The Perception of Cancer Risk in Patients With Prevalent Barrett's Esophagus Enrolled in an Endoscopic Surveillance Program

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Background & Aims: **Patients with Barrett's esophagus (BE) have a risk of esophageal adenocarcinoma of approximately 0.5% per year. Patients may have difficulty understanding this risk. This study assessed the perceived risk of cancer in patients with BE, and correlated their risk estimates with their health care use behaviors.** ***Methods:*** **We performed a survey of patients with BE participating in an endoscopic surveillance program at 2 sites: a university teaching hospital and a Veterans' Administration hospital. A questionnaire also elicited their demographics as well as their sources of health information. Health care behaviors, including physician visits and endoscopic surveillance behaviors, were assessed. Patients were classified as either overestimators or nonoverestimators of risk. Characteristics of overestimators, as well as health care use patterns, were assessed.** ***Results:*** **One hundred eighteen patients met entry criteria, and 92 (78%) completed all the questionnaires. Sixty-eight percent of patients overestimated their 1-year risk of cancer, with a mean estimated 1-year cancer risk being 13.6%. The lifetime risk also was overestimated by 38% of patients. Patients who overestimated risk were more likely to be Veterans' Administration medical center patients, have more symptomatic reflux, and were more likely to use the Internet to get health care information. There was no significant difference in physician visits between overestimators and nonestimators (1.2 visits per year vs 1.0, $P = .20$), nor in endoscopy use (5.7 endoscopies per 5-year period vs 5.0, $P = .42$).** ***Conclusions:*** **The majority of patients with prevalent BE participating in an endoscopic surveillance program overestimated their chances of developing adenocarcinoma of the esophagus. Efforts to improve education of such patients with BE are warranted.**

Barrett's esophagus (BE) is a metaplastic change of the esophageal mucosa with the normal squamous epithelium being replaced by specialized or intestinalized columnar epithelium.[1,2] This metaplastic change is thought to occur secondary to chronic acid reflux disease. BE is a common condition and as many as 3 million Americans may harbor this lesion.[3] The clinical significance of BE lies in the increased risk for adenocarcinoma of the esophagus associated with BE. Although baseline risks for adenocarcinoma of the esophagus are quite low in the general population, they are 30–125 times higher in patients with BE.[4,5] Although the relative risk for adenocarcinoma in the setting of BE is quite high compared with those without BE, the absolute risk still is low, with the yearly risk for cancer in nondysplastic BE approximating .5% per person-year.[4,6,7]

Despite the lack of direct evidence showing an improvement in life expectancy in patients with BE, endoscopic surveillance is practiced widely in the United States.[8] The hope is that periodic endoscopic examinations might allow for early detection of either high-grade dysplasia or cancer, enabling intervention that subsequently would decrease the incidence of metastatic disease and death from cancer.[9]

Patients with BE may have a difficult time understanding the risk for cancer associated with the condition. Gross misperception of cancer risk may in turn increase anxiety and decrease health-related quality of life. In addition, patients' health-seeking behaviors also may be colored by their perception of the risk for cancer.

Abbreviations used in this paper: BE, Barrett's esophagus; UNC, University of North Carolina; VAMC, Veterans' Administration Medical Center.

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For instance, patients with BE who greatly overestimate their risk for cancer may be more apt to pursue frequent surveillance endoscopies. Conversely, if patients consider death from cancer inevitable, they may de-emphasize other preventative health measures because they reason that their life expectancy is too short to justify the time, expense, and inconvenience inherent in addressing these issues.

The degree to which patients with BE understand their risk for adenocarcinoma is unknown. Similarly, the effect that perceived cancer risk has on endoscopic screening behavior and other health-seeking behaviors is unclear. This study assessed the perceived cancer risk in patients with BE and assessed the correlation between the perceived risk for cancer and health care use.

