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Patient knowledge, risk perception and barriers to Barrett's esophagus screening

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Abstract

Background—Most patients with esophageal adenocarcinoma (EAC) do not have a previous diagnosis of Barrett's esophagus (BE), demonstrating a failure of current screening practices. An understanding of patient attitudes and barriers is essential to develop and implement interventions to improve BE screening adherence.

Methods—We conducted a web-based survey of patients >50 years old with chronic gastroesophageal reflux disease (GERD) at three academic medical centers and one affiliated safety-net health system. Survey domains included patient characteristics, endoscopy history, familiarity with screening practices, perceived BE/EAC risk, and barriers to screening.

Results—We obtained a response rate of 22.6% (472/2084) (74% males, mean age 67.9 years). Self-identified race and ethnicity of participants was 66.5% non-Hispanic White, 20.0% non-Hispanic Black, 13.4% other race, and 7.1% Hispanic. Screening for BE was recommended in only 13.2%, and only 5.3% reported prior screening. Respondents had notable gaps in knowledge about screening indications; only two-thirds correctly identified BE risk factors and only 19.5% felt BE screening was needed for GERD. More than one in five respondents believed they would get BE (31.9%) or EAC (20.2%) but reported barriers to screening. Compared to White respondents, more Black respondents were concerned about getting BE/EAC and interested in screening but report higher barriers to screening.

Conclusions—Patients at risk for BE, particularly racial and ethnic minorities, are worried about developing EAC but rarely undergo screening and have poor understanding of screening recommendations.

Keywords

esophageal cancer; survey; shared decision making; disparities

INTRODUCTION

Esophageal adenocarcinoma (EAC) has been increasing in incidence in the United States from 2.9 to 3.3 per 100,000 person-years between 2000 and 2017 and has a dismal 5-year survival of 15–25%.[1, 2] Stage-dependent survival of EAC coupled with the fact that cancers are believed to arise from the precursor lesion Barrett's esophagus (BE) emphasize the importance of early detection.[3] Accordingly, professional gastroenterology societies recommend screening for BE using upper endoscopy in at-risk individuals, which includes those with chronic gastroesophageal reflux disease (GERD) in addition to other risk factors such as age >50 years, male sex, white race, smoking, obesity, and family history of BE or EAC.[4–6] However, less than 10% of EAC cases have a prior diagnosis of BE, suggesting that current screening programs are ineffective.[7, 8]

BE/EAC screening algorithms largely rely on the presence of GERD, which affects nearly 60 million Americans, making the possible pool of patients for testing enormous with only a minority potentially experiencing health benefits. On the contrary, a large proportion of BE occurs in patients without reflux symptoms, only 5–15% of GERD patients have BE, and 20–50% of EAC patients have no prior GERD symptoms.[9–11] Taken together, these nuances make effective implementation of BE screening in the US a major challenge.

There are additional complexities in identifying the right patient population for screening. Current guidelines place a high priority on screening according to race and gender with Caucasian males as the primary target demographic. However, across all guidelines, race is poorly defined and lacks nuance, particularly with increasing proportions of patients with mixed race and ethnicity, which may have implications for health disparities.[12] Furthermore, an optimal paradigm for cancer screening should incorporate a patient centered approach to have the highest potential impact. As part of the SCREEN-BE study (Study of Compliance, Practice patterns, and Barriers Regarding Established National Screening Programs for Barrett's esophagus), we recently elucidated several barriers at the provider-level to successful implementation of BE screening.[13] However, minimal data describe how patients understand and perceive risks and benefits of screening, and prior literature in this domain has predominantly focused on cancer risk perception among those already diagnosed with BE.[14, 15] To address these knowledge gaps, we performed a survey study of patients at risk for BE/EAC to define their knowledge, attitudes, and barriers regarding BE screening to identify potential modifiable targets to inform future interventions.

