping PCa patients understand the full implications of PSA testing and treatment; motivating shared decision-making, and support-seeking for anxiety relief. DA DVD interventions can be a useful patient education tool for bringing higher quality decision-making to prostate cancer care.

1. Introduction

Physicians are typically patients' primary and most reliable source of medical knowledge [1]. However, physicians are frequently challenged to provide patient education within strict time constraints of busy clinical practices. To help augment patient knowledge of various medical conditions, healthcare providers increasingly use decision-aids (DAs) as supplemental tools [2,3].

DA's play a key role in imparting knowledge for conditions ranging from breast self-examination to sunscreen adherence, HIV testing, female condom use, and prostate cancer (PCa) screening [4]. The type of DA used can make a difference in knowledge acquisition and treatment decision-making. For instance, video DAs are considered more effective than brochures [5], especially when they are brief; used prior to clinical encounters to facilitate patient-physician shared decision-making [6]; are informationally "balanced" [7]; and are "gain-framed" rather than "loss-framed" [4,5]. Interactive videos are an excellent format for meeting these criteria.

In the case of PCa, the role of patient anxiety in decision-making for treatment initiation is paramount. In an earlier study, Dale et al. [8] showed cancer-specific anxiety predicts the often unnecessary early initiation of Hormone Therapy (HT), despite associated toxicities and questionable impact on life expectancy. One way anxiety is reduced is through improved knowledge, in turn reducing uncertainty [9–12]. Several studies have shown, DAs are effective for increasing patient knowledge [5,13–15] through providing an improved understanding of specific mechanisms implicated, such as increasing knowledge of treatment options, their advantages and disadvantages [3] and,

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reducing anxiety [16]. Also, DAs have several advantages such as: increasing patients' participation in care-decisions, resulting in decreased use of PSA testing [17]; facilitating shared decision-making between patient and physician [13,18,19]; lowering patient levels of decisional conflict [19]; and eliminating searches for additional information [1].

To better understand the role of DA's in PCa patient decision-making on HT treatment, we designed a two-part study: Study 1 included a randomized control trial of a DA in PCa patients (with biochemical recurrence) starting HT and measured on a battery of instruments asking about knowledge comprehension, decision-making, and anxiety [20]. The present research, Study 2, was designed to elicit and qualitatively analyze patients' self-reports of their perceptions on recurrent PCa and starting HT. The methods used for the current, Study 2, are described below (for Study 1 details, see [20]).

2. Methods

Patients with recurrent PCa were recruited at three academic medical sites (two in the Midwest, one in northeast US), and phone interviews with them were conducted one-week post consultation, from one Midwest site. Patients were randomized to two groups by random draw of sealed envelopes to receive Standard-of-Care (SoC) treatment or a DA (intervention) of a DVD about HT. Patients were seen by two board-certified medical oncologists, experts in GU cancers. Analysts were blinded to the identity of the groups, known to them as only Group A and Group B. Further, prior to the coding process, a team member redacted those parts of the transcripts bearing any reference to the DA to preclude any chance of analysts conjecturing their Group identification. The present research focuses on the qualitative analysis of Groups A and B. Internal Review Board (IRB) approval for this study was obtained at all three sites.

2.1. Sample

In line with qualitative research methodology, "theme saturation" [24], i.e. the point at which no new themes emerge from the data, was found to occur upon the completion of 11 interviews in both groups. To ensure we had captured all emergent themes for analysis, we continued to interview patients and collect data for two additional patients, bringing the sample size in the two groups to 13 each, for a total sample size of 26. Inclusion criteria for both groups were: patients be over 50 years of age; have had previous localized treatment for PCa (i.e. surgery or radiation); have evidence of biochemical recurrence of PCa (two consecutive 0.2 ng/mL increases in PSA after previous treatment) [21]; be English speaking; not be diagnosed with cognitive impairment; not have metastatic cancer on imaging studies; not be enrolled in any clinical treatment trial; have no other cancer diagnosis (within past year); and, not have received HT treatment within past year. This being a field study, we ended–up recruiting a sample (including both DA and SoC groups) comprising two-thirds of patients (65.4%) over the age of 65, with a mean age of 69.04 years (see Table 1). Thus, the sample mainly represents older men.

