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To link to this article: http://dx.doi.org/10.1081/CNV-100106143

Published online: 30 Sep 2001.

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Health Literacy and Shared Decision Making for Prostate Cancer Patients with Low Socioeconomic Status

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ABSTRACT

Quality of life (QOL) considerations are important in the treatment decision making process for prostate cancer patients. Although patient involvement in the treatment decision process has been encouraged, low health literacy can limit patient understanding of the complex information about treatments and their probable QOL outcomes and is a barrier to patient participation in the decision-making process. The objectives of the study were to evaluate (i) knowledge, level of satisfaction, and treatment preferences and intentions of men newly diagnosed with prostate cancer after participation in a CD-ROM shared decision making program; and (ii) the relationship between prostate cancer knowledge and health literacy. Thirty newly diagnosed prostate cancer patients from two Veteran’s Administration (VA) hospitals in Chicago completed a demographic questionnaire and participated in an interactive CD-ROM shared decision making program. Subsequently, knowledge of pros-

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Shared Decision Making for Prostate Cancer

Prostate cancer is the most prevalent neoplasm and the second leading cause of cancer death among men in the United States, with approximately 180,400 new cases and 31,900 deaths expected annually (1). There are currently no data that indicate the superiority of any treatment with regard to survival. Each prostate cancer treatment affects the patient’s quality of life (QOL) differently; consequently, QOL considerations, as well as clinical characteristics, such as tumor stage and grade, and patient age and comorbidities, are important in treatment decision making (2–10).

Treatment decisions require an understanding of possible treatments and their expected outcomes, and an understanding of patients’ preferences for the possible outcomes. However, there may be limitations in physician understanding of patient outcome preferences. Crawford et al., in a survey of prostate cancer patients and an independent sample of urologists, found that patients and physicians differed in their perceptions about what QOL issues were important in selecting a treatment (11). A majority of patients could not recall any discussion with their doctors about expectant management, patient preferences, treatment costs, and changes in sexual function with treatment. Although patient involvement in the treatment decision process has been encouraged, low health literacy can limit patient understanding of the complex information about treatments and their probable QOL outcomes, and is a barrier to patient participation in the decision-making process. Low health literacy has been associated with later stages of prostate cancer at the time of diagnosis (12), but there is little information on the role of health literacy in medical decision making.

A wide variety of shared decision making programs in video or CD-ROM format have been developed to facilitate patient involvement with treatment decisions (13,14). These programs typically provide the patient with information about the medical condition and the benefits and risks associated with each treatment option. Video shared decision making programs have advantages of being affordable, widely available, and easy to use in a clinic setting. Previous studies have indicated that video programs improve patient knowledge about the disease,
its risk factors, treatments, and side effects of alternative treatments, and increase patient involvement in treatment decisions (15,16).

The CD-ROM shared decision making program is an alternative to the “one-size-fits-all” approach of many video programs. The interactive CD-ROM program can pose questions to the patient and then tailor the information presentation according to the patient’s responses. For example, an interactive CD-ROM program for prostate cancer will present different information to a patient who indicates that he is 78 years old, has a low-grade tumor, and has diabetes and heart disease, compared to what it will provide to a patient who indicates that he is 48 years old, has a high-grade tumor, and has no other health problems. In addition to providing information, interactive programs using CD-ROM technology elicit patient preferences and some use a decision analytic model to incorporate the preferences and clinical characteristics to generate a treatment recommendation.

The feasibility of interactive CD-ROM technology in treatment decision making with respect to benign prostatic hyperplasia has been assessed in two studies (17,18). Both investigations revealed an association between the use of the CD-ROM program and high levels of patient satisfaction, improved patient and physician communication, and a lower rate of transurethral prostatectomy (TURP). Although use of the CD-ROM program seemed to produce more focused discussions about the benefits and risks of various treatments between patients and their physicians, the program required a number of face-to-face sessions to introduce and implement it and to address follow-up questions. Despite the potential to improve patient participation in the decision-making process, there is little information on the efficacy of video or CD-ROM decision support programs across various levels of health literacy.

This study of newly diagnosed prostate cancer patients from two Veteran’s Administration (VA) medical centers expands upon the results of the previous studies and builds on our investigations of literacy and treatment decision making among prostate cancer patients. Specifically, we investigated an interactive CD-ROM shared decision making program among men recently diagnosed with prostate cancer, many of whom are of lower socioeconomic status and have lower levels of health literacy. We evaluated the following: (i) knowledge, level of satisfaction, and treatment preferences and intentions of men newly diagnosed with prostate cancer after participation in the CD-ROM shared decision making program; and (ii) the relationship between prostate cancer knowledge and health literacy.