METHODS

Study Population and sampling methodology

This was a survey study of patients with GERD at three large health systems in the U.S., including tertiary care referral centers (University of Colorado Anschutz Medical Campus, Hospital of the University of Pennsylvania Health System, University of Texas Southwestern Medical Center) and one affiliated safety-net health systems (Denver Health Hospital) (ClinicalTrials.gov NCT04408105). Patients aged 50–79 with a diagnosis of GERD (ICD-10 code K21*) at any time and at least one outpatient clinic visit for any reason in the prior year (to identify patients actively using healthcare services) were identified through query of the electronic health record using ICD codes. Patients were excluded if they had a prior diagnosis of BE or EAC (ICD-10 code K22.7*, C15*) or were non-English speaking patients. With the goal to recruit a diverse population from this large number of potentially eligible patients, a random stratified sample was taken within each healthcare system according to 3 strata: white males, non-white males, and female. This sampling strategy and selection of centers was designed to target a diverse group of patients based on gender, race, and ethnicity to improve generalizability of results.

Survey Design

Surveys were designed using a theoretical model of patient behavior based on Social Cognitive Theory[16] and the Theory of Reasoned Action[17] and adapted from earlier validated cancer screening-based surveys (Figure 1).[18, 19] These models are grounded in strong theory

and share many of the same constructs as the more recently proposed I-SAM model[20] which appears to be a useful framework for evaluating esophageal cancer screening.[21] This process included input from experts in survey design and survey study methodology, cancer screening, and BE/EAC content. Domains included patient demographics, knowledge regarding BE/EAC, attitudes and risk perception. The study investigators defined eleven potential barriers to BE screening completion. To refine the survey (Supplemental Figure 1), pretesting and cognitive interviewing was performed among a sample of ten randomly selected patients to understand their thoughts and opinions of the questions and insight into their responses.

Survey Administration

Patients were recruited to complete the survey via telephone, with three follow-up opportunities to participate. After agreeing to study participation, patients were given the option to complete the survey over the phone or through the REDCap electronic database (NIH/NCATS Colorado CTSA Grant Number UL1 TR002535) via a personalized emailed link. Research coordinators across all sites administered surveys by phone following a standardized script and were instructed to not address or react to responses.

Statistical Analysis

To assess respondents' knowledge, attitudes, and perceived barriers to BE screening, survey responses were reported using descriptive statistics. Differences in attitudes, barriers, and knowledge scores by sex, race ethnicity, and receipt of a prior EGD (yes versus no/not known) were assessed using Fisher's exact test (for attitudes and barriers) and binomial regression (for knowledge). All analyses were conducted in R version 4.0.2.

RESULTS

Patient respondent characteristics and endoscopy history

Of 2084 patients invited to participate, 472 completed the survey for a response rate of 22.6%. (Table 1). The cohort was 74.2% male with a mean age 67.9 years. Participants self-reported their race as White (66.5%), Black (20%), Asian (3.2%) or other (8.1%) and 7.1% identified as Hispanic. Most respondents had at least some college education (86%). Demographic data for 1,612 non responders are provided in Supplemental Table 1. Overall, White and Hispanic participants had a higher response rate than Black and Asian participants. Over half (59%) of patients reported prior upper endoscopy, mostly for GERD (38.6%), dysphagia (10.4%), or abdominal pain (9.3%); however, only 13.2% and 5.3% had been recommended for and completed prior BE screening, respectively.

Patient knowledge and beliefs regarding BE/EAC

Most respondents felt that that esophageal cancer is deadly if not treated (80.9%) and earlier detection of EAC leads to curative treatments (88.5%), however, they had varying knowledge about risk factors for BE/EAC (Supplemental Table 2). Over one-third of respondents were unsure or disagreed that chronic GERD, obesity, and smoking increased BE/EAC risk. Only half of individuals appropriately understood that screening for BE is needed even if GERD is controlled with acid lowering medications. Individuals reported

varying levels of interest in learning more about BE/EAC (44.1% interested, 36.7% not interested, 19.2% maybe). Compared to individuals who had prior EGD, those without a prior EGD were less knowledgeable about BE/EAC risk factors and indications for screening (knowledge score 60.5 vs 68.9, p<0.001) but more agreed that screening for EAC is a one-time procedure (20.7 vs 14.4, p<0.001) (Table 2).

