Patient Misunderstanding of the Individual Questions of the American Urological Association Symptom Score

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Purpose: Lower urinary tract symptoms are often assessed using the American Urological Association symptom score. However, some patients may experience difficulty completing the AUA questionnaire. We hypothesized that certain individual questions may generate more misunderstanding than others.

Materials and Methods: This study involved patients at 2 hospitals who completed the American Urological Association symptom score twice, that is 1) self-administered and 2) physician assisted. Analyses compared self-reported and physician obtained responses to each individual question. One-way ANOVA with the Tukey HSD post hoc test was done to assess whether mean disagreements between self-reported and physician administered American Urological Association symptom scores differed significantly by patient education level.

Results: The study group consisted of 998 patients. For each symptom score question we found an inverse relationship between education level and symptom misrepresentation. This discrepancy was the largest for questions on frequency (question 2) and urgency (question 4), which are related to irritative symptoms. Mean misrepresentation of the total American Urological Association symptom score was 2.42 and 5.33 for patients with greater than 12 and fewer than 9 years of education, respectively ($p < 0.001$). Of patients with more than 12 years of education 28% misreported their symptoms by 4 points or greater and 1% misreported them by 10 points or greater, while 58% with fewer than 9 years of education misreported their total score by 4 points or greater and 21% misreported it by greater than 10 points.

Conclusions: While the American Urological Association symptom score is a useful tool for the rapid diagnosis of benign prostatic hyperplasia, patients with low education misrepresent their scores more often and to a higher degree, possibly predisposing them to inappropriate care.

Key Words: prostate, questionnaires, educational status, urination disorders, diagnosis

In 2004 the Institute of Medicine reported that almost half of all American adults might be unable to understand health information, which is a prerequisite of success modern medicine.[1] Consequently almost 90 million men and women in the United States might not be able to learn from patient information materials or effectively use self-administered clinical assessment or screening tools.[2–4]

Treatment for BPH has largely ignored the effect of literacy on patient care. BPH represents a significant economic burden on patients and health care in general with individual costs of up to $25,000 per year and accounting for more $1 billion in nonpharmaceutical treatment annually in the United States.[5,6] The costs of BPH are not limited to medical and surgical interventions. Several studies have demonstrated the significant impact that BPH related symptoms such as nocturia, frequency and urgency have on quality of life, vitality and productivity.[7–10] These symptoms not only account for significant expenditures in treatment, but also exact a substantial cost on individual quality of life and national productivity, necessitating rapid and accurate diagnosis.[7–10]

Many physicians use the AUA-SS to assess and screen patients, chart clinical progress and predict prognoses.[11–13] This questionnaire is widely regarded as a valid, responsive measure of the patient disease state and several studies have shown the efficacy of the AUA-SS in well educated, literate patient populations.[14–16] In a previous study we analyzed the ability of patients to comprehend the AUA-SS and the rates of symptom misrepresentation, and found that patients with low education and literacy often could not correctly self-report their true symptoms using the AUA-SS.[17] We particularly noted that patients misunderstood some AUA-SS questions more than others, resulting in seemingly higher error rates of these questions.

Given the poor understanding of the AUA-SS in patients with education and literacy levels closer to those of the national average, it is important to assess the strengths and weaknesses of individual AUA-SS questions in this population.[18] We identified specific AUA-SS questions that may show significant problems with patient comprehension.

MATERIALS AND METHODS

Study Setting and Population

This study enrolled 998 male patients from the urology clinics of Grady Memorial Hospital and Emory University

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Hospital. Grady Memorial Hospital, located in downtown Atlanta, is a tertiary care facility serving the needs of a primarily underprivileged urban patient population. The Emory University urology department is a tertiary care university clinic. Exclusion criteria consisted of age less than 40 years and the inability to speak English.

Data Collection Procedures

Participants were asked to self-administer the AUA-SS. Designed by the AUA in 1992, this questionnaire aims to assess the symptoms commonly associated with BPH, including incomplete emptying, frequency, intermittence, urgency, weak stream, straining and nocturia. Except for nocturia the AUA-SS assesses the frequency with which patients experience symptoms associated with urinating on a scale from not at all to almost always. For nocturia the scale corresponds to the number of times that a patient urinates per night. The answers to the 7 symptom questions are totaled to determine the severity of patient urinary symptoms, including mild—0 to 7, moderate—8 to 19 and severe—20 to 35.

