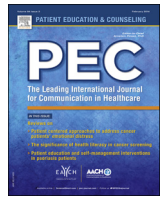




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Research Paper

Impact of a decision aid on newly diagnosed prostate cancer patients' understanding of the rationale for active surveillance

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ABSTRACT

Objective: To compare newly diagnosed localized prostate cancer patients who did and did not view a decision aid (DA) on their knowledge of the rationale for active surveillance (AS).

Methods: A cross-sectional study was conducted among 452 newly diagnosed low-risk localized prostate cancer patients. Patients were mailed the video/DVD DA and completed a web-based questionnaire that contained two multiple choice questions assessing knowledge of the rationale for AS. Multivariable logistic regression was used to estimate the effect of the DA on knowledge of the rationale for AS.

Results: Patients who watched the DA were more likely to correctly respond to each rationale for AS question; both comparisons were statistically significant. After adjustment, men who viewed the DA were 2.9 times as likely to correctly respond to both rationale for AS questions than men who did not view the DA (95% CI: 1.9–4.5).

Conclusion: Patients who viewed a DA better understand the reasons why AS is a viable treatment option for localized prostate cancer than patients who did not view a DA.

Practice implications: Urology clinics and practices should implement the utilization of a treatment DA for newly diagnosed, localized prostate cancer prior to the patients' first cancer consultation.

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1. Introduction

Prostate cancer is the second leading diagnosed cancer and cause of cancer-related death among men in the United States. The American Cancer Society estimates there will be 180,890 new cases of prostate cancer along with 26,120 deaths in 2016 [1]. While prostate cancer is a significant cause of morbidity and mortality, over 80% of newly diagnosed prostate cancer cases have localized disease [2] and most are considered to have a low-risk of progression [3]. Survival rates for low-risk prostate cancer are exceptionally high and most cases will die of causes other than their prostate cancer [4,5]. Accordingly, the overtreatment of localized prostate cancer has been a growing concern of healthcare providers and researchers [6–12], with estimates of up to 67% of low-risk prostate cancer patients receiving unnecessary treatment [7]. Common active treatment options include surgery and radiation, but both can have significant side effects, such as

urinary incontinence, bowel problems and erectile dysfunction [13]. Overtreatment of localized prostate cancer not only impacts quality of life, but has economic implications, as well. A recent study estimated the annual cumulative costs attributable to the overtreatment of low-risk prostate cancer in the United States to be \$58.7 million [7].

Active Surveillance (AS) is an alternative to active treatment that involves monitoring disease progression with a combination of serial prostate specific antigen (PSA) tests, digital rectal examinations, imaging and biopsies and has a goal of reducing overtreatment [14]. Several studies have shown that men on AS have low rates of disease progression and low mortality rates [4,15–17], and AS is considered an appropriate treatment option for low and intermediate risk prostate cancer by the American Urologic Association [18].

While use of AS has increased over the last decade, its use is still under-utilized for a multitude of reasons such as patient knowledge of prostate cancer, both patient and physician anxiety associated with leaving the cancer untreated, and patient awareness of active surveillance [19–22]. Even among patients with awareness of AS, the misconceptions surrounding it prevent many from choosing it [23,24]. For example, in a qualitative study

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designed to describe treatment decision making among men with recently diagnosed localized prostate cancer, Xu et al. found that most men do not understand the appropriateness of active surveillance as a treatment option [25]. Therefore, improving patients' understanding of the rationale for AS has the potential to decrease the over-utilization of more aggressive therapies.

Decision aids (DA) for localized prostate cancer treatment decision making have been demonstrated to improve knowledge of the natural history of disease and the risks and benefits of the various treatment options presented [26–28]. However, in a recent review of treatment decision aids for newly diagnosed localized prostate cancer patients, almost 30% of the DAs reviewed did not present any information on active surveillance as a treatment option [26]. And, while DAs have been shown to increase general prostate cancer knowledge, it is unknown if patient understanding of the rationale for active surveillance specifically, is improved through the use of the DAs.

