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## Satisfaction with Information Used to Choose Prostate Cancer Treatment

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### Abstract

**Purpose**—After being diagnosed with prostate cancer men must assimilate information regarding the cancer. Satisfaction with information reflects the evaluation of information sources used before treatment to select a therapy. We describe the use and helpfulness of several information sources available to prostate cancer survivors. We also identified factors associated with satisfaction with information.

**Materials and Methods**—A total of 1,204 men with newly diagnosed prostate cancer were enrolled in the prospective, multicenter Prostate Cancer Outcomes and Satisfaction with Therapy Quality Assessment study. The validated satisfaction with information domain of the Service Satisfaction Scale-Cancer was administered to subjects 2 months after treatment. The relationship between several factors, such as demographics, socioeconomic factors, cancer severity and types of information sources, and satisfaction with information were evaluated using multiple regression.

**Results**—Sources of information endorsed by subjects varied by race, education and study site. The most helpful sources were treatment description by the treating physician (33.1%), Internet sites (18.9%) and books (18.1%). In multiple variable models patient age ( $p = 0.005$ ) and

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information provided by the physician regarding outcomes in their patients ( $p = 0.01$ ) were independently associated with patient satisfaction with the information provided.

**Conclusions**—Various information sources were used and endorsed as helpful by subjects, although results for physician patients was the only source independently associated with satisfaction with information. Providing patients with information about possible or expected courses of care and outcomes may improve satisfaction.

### Keywords

prostate; prostatic neoplasms; consumer health information; consumer satisfaction; questionnaires

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In diseases characterized by several effective treatment options such as prostate cancer therapy selection is often based on expected outcomes. Consequently, assessing the information needs of patients as well as the availability, use and helpfulness of various sources of information is crucial.<sup>1</sup> The benefits of informing patients are broad. For many cancer survivors information translates to greater involvement in management decisions, improved coping ability,<sup>2</sup> decreased anxiety and distress,<sup>3,4</sup> improved communication with family members<sup>5-7</sup> and increased satisfaction with treatment choices.<sup>8,9</sup> Although this has been an active general area of research, relatively little is known about the use and helpfulness of information sources for prostate cancer survivors.<sup>10</sup>

The impact of information availability and quality on preference sensitive treatment decisions is particularly relevant in prostate cancer, which affects a large number of men<sup>11</sup> and is associated with significant treatment related impairments.<sup>12</sup> While several different information sources are available, issues related to content, quality and accessibility may limit the overall use and helpfulness of these materials. For example, in prostate cancer many information sources do not adequately describe the consequences of treatment while others use relatively complicated descriptions.<sup>13</sup>

Patient SWI is an indicator of how helpful information sources were in selecting therapy and it may reflect how well pretreatment expectations were fulfilled by the treatment experience and outcomes. As a result, SWI reflects the quality of information used to make treatment decisions, the extent to which patients are well informed and the relationship between expectations and outcomes.

Despite the high prevalence of prostate cancer there is limited information on how frequently various information sources are used by patients, whether they are helpful or whether they are associated with greater patient satisfaction. We addressed this gap by evaluating information use and satisfaction in a sample of men recently diagnosed with prostate cancer and undergoing definitive therapy.

## METHODS

### Cohort

The study cohort consisted of subjects followed as part of the PROST-QA Consortium. The PROST-QA study is a prospective, multi-institutional, observational study designed to

assess longitudinal changes in health related quality of life and patient/spouse satisfaction with processes of care among men with early stage prostate cancer treated primarily with local therapy (radical prostatectomy, external radiation or interstitial brachytherapy).<sup>14</sup> This analysis focused on patient satisfaction with information after treatment from March 2003 until March 2006. During this interval 1,204 patients diagnosed with early stage (T2NXMX or less) prostate cancer enrolled in the PROST-QA study and were followed longitudinally with repeat surveys.

## Study

**Measures**—Study participants completed several patient directed questionnaires before treatment and during followup through CATIs. Standardized response forms were used to record the use and helpfulness of various information sources among study participants. Endorsable information sources included physician description of treatments, print material (books, pamphlets and brochures), Internet based information (websites), video material, physician referral to other patients previously treated for prostate cancer, consultant physician specific outcomes, and family and friends. For study purposes subjects were explicitly asked which sources they used and which they found most helpful. SCA, a reliable and responsive instrument adapted from the Service Satisfaction Scale,<sup>15,16</sup> was used to measure patient satisfaction with information during followup. SCA consists of 16 items measuring patient satisfaction across several treatment related domains, including 3 that measure satisfaction with information used to make treatment related decisions. Higher scores indicate higher satisfaction levels. SCA assesses the satisfaction of information sources using 7-point Likert scale responses converted to a scale of 0 to 100.