Following the initial self-administration 2 health care professionals with no difference in training or education level served as individual interviewers and re-administered the AUA-SS to determine the patient symptom score. The administered score was the standard against which the patient administered score was measured. A difference of 2 points or more between the measures of an individual question was the criterion used to define poor comprehension. This criterion was selected a priori based on the change in symptoms represented by these values. Before the initiation of the study this criterion was confirmed by administering similar tests to a select group of highly literate patients, usually those with graduate education, who completely understood the questionnaire. It was found that, while the score of these patients could sometimes change by 1 point depending on how the question was asked, a change in score of 2 points on a given question virtually never occurred. Patients were asked an additional 7 questions on education level, native language, ethnicity, race, socioeconomic status, homelessness and employment status.

Statistical Analysis

The main outcome in this study was the magnitude of error for each question, measured as the difference between the number of points obtained by the self-administered questionnaire and the number of points obtained with physician assistance. Additional outcome measures included the distribution of disagreement between the total self-reported and interviewer administered AUA-SS. Descriptive statistics were calculated to assess the patient population characteristics. The magnitude of errors for each individual question and for the total AUA score was compared across patient education categories. One-way ANOVA with the Tukey HSD post hoc test was performed to assess whether mean errors differed significantly by patient self-reported years of schooling.

RESULTS

In the 998 men enrolled in our study the average age was 63 years and earned monthly income was $2,268 (table 1). Of the patients 7% reported being homeless, while 33% reported being employed. Of study participants 67% were black and 93% were native English speakers. Approximately 43%, 43% and 14% of patients were in the mild, moderate and severe AUA-SS symptom categories, respectively (table 2). Median physician administered AUA-SS was 9.00 (mean 10.59, SE 0.25 and SD 7.83).

TABLE 1. *Study population characteristics*

No. pts	998
Mean ± SEM age	63 ± 13
Mean ± SEM school yrs completed	12.76 ± 3.65
Mean ± SEM income/mo ($)	2,268 ± 8,203
No. race (%):	
White	311 (31.7)
Black	656 (66.8)
Asian	15 (1.5)
No. English as primary language (%)	931 (93.3)
No. currently employed (%)	329 (33.1)
No. currently homeless (%)	74 (7.4)

Figure 1 shows mean absolute differences in self-administered and physician administered score for each AUA-SS question. For each question there was an inverse relationship between the patient education level and the magnitude of the observed error. While most questions had a modest discrepancy in values for patients with more than 12 and fewer than 9 years of education, question 2 on frequency and question 4 on urgency demonstrated the largest mean differences (0.98 and 0.87 points, respectively). Question 6 on straining demonstrated the smallest average discrepancy (0.24 points).

Average differences in total self-administered and physician administered AUA-SS for patients with greater than 12, 12, 9 to 11 and fewer than 9 years of education were 2.42, 3.68, 5.22 and 5.33, respectively. There was no discernible difference in total AUA-SS for patients with fewer than 9 and 9 to 11 years of education. Patients with greater than 12 years of education were significantly different from those whose education ended at 12 years ($p = 0.04$). Each of these groups was significantly different from patients with fewer than 9 and 9 to 11 years of education (each $p < 0.001$).

Figure 2 shows the proportions of errors of different magnitude and direction within each education level. Of patients with more than 12 years of education 28% misreported their symptoms by 4 points or greater compared to 53% with 9 to 11 and 58% with fewer than 9 years of education. While only about 1% of patients with more than 12 years of education misreported their score by 10 points or greater, the corresponding proportion was 14% in patients with 9 to 11 years of education and 21% in those with fewer than 9 years.

DISCUSSION

In the treatment of BPH the AUA-SS remains one of the best physician tools for screening and charting the severity of patient symptoms.[11] Several studies have validated the robustness of the AUA-SS, affirming its goal as an easy-to-use clinical assessment tool designed for patient self-administration.[11,14–16] However, these studies only assessed AUA-SS efficacy in a limited number of patients from select populations. In a recent study patients with limited education or literacy levels demonstrated profound inability to understand the AUA-SS with only 16% able to fully understand the AUA-SS. Moreover, 60% of those who completed the AUA-SS questionnaire reportedly did not understand it.[17]