At Dartmouth Hitchcock Medical Center (DHMC), a video/DVD-based DA has been used since August 2007 as a supplement to provider counseling of newly diagnosed clinically localized prostate cancer patients. The use of this DA institutionally provides an opportunity to evaluate the effect of a DA on patient understanding of active surveillance. Therefore, the objective of the current research is to compare knowledge of the rationale for active surveillance among newly diagnosed localized prostate cancer patients who did and did not view the DA.

2. Methods

2.1. Patients

We conducted a cross-sectional study among newly diagnosed low-risk localized prostate cancer patients seen at DHMC from August 2007 to February 2011. All newly diagnosed prostate cancer patients were identified using ICD-9 code 185 (malignant neoplasm of the prostate) [29]. As part of standard care at DHMC, newly diagnosed prostate cancer patients were required to complete a comprehensive questionnaire prior to their first clinic consultation. Patients who could not read, write or speak English, or were unable to make healthcare decisions for themselves were not given the questionnaire. Patients who had a prostate cancer consultation with a DHMC radiation oncologist or urologist prior to completion of the questionnaire (i.e. hospital consultation) were excluded. Medical charts were reviewed to identify the risk level of prostate cancer patients using the D'Amico risk classification system [30,31]. Patients with low-risk prostate cancer include those with a prostate specific antigen (PSA) < 10, Gleason score < 6,

and clinical stage T1–T2a. Patients with intermediate-risk prostate cancer include those with a PSA ≥ 10 –20, and/or a Gleason score = 7, and/or clinical stage T2b, but not classified as high risk. Patients with high-risk prostate cancer include those with a PSA > 20, or Gleason score ≥ 8 , or clinical stage T2c–T3a. Rates of disease progression are increased among high-risk patients and active treatment may be preferred [18]; therefore, patients classified as high-risk were excluded.

2.2. Procedure

As part of standard care at DHMC, prior to the first prostate cancer clinic visit, all patients were mailed the prostate cancer DA in video or DVD format. The DA was produced by the Foundation for Informed Decision Making and presents evidence-based information designed specifically for patients with early stage prostate cancer. The DA contained facts about prostate cancer, patient testimonies, and equitable information on surgical and radiation-based therapies, as well as active surveillance. In addition, a folder of information on prostate cancer was mailed to all prostate cancer patients including the National Comprehensive Cancer Network patient guidelines and lists of prostate cancer books, websites, and support groups.

Patients were required to complete a questionnaire through a web-based application (either at home or in-clinic prior to appointment) that includes information on demographics, health behaviors, medical information, and prostate cancer knowledge. Questionnaire responses are automatically downloaded into the patients' medical records and viewable reports were generated for the healthcare providers. Patients consent to participate in research through the web-based application. The study was approved by the Institutional Review Board at DHMC (IRB #: 00023341).

2.3. Questionnaire and medical chart information

The questionnaire contained 2 multiple choice questions assessing knowledge of the rationale for active surveillance (see Table 1). Responses to the questions were dichotomized as correct or incorrect and were assessed individually, as well as in combination. The questionnaire also included information on whether or not the patient viewed the DA. Demographic information ascertained from the questionnaire included race/ethnicity, education and marital status. Patients were also asked about their family history of prostate cancer among immediate family members (brother or father). Information ascertained from medical chart review included date of birth, clinical stage, PSA,

Table 1
Rationale for Active Surveillance Multiple-Choice Questions.

Question Label	Question	Responses
Question 1 (Survival)	Without treatment, about how many men diagnosed with early prostate cancer will eventually die of prostate cancer?	(1) Most will die of prostate cancer (2) About half will die of prostate cancer (3) Most will die of something else ^a (4) I am not sure
Question 2 (Reasons)	Which of the following are good reasons for a man with early prostate cancer to consider not having active treatment (surgery or radiation) right away?	(1) To avoid or delay the possible harms of active treatment (2) To make sure active treatment is really needed (3) Both to avoid or delay the possible harms and to make sure active treatment is really needed ^a (4) I am not sure

^a Correct Response.

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