**Procedures**—Institutional review board approval was obtained at each clinical center, in addition to the data coordinating center. Informed consent was obtained from each participant. Baseline demographic and clinical information was collected before treatment. Also, participant use of the different sources of information was documented before treatment initiation (table 1). Additional clinical information, including pathological data as well as functional and health related quality of life outcomes, was collected after therapy. For this analysis we used satisfaction with information measured 2 months after the initiation of therapy using SCA. Questionnaire items regarding the helpfulness of used information sources were collected through CATIs between 2 and 36 months after treatment.

## Statistical Analysis

The principal study end points included source of information used, source helpfulness and satisfaction with information. Bivariate comparisons and multivariate logistic regression was used to separately determine factors associated with each end point (use, helpfulness and satisfaction). Multivariate analyses were adjusted for several independent variables, including disease severity (clinical stage and Gleason score) and patient characteristics such as age, race, education, income and marital status. Backward model selection retaining only significant independent variables was used to arrive at the final models. All statistical analysis was done at a 0.05 threshold for significance using SAS® 9.1.

## RESULTS

### Information Source

**Utilization and cohort characteristics**—Study subjects included 1,204 patients with early stage prostate cancer who enrolled in the study before March 2006 (table 1). A broad range of ages was represented (median 63 years, range 38 to 84). Although 88.2% of participants were white, 135 minority men also participated. Primary treatment included radical prostatectomy, external beam radiation therapy or brachytherapy, each with or without concomitant androgen deprivation therapy (table 1). Physician description was the most commonly used source of information (93.2% of cases), followed by print sources such as pamphlets and brochures (82.5%). Most men also used other sources, including websites (68%), family and friends (63.7%), and books on prostate cancer (59.1%). Other sources, such as video media, access to other men treated for prostate cancer and summaries of physician specific outcomes, were used less commonly.

Information sources used by patients varied significantly by race, education and study site. In general, use of physician treatment description was common, although lower income men were less likely to use this particular source of information than men of higher socioeconomic status. Internet based sources were less commonly used by older, black, unmarried men without a college education and with a relatively low income. Nonblack, college educated men who were married and had a higher income were more likely to use family and friends as a source of information. Use of books also correlated significantly with high education, higher socioeconomic position and marital status. However, a college education was the only factor associated with the use of physician specific outcomes while access to other men previously treated for prostate cancer was used more frequently by younger, nonblack men with a college education and relatively higher income. Video media were more commonly used as a source of information by black men (table 2).

Although the use of information sources varied across different demographic groups, endorsement of helpfulness by those using a given source did not vary and was consistently high for each source. For instance, the proportion of study participants who reported that various sources were helpful varied narrowly, ranging from 81.3% for access to previously treated patients to 100% for several other information sources. Five of the 7 information sources achieved a helpful rating by greater than 95% of participants and all except one (access to previously treated patients) was endorsed by greater than 90% regardless of demographic background (table 2).

**Patient endorsement of helpfulness**—Endorsement regarding which information sources patients found helpful, most helpful and least helpful was evaluated by patient report collected by CATI 2, 6, 12, 24 and 36 months after treatment (table 3). A high percent of patients endorsed sources of information as helpful. Of these sources physician description of treatment was identified as most helpful (33.1%), followed by Internet based information (18.9%) and books (18.1%). However, many other patients found the Internet to be the least helpful source of information. In addition to information from family and friends, print information in the form of pamphlets and brochures was also reported as being among the least helpful sources of information.

## Determinants of Effectiveness of and Satisfaction with Information

Although satisfaction with information was relatively high in most settings, scores varied across demographic groups, and according to the endorsed use and helpfulness of particular information sources. While endorsed use and helpfulness did not substantially impact SWI scores for most information sources, unhelpful information partially explained observed differences in satisfaction with information for some sources. For example, in the case of physician description satisfaction scores were particularly low when the description was used to make a treatment choice but it was reported to be not helpful (table 3). In adjusted models older age ( $p = 0.005$ ), use of print materials, including pamphlets and brochures ( $p = 0.02$ ), and physician description ( $p < 0.001$ ) were independently associated with information use and helpfulness. In contrast, physician specific outcome was the only information source independently associated with satisfaction scores ( $p < 0.001$ ). However, satisfaction scores were relatively favorable despite these observed differences. Mean model adjusted SWI scores were 90.0 and 87.9 on a 100-point scale for study participants who did and did not receive information on physician specific outcomes, respectively. These scores compared similarly to those of patients with other cancers.<sup>13</sup>

## DISCUSSION

Pretreatment information sources are used to select cancer therapy. Accordingly, they are important determinants of care in the management of prostate cancer. Patient satisfaction is the affective response of the patient to the cognitive evaluation of service and performance during a health care related experience.<sup>1</sup> This applies to information sources used to make health care decisions. Source specific factors, such as availability, format, content, amount and clarity,<sup>17</sup> as well as perceived reliability<sup>18</sup> contribute to satisfaction with information. More importantly, information sources must not only be used but also be helpful to achieve better satisfaction.