METHODS

Newly diagnosed prostate cancer patients from two VA hospitals in Chicago were eligible to participate in the study. At the follow-up visit after the initial diagnosis of prostate cancer, a urology nurse case manager (K.M.C.) introduced eligible patients to the project and its objectives. Upon obtaining written informed consent, patients completed a demographic questionnaire and participated in an interactive CD-ROM shared decision making program. A research assistant was available in the room to answer questions and assist participants with navigating through the CD-ROM program screens.

The CD-ROM program was produced by Schering Plough, Inc. for a general audience of prostate cancer patients. The CD-ROM included textual descriptions of various stages of prostate cancer and associated treatment options, illustrated by anatomical drawings. The program included video presentations by physicians, video clips showing patients receiving treatment, and video testimonials by prostate cancer patients and their families about their experiences with the disease and different treatments they received. The CD-ROM listed each treatment option separately and stated that some patients may receive a combination of the described treatments. Once patients completed the overview of prostate cancer treatments, the CD-ROM presented patients with a questionnaire regarding specific details of the patients’ disease and the subsequent screens were tailored to each patient’s stage of disease and specific treatment options.

After patients participated in the CD-ROM program, the research assistant administered questionnaires assessing knowledge of prostate cancer, satisfaction with the information in the computer CD-ROM program, treatment preference, and likelihood of following treatment preference (see Appendix). Prostate cancer knowledge was assessed by the Prostate Cancer Knowledge Questionnaire (PCKQ), a 23-item questionnaire developed by the investigators to correspond to the language of the CD-ROM program. Treatment preference was assessed by having patients choose from a list of all possible treatment options that had been presented as a part of the CD-ROM program. Because the CD-ROM program stated that patients might receive a combination of treatments, combined treatments were also included (e.g., radical prostatectomy and radiation).

The research assistant also administered a health literacy assessment, the Rapid Estimate of Adult Literacy in Medicine (REALM), which has been validated in various clinical settings and in research studies for prostate can-
In the REALM word recognition test, the raw score (0–66) can be converted to four reading levels: 0 to 3rd grade (0–18), 4th to 6th grade (19–44), 7th to 8th grade (45–60), and 9th grade or higher (61–66) (19). After the patient interview, medical charts were abstracted to determine each participant’s date of diagnosis, stage of disease, and treatment received.

**Statistical Analysis**

Descriptive statistics (frequency, mean, standard deviation, and standard error of the mean) were calculated for demographic and clinical variables, CD-ROM satisfaction items, treatment preference and intention items, PCKQ, and the REALM. The REALM was scored according to instructions outlined by Davis et al. (19). The percentage of correct responses was used to obtain a score in the PCKQ. Patients rated satisfaction and intention items for treatment preferences on a 5-point Likert scale, where 5 represented the highest score and 1 represented the lowest score. The frequency of responses in each preference category was calculated for the satisfaction and intention items.

The REALM was also used as a continuous measure for correlation analyses. The Pearson correlation test was used to assess the relationship between REALM and PCKQ scores. The **χ²** test was used to evaluate the relationships between demographic and clinical variables on CD-ROM satisfaction, treatment preference and intention, PCKQ, and REALM. The Fischer exact test was used to assess the relationship and differences between patient demographics and selected treatments. A *p* value of 0.05 was used to determine significance.

**RESULTS**

**Demographics and Clinical Characteristics**

Thirty-one patients agreed to participate in the CD-ROM intervention (Table 1). Of these participants, 1 patient declined to complete the subsequent questionnaires after viewing the CD-ROM tool. One-half of the 30 participants were African American, 43.3% were white, and 6.7% were Asian American. The mean age of the sample was 67.0 years (SD = 9.5) and 63.3% were married. The majority of participants were diagnosed with clinically localized disease (stages A or B) (86.7% or *n* = 26), 3.3% were diagnosed with stage C disease (*n* = 1), and the remaining patients were diagnosed with metastatic disease (*n* = 3). More than 70% of the sample had graduated from high school, and 33.3% had entered college or a professional school, whereas 23.3% had received some high school education or less.