2.2. Recruitment

Patients with follow-up oncology appointments, meeting inclusion criteria, were approached in clinic waiting areas, by Research Assistants (AW, KVV), and invited to participate in the study. If they agreed, written consent was obtained, and they were assigned by random draw of sealed envelopes to receive SoC treatment, or DA intervention of a DVD about HT. Before their physician visit, on the same day, Group B patients were escorted by one of the Research Assistants to a viewing room, and the DA DVD was started for them.

Table 1
Demographic charactersitics of recurrent prostate cancer patients, n = 26.

	Demographic variables	Decision aid group	Control group	T-test
		Mean ± sd or %	Mean ± sd or %	p value
1	Age			
	Overall	67 ± 11.29	71.08 ± 8.06	p = 0.301
	Less than 64	46.2	23	
	65–74	23.1	38.5	
	75–84	23.1	38.5	
	85 or older	7.6		
2	Ethnicity			p = 0.063
	White	53.8	84.6	
	Black/African American	23.1	15.4	
	Other[a]	23.1	0	
3	Education			p = 0.650
	High school graduate or less	38.5	23.1	
	College graduate or less	30.8	38.5	
	Graduate-level education	30.8	38.5	
4	Income			p = 0.876
	$2500 to $25,000	15.4	15.8	
	$25,001 to $50,000	15.4	15.4	
	$50,001 to $100,000	30.8	60.8	
	$100,001 to $200,000	23.1	15.4	
	Over $200,001	0.0	15.4	
	Do not wish to answer	15.4	7.7	
5	Marital status			p = 0 .352
	Single (never married, engaged, not living with partner)	0.0	0	
	Married, engaged or living with partner	69.2	84.6	
	Divorced	7.7	0	
	Widowed	15.4	7.7	
	Separated	7.7	7.7	
6	Years in Marriage	30 ± 8.2	41 ± 14.8	
	Years separated	22	31 ± 26.9	
	Years widowed	19 ± 8.5	20	
7	Clinical variables			
	PSA level at time of visit	5.49 ± 8.27	3.185 ± 2.60	p = 0 .350
	Gleason grade	7.11 ± 1.17	6.85 ± .56	p = 0.540

[a] Category "Other" consisted of Asian/Pacific Islander, American Indian/Alaskan, and Else.

2.3. Intervention

The intervention comprised a DA-DVD entitled "Hormone Therapy: When the prostate-specific antigen (PSA) rises after prostate cancer treatment" [22],—a 37 min long DVD (accompanied by a booklet with the same verbatim content) presented an elderly-looking (mid-60's) African-American gentleman narrating a monologue about the treatment option of HT with comprehensive information on five major aspects including: 1) what does a rising PSA mean; 2) what is HT; 3) timing of HT; 4) types of HT; and 5) toxicities of HT, especially pertinent for older men. All contextual elements of the video—narrator, his voice tone, and comforting context he was portrayed in—conveyed a message of comfort for the patient/loved one.

2.4. Phone Questionnaires

One week post-consultation, follow-up semi-structured telephone interviews were conducted (RGB) with patients in both Groups A and B. Two separate questionnaires, one each for Group A and B were developed (JH, WD, RGB). Each questionnaire comprised two sections: Section 1 – common to both – included a battery of instruments for measuring knowledge comprehension, decision-making, and anxiety (total 31 items); Section 2 comprised a separate series of open-ended qualitative questions for Groups A and B (see Appendix 1). For Group B, Section 2 questions pertained to satisfaction with office visit, comprehension on DA DVD, and implications for decision-making (10 items)