Men with recently diagnosed prostate cancer must assimilate disease and treatment related information before selecting a treatment. Therefore, the use, helpfulness and satisfaction with sources of information are important considerations in this population. We found that physician description was the most commonly used and helpful source of information endorsed by men who recently made the treatment decision. Men also found Internet sources and books helpful but to a lesser degree.

Our analysis also suggests that the use and helpfulness of different information sources vary by socioeconomic factors such as age, race, education level, income and marital status. Differences in source use were apparent among men of different backgrounds. In general, younger, nonblack, married men with a college education and higher income used more information sources. This was most apparent in the use of Internet based sources, for which there were significant differences between men of different socioeconomic and educational backgrounds. Significant differences were also seen in the use of books, family and friends, and access to other men with previous experience with prostate cancer treatments. These differences may be related to knowledge of and access to greater resources, although variation in information seeking behaviors<sup>19</sup> and coping mechanisms<sup>20</sup> among men of different demographic backgrounds cannot be discounted. Among men who used a

particular information source the helpfulness of that source did not vary significantly by socioeconomic strata, suggesting that disparity occurred due to the availability or accessibility of the information source rather than its value, for example as observed previously for Internet use to access health information.<sup>21</sup> We also noted that satisfaction with information scores were highest among information users who found information sources helpful and lowest among users who did not find the source helpful. However, men who did not use information sources were as satisfied as men who used information sources and found them helpful.

The only information source independently associated with SWI was physician specific treatment outcomes provided by the treating physician. The implications of this finding are significant. Despite availability and access to a multitude of information sources physician based information may be the most important, relevant information source used by patients to select therapy. Moreover, the fact that this information is physician specific and related to treatment outcomes indicates that patient satisfaction with treatment and outcome may be directly related to patient expectation based on pretreatment counseling. From a broader perspective these findings suggest that patients value information that is specific to their practitioner and their situation over general outcome information found in other, more diffuse information sources. However, satisfaction scores were relatively high for most information sources, suggesting a possible ceiling effect. Nevertheless, these data highlight the pivotal role of physician counseling and demonstrate a potential negative impact when patients perceive that physician descriptions of treatment options and outcomes are unhelpful.

These data provide insight into the decision making process of patients with prostate cancer and serve as a foundation from which future decision aids may be developed. Previous research in this area shows that patients with cancer want as much information as possible after diagnosis.<sup>22,23</sup> To date most prostate cancer research has focused on the information needs and sources used.<sup>24,25</sup> While patients with prostate cancer require information throughout the cancer care continuum,<sup>26</sup> their needs appear to be greatest during the period before their treatment decision.<sup>27</sup>

Although most patients believe that they receive adequate information, a substantial number are not satisfied.<sup>28</sup> In 1 study 20% of patients with cancer were dissatisfied with the information provided.<sup>29</sup> Furthermore, information on treatment side effects is important for patients with cancer. For those with prostate cancer the impact of treatment on health related quality of life is an important consideration. Reliable pretreatment information may allow patients to set expectations regarding treatment outcomes and make informed decisions when selecting therapy. Our results indicate that outcome information specific to the treating physician is associated with greater patient satisfaction after treatment and this type of information may assist patients in the decision making process.

A limitation of our study is the relatively high proportion of white men. In addition, recruitment sites for PROST-QA include academic referral centers where there is surgical and radiation therapy expertise. Consequently, results may not be generalizable to nonreferral practice settings. The information types offered also varied among treatment



sites and study participants were not counseled using a standardized set of information sources. However, since this is what would be expected in the setting of general practice, it may be more reflective of the types of information sources available to most men treated for prostate cancer in the United States. Lastly, because study objectives consisted of studying men undergoing definitive therapy, results regarding the use of and satisfaction with information sources among men treated with active surveillance was not available.

Despite these limitations this study offers important information on how patients are counseled, the types of information that they find helpful and factors associated with satisfaction with information.

## CONCLUSIONS

Use, helpfulness and satisfaction with information are important to selecting prostate cancer treatment. Physician based sources such as descriptions of treatment procedures as well as outcomes specific to the treating physician appear to be important determinants of patient satisfaction. These findings suggest that a multitude of information sources may be used and found helpful but physician specific outcomes may lead to higher patient satisfaction.