**Health Literacy and PCKQ**

Participants’ mean REALM score was 57.1 (SD = 10.9), equivalent to a 7th–8th grade literacy level. More than one-third of participants (36.7%) had lower than 9th grade literacy levels. Participants achieved a mean score of 74.0% on the PCKQ (Table 1). Seven patients scored 90.0% or higher, 13 patients scored between 70.0 and 89.9%, and 10 patients scored 69.9% or lower (Table 2). Participants’ PCKQ scores correlated with their REALM scores (Pearson correlation *r* = 0.65 *p* = 0.0001). Participants who did not attain a high school diploma tended to score lower on the PCKQ (62.1%) when compared to high school graduates (74.1%) and patients who went on to further education (82.2%), however this trend was not
Table 2
Treatment Preference at the Time of the CD-ROM Intervention and Treatments Received for Study Patients (N = 30)

<table>
<thead>
<tr>
<th>Treatment Preferences</th>
<th>Treatments Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (percent)</td>
<td>N (percent)</td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>3 (10.0)</td>
</tr>
<tr>
<td>Radiation</td>
<td>4 (13.3)</td>
</tr>
<tr>
<td>Hormone</td>
<td>6 (20.0)</td>
</tr>
<tr>
<td>Radical prostatectomy and radiation</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>Radical prostatectomy and hormone</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>Radiation and hormone</td>
<td>4 (13.3)</td>
</tr>
<tr>
<td>Watchful waiting</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Undecided</td>
<td>9 (30.0)</td>
</tr>
</tbody>
</table>

significant. PCKQ scores did not vary by any other demographic variables.

Patient Satisfaction with CD-ROM Program

More than three-quarters of the patients rated the information in the CD-ROM as “very satisfactory” (highest possible rating). The remaining patients rated the program as “somewhat satisfactory” (13.3%), “neither satisfactory of unsatisfactory” (3.3%), or “somewhat unsatisfactory” (3.3%). Ratings for satisfaction with the information presented in the CD-ROM tool and the likelihood of following treatment preferences did not vary by age, literacy, and educational attainment.

Treatment Preferences, Confidence in Treatment Choice/Preference, and Treatments Received by Study Patients

The leading treatment preferences selected by participants after viewing the CD-ROM tool were hormonal therapy (20.0%), radiation (13.3%), radical prostatectomy (10.0%), and combined hormonal and radiation therapy (13.5%). Another 11.5% preferred the combined treatments of radical prostatectomy and either adjuvant hormone therapy or radiation. Approximately one-third of patients were undecided about treatment preferences after viewing the CD-ROM. Treatment preferences varied according to age. When compared to patients greater than 70 years of age, younger patients were more likely to select surgically invasive treatments (40.0 vs. 0.0%; p < 0.05).

Of participants who selected a treatment after completing the CD-ROM tool (n = 21), 47.6% stated that they were “very likely” to follow their treatment preferences, 42.9% were “somewhat likely,” and the remaining were “neither likely nor unlikely.”

Of these 21 participants, 66.7% went on to receive treatments that differed from those reported to be preferred at the time of the CD-ROM intervention. Although 19.0% of the patients selected surgery followed by adjuvant treatments as their treatment preference, none of these patients went on to receive these combined treatments. Four patients selected the combined treatment of radiation and hormone therapy, but only 1 of these patients received this combined treatment. Only 1 of the 4 patients who initially selected radiation therapy received this treatment. Half of the patients that selected hormonal therapy (n = 6) later received other treatments (n = 3), such as radical prostatectomy (n = 1), and 2 patients who originally preferred hormonal treatments were treated more aggressively with the combined treatments of hormone and radiation therapy.

Overall, radiation therapy was the most common treatment that participants received for prostate cancer (26.7%). Approximately one-fourth of the participants received hormonal therapy, 20.0% underwent radical prostatectomy, and 10% received the combined treatments of radiation and hormone therapy. In addition, 20.0% of participants did not receive any treatment and were placed under physician surveillance (see Table 2).

DISCUSSION

Our results indicate that patients were satisfied with the interactive shared decision making CD-ROM pro-
gram, and two-thirds of patients were able to select a preferred treatment that they intended to follow based on the information presented in the program. However, prostate cancer knowledge scores varied among participants after participation in the CD-ROM program, raising doubts that patients were adequately informed to make appropriate choices regarding their treatment. In addition, prostate cancer knowledge varied with literacy scores, with lower knowledge scores corresponding to lower literacy scores, indicating that low literacy may hinder patient understanding of the shared decision making program.

These findings support the results of a previous study of veterans by Schapira and others in which low literacy was associated with poor results on knowledge questionnaires that followed a shared decision making intervention (16). According to the Ad Hoc Committee on Health Literacy, low literacy is frequently associated with low knowledge about disease and low comprehension of written materials, and may have presented a significant barrier to comprehension of information presented in the CD-ROM (20). Because many patients in our study did not receive the treatment they selected after participating in the CD-ROM program, it is likely that low knowledge about the disease and low health literacy ultimately limited patient participation in the shared decision making process with the treating physician.