Patients and Methods

Patients

Patients for this study were recruited from the outpatient clinics and the endoscopy centers of 2 institutions. The University of North Carolina (UNC) Hospitals System is a large academic medical center that serves a population composed of approximately 50% local patients (within 25 miles of campus), and 50% referral patients. The Durham Veterans' Administration Medical Center (VAMC) is an academic hospital affiliated with Duke University that serves as a tertiary referral center for veterans in North Carolina, South Carolina, and Virginia. All patients presenting for either surveillance upper endoscopy or outpatient clinic visit with a known diagnosis of BE during a 4-month period in 2003 were screened for inclusion. Patients were identified by assessing previous endoscopy records for those presenting for upper endoscopy, and by problem list for those presenting to the clinic, with continuing weekly review of records. Initial screening was performed by a review of medical records, followed by a review of pathologic records to confirm the histologic diagnosis and ascertain dysplasia status. Screening was performed by a study coordinator at UNC (S.M.S.) and by a clinical fellow at Durham VA (B.G.).

Inclusion criteria for the study were as follows: (1) endoscopically evident, histologically proven, prevalent BE, with either no dysplasia or past transient low-grade dysplasia without current dysplasia. BE was defined as any detectable upward displacement of the squamocolumnar junction into the tubular esophagus, with at least 1 biopsy specimen showing columnar epithelium with goblet cells. Patients with goblet cells on biopsy examination but no endoscopic appearance of BE were not eligible for inclusion. (2) Age 18–80 years, and (3) the ability to read and understand both the consent form as well as the questionnaires used in the study.

Exclusion criteria were as follows: (1) patients having undergone endoscopic ablation of their BE, (2) patients having undergone esophageal resection for any reason, and (3) patients with adenocarcinoma or high-grade dysplasia on any endoscopy.

Potential patients were identified using the clinic schedules and the endoscopy center schedules. Patients who agreed to participate then provided informed consent. This protocol was approved by the Committee on the Protection of Rights of Human Subjects at the University of North Carolina, and the Research and Development Committee and the Human Studies Subcommittee at the Durham VAMC.

Risk Perception Questionnaire

All patients completed the Risk Perception Questionnaire, a 49-item questionnaire developed by the investigators and β-tested on 15 subjects at UNC. The questionnaire assessed the patients' personal medical histories and family histories, as well as their health habits. Patients' other health screening practices such as mammography, Papanicolaou smears, prostate examinations, and colorectal cancer screening behaviors were assessed. The patients were asked to estimate their risk for developing common medical conditions such as diabetes and high blood pressure. The questionnaire then assessed the patients' perceived risk for developing adenocarcinoma in their BE in both the next year and in their lifetime. This portion of the questionnaire used a previously validated visual analog scale featuring a magnifying glass in the low probability range (<1%)[10]; patients indicated their risk for cancer by placing an X in either the magnified portion of the VAS or along the line representing higher risks (Figure 1). This modified scale has been shown to elicit perceptions of low-probability risk more accurately than normal VAS scales or *1 in X* questionnaires.

Because the patients' reports of their screening behaviors may vary from their actual participation, we also performed an audit of the complete medical records of 25% of the participants in the study to assess the validity of their self-report. Patients' upper endoscopy records were compared with their reports on the risk assessment questionnaire.

Analysis

Simple descriptive statistics were used to calculate the means, medians, interquartile ranges, and SDs for perception of yearly and lifetime risk. A dichotomous variable, overestimator vs nonoverestimator, was created to denote whether patients overestimated their yearly and lifetime risk for developing adenocarcinoma of the esophagus. Patients who reported their annual risk at greater than twice the estimated annual risk of .5% per year (ie, a reported risk of ≥1% per year) were considered overestimators of yearly risk. To classify patients as overestimators of lifetime risk, the expected lifetime risk for cancer (R_k) was determined by using the incidence rate of cancer (I_k) and the average life expectancy ($\triangle t_k$) was determined by using the following formula: $R_k = 1 - e^{(-I_k \triangle t_k)}$.

The average life expectancy was calculated separately for each participant based on age, race, and sex classification using National Vital Statistics Reports.[11] Overestimation of lifetime