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## Abbreviations and Acronyms

<b>CATI</b>	computer assisted telephone interview
<b>PROST-QA</b>	Prostate Cancer Outcomes and Satisfaction with Therapy Quality Assessment
<b>SCA</b>	Service Satisfaction Scale-Cancer
<b>SWI</b>	satisfaction with information

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**Table 1**

## Population characteristics

	No. Pts (%) <sup>*</sup>
Race:	
White	1006 (88.2)
Black	112 (9.8)
Other	23 (2.0)
Marital status:	
Married	925 (79.9)
Single	231 (20.0)
Education level:	
Greater than high school	39 (3.4)
High school	456 (39.4)
College or greater	663 (57.2)
Income (\$):	
30,000 or Less	134 (12.1)
Greater than 30,000	970 (87.9)
Gleason score:	
6 or Less	703 (61.5)
7	378 (33.0)
8–10	63 (5.5)
Stage:	
T1c	851 (74.4)
T2a	188 (16.4)
T2b/c	105 (9.2)
Treatment:	
Surgery	578 (49.9)
Radiation	280 (24.2)
Brachytherapy	278 (24.0)
Combination therapy	22 (1.9)

\* Not all categories sum to 1,204 patients due to missing data or withdrawal.

**Table 2**

Used and helpful information sources by demographics

<i>Used</i>	% Physician Description	% Pamphlets/Brochures	% Internet	% Family/Friends	% Books	% Physician Outcomes	% Access to Pts	% Video
Age:								
63 or Less	94.0	81.1	79.5*	66.2	61.7	32.4	27.9*	10.7
64+	92.3	84.0	54.9	60.9	56.2	35.4	19.6	9.7
Race:								
Nonblack	93.7	82.2	70.2*	65.4*	59.7	33.1	25.1*	9.6*
Black	90.1	84.7	47.3	51.8	50.9	40.9	14.3	17.0
Education:								
Less than college	92.5	83.5	56.9*	59.4*	51.8*	38.2*	19.8*	11.0
College or greater	93.8	81.7	76.3	67.0	64.6	30.4	27.2	9.7
Income (\$):								
Less than 30,000	85.6*	83.2	38.8*	53.0*	41.8*	39.1	11.9*	11.2
30,000 or Greater	94.3	82.5	72.4	65.9	62.1	33.4	26.4	10.4
Marital status:								
Married	93.0	82.8	69.5*	65.4*	60.6*	34.7	25.2	10.8
Not married	93.9	81.1	62.3	56.7	53.3	29.8	19.6	7.8
<i>Helpful</i>								
Age:								
63 or Less	97.9	98.6	98.8	95.6	98.7	97.5	88.2	92.4
64+	99.4	97.3	99.0	92.4	99.0	97.3	92.4	90.4
Race:								
Nonblack	98.9	98.1	98.8	94.2	98.9	97.0	90.2	90.8
Black	98.0	97.9	100.0	94.8	100.0	100.0	81.3	94.7
Education:								
Less than college	98.5	98.0	98.6	93.8	99.2	97.3	92.7	92.6
College or greater	98.7	98.0	99.0	94.4	98.6	97.5	88.3	90.6
Income (\$):								
Less than 30,000	98.2	98.2	98.1	95.7	98.3	100.0	87.5	93.3

	% Physician Description	% Pamphlets/Brochures	% Internet	% Family/Friends	% Books	% Physician Outcomes	% Access to Pts	% Video
30,000 or Greater	98.7	99.0	99.0	93.7	98.8	96.9	90.1	91.1
Marital status:								
Married	98.8	97.8	98.8	94.0	98.6	96.9	90.0	90.9
Not married	97.7	98.9	99.3	94.6	100.0	100.0	88.9	94.4

\* Statistically significant pairwise difference between demographic strata (p<0.05).

**Table 3**

Used and helpful information, and information source SWI scores

	Physician Description	Pamphlets/Brochures	Internet	Family/Friends	Books	Physician Outcomes	Access to Pts	Video
Used + helpful (% pts):								
Used	93.2	82.5	68.0	63.7	59.1	33.8	24.0	10.2
Helpful*	98.6	98.0	98.9	94.2	98.8	97.4	89.8	91.5
Most helpful*	33.1	11.4	18.9	16.1	18.1	0.3	1.9	0.4
Least helpful*	8.1	22.9	18.1	30.2	11.4	3.4	3.1	2.8
SWI score (range 0-100):								
Used/helpful	88.8	89.0	87.9	88.4	88.4	90.2	89.7	88.9
Used/not helpful	67.9	80.8	88.0	90.0	86.1	84.5	87.1	80.0
Not used	88.3	87.1	89.9	88.6	88.7	87.9	88.3	88.6
p Value	<0.001	0.08	0.05	0.40	0.83	0.04	0.24	0.04

\* Of patients who used this source.