Previous studies indicated that use of shared decision making programs was associated with improved patient knowledge and patient-physician communication in addition to high levels of patient satisfaction (15,16). We did not evaluate any changes in knowledge or physician-patient communication prior to and after participating in the CD-ROM intervention. However, the variable knowledge scores suggest that even if patient knowledge improved after the intervention, this knowledge may not have been sufficient to allow the patient to be an informed party in the medical decision making process in our population.

The success of the previous studies’ interventions may be due to factors associated with their cohorts’ higher socioeconomic status. According to the National Adult Literacy Survey (NALS), low literacy is significantly more common in populations of lower socioeconomic status, with nearly one-half of the functionally illiterate living in poverty (21–23). Low literacy skills are also associated with lower educational levels. Although the majority of those with low literacy skills are white, ethnic minorities are disproportionately affected. Because our population has a higher percentage of ethnic minorities, patients of lower socioeconomic and educational status, and patients with low literacy skills, the demographic characteristics of our population are likely to explain our results. Because knowledge scores were only associated with literacy scores, literacy may be the most important factor influencing our findings. To examine patient comprehension of interactive shared decision making programs in greater depth, more extensive studies with larger patient cohorts must be undertaken. Although our study had a small number of participants, our findings indicate that low literacy may be an overlooked factor in the implementation of shared decision making tools.

To increase patient participation in shared medical decision making, programs that are specifically tailored to low literacy populations must be developed. In previous studies of written patient educational materials on cancer, most materials exceeded the reading levels of the patients (24,25). When low literacy pamphlets were introduced, patients preferred these pamphlets, however, the improvement in comprehension was not clinically significant (26). Hence, simplification of the text presented in written format in the CD-ROM program alone is unlikely to produce a significant comprehension difference. In successful intervention programs, educational materials were developed in collaboration with the target population (27,28). The educational video produced with patient participation on mammography contained specific low literacy educational strategies (i.e., simplified explanations and lower-grade-level vocabulary) presented in a culturally sensitive and appealing manner for the target population (27). Future studies should use similar approaches to improve the success of shared decision making programs in populations affected by low health literacy.

APPENDIX

Prostate Cancer Knowledge Questionnaire

1. THE CORRECT DESCRIPTION(S) OF THE PROSTATE ARE:
   T F DNK (a) One of the male sex glands
   T F DNK (b) Normally the size of a walnut
   T F DNK (c) Located between the bladder and penis, in front of the rectum; surrounds the urethra
   T F DNK (d) Male sex hormones, like testosterone, do not stimulate the growth of the prostate

2. INDIVIDUALS AT HIGH RISK TO GET PROSTATE CANCER ARE:
   T F DNK (a) Men aged 50 and older
   T F DNK (b) African-American men aged 40 and older are not at risk
3. PROSTATE CANCER CAN BE DIAGNOSED BY:
   T F DNK (a) Symptoms of the need to urinate less frequently and decreased urge or need to urinate
   T F DNK (b) Blood test: PSA
   T F DNK (c) Physical examination: digital rectal examination
   T F DNK (d) Biopsy

4. THE DEFINITION OF STAGING IS:
   "The stage of your prostate cancer is a measure of where the tumor is located, how much the cancer is found in the prostate itself and if it has spread, to other organs."
   T F DNK

5. POSSIBLE TREATMENTS FOR PROSTATE CANCER ARE:
   T F DNK (a) Radical Prostatectomy
   T F DNK (b) External Beam Radiation
   T F DNK (c) Hormonal Therapy
   T F DNK (d) Antibiotic therapy
   T F DNK (e) Cardiovascular Surgery
   T F DNK (f) Watchful Weighting

6. POTENTIAL SIDE EFFECTS OF TREATMENTS FOR PROSTATE CANCER ARE:
   T F DNK (a) Incontinence
   T F DNK (b) Impotence
   T F DNK (c) Hot flashes
   T F DNK (d) Bowel problems (e.g., rectal irritation or bleeding)
   T F DNK (e) Decreased sex drive

Patient Satisfaction and Likelihood of Following Treatment Preference
1. How satisfied are you with the information you received from the shared decision tool?
   □ Very Satisfied □ Somewhat Satisfied □ Neither Satisfied nor Dissatisfied
   □ Somewhat Satisfied □ Dissatisfied

2. How likely are you to follow the recommendation you derived from the shared decision tool?
   □ Very Likely □ Somewhat Likely □ Neither Likely nor Unlikely
   □ Somewhat Likely □ Very Unlikely

ACKNOWLEDGMENTS
Funding for this research was received in part from an unrestricted grant from Schering Plough Incorporated. This study was supported in part by a grant from the Department of Veterans Affairs (Treatment Decision-Making Intervention for Veterans with Prostate Cancer RCD-98337-2). We would like to thank Adam G. Tennant for his contributions to the study.

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