Risk perception for BE/EAC

More than one-fifth of respondents believed they would get BE (31.9%) or EAC (20.2%) and were moderately or extremely concerned about developing BE or EAC (22.1% and 22.5%, respectively) (Supplemental Table 3). Most participants felt that BE/EAC screening is important to their overall health (62.3%) and getting an upper endoscopy would reduce their level of concern (68.7%). Individuals without a prior EGD felt less likely to get BE (25.4% vs 36.5%, p=0.03) and placed lower value on BE screening as a health priority (53.4% vs 68.6%, p=0.003), but otherwise had similar levels of concern about getting BE/EAC as those with a prior EGD. (Table 3).

Barriers to BE screening

Participant responses varied widely about their perceived eligibility for BE screening; 30.1% felt they did not need screening and 27.4% were unsure (Supplemental Table 4). Fear of discomfort during endoscopy was identified as a barrier to BE screening (20.4%). Logistical details of upper endoscopy including procedural scheduling, not knowing where to get it done, location, wait time, procedure length/time, ride home, and cost/insurance coverage were rare (<10% of the time) as barriers to BE screening. Participants who had no prior endoscopy acknowledged more barriers across all categories compared to those who had prior EGD, specifically feeling they do not need screening for BE, greater fear of discomfort during the procedure, and more uncertainty about where to get it done (Supplemental Table 5, Figure 2).

Subgroup Analyses: Differences by race, ethnicity, and sex

Knowledge, risk perception, and barriers to screening were compared across 3 racial groups (Black, White, other) (Table 4). More Black participants were extremely or moderately concerned about getting BE and EAC compared to other racial groups (BE 37.2% vs 16.3% and 28.1% p<0.001, EAC 34% vs. 17.6% vs. 29.7% p=0.007). Compared to White participants, more Black participants and those of other race groups felt that getting screened for BE/EAC was somewhat or very important to their overall health (51.3% vs. 87.2% vs. 79.7%, p<0.001). Knowledge about BE screening was similar across racial subgroups, although barriers to screening differed by race. Non-white participants felt they needed screening for BE at higher rates than white participants (60.6% vs 52.3% vs. 34.9% for Black, Other, White, respectively, p<0.001), however they were also more unsure if EGD is the best test (8.5% vs. 4.6% vs. 1.9% p=0.42). Black respondents more frequently reported difficulty scheduling an appointment for upper endoscopy compared to white and other race (8.5% vs 3.5% vs. 1.5% p=0.04). Respondents who identified as other race were more unsure where to undergo upper endoscopy compared to those identifying as white or black (18.8% vs 8.3% vs. 6.4% p=0.02). Black and other respondents more often indicated concerns about out-of-pocket expenses (10.6% vs. 14.1% vs. 6.1% p=0.002) (Figure 3).

Given the small number of participants who identified as Hispanic, analyses by ethnicity were underpowered to detect meaningful differences (Supplemental Table 6). Subgroup analyses by sex did not show meaningful differences in knowledge, risk perception, or barriers between male and females (Supplemental Table 7).

DISCUSSION

This multicenter survey study of patients at risk for BE/EAC evaluated knowledge, attitudes, and barriers to BE screening with upper endoscopy. Across a demographically and geographically diverse patient population at-risk for BE/EAC, most participants had never discussed BE screening with their providers. Although participants felt that early detection of BE/EAC is important and leads to better outcomes, overall knowledge on risk factors and indications for screening was poor. Individuals who had no prior EGD (40% of respondents) were less aware about BE/EAC risk and screening recommendations and identified more barriers to completing endoscopy. Compared to white participants, black and other race participants were more concerned about BE/EAC but experience more barriers to accessing screening. These results indicate large gaps in knowledge and inconsistent risk perceptions among patients with risk factors for BE/EAC, as well as critical differences across racial groups that need to be addressed prior to implementation of widespread BE/EAC screening.

In this cohort of 472 individuals who all qualify for BE screening and had a recent outpatient clinic visit with their primary care provider (PCP), very few patients had ever been recommended to get endoscopy for BE screening. While it is certainly possible that patients did not remember or did not realize screening was recommended or may have misclassified the reason for their endoscopy as GERD when it was really screening, it is likely that a conversation on screening for BE/EAC never occurred given the suboptimal uptake of screening nationwide.[22] Although PCPs are often the first line for patients with symptomatic acid reflux and the gateway for preventative cancer screening, recent data indicates that they have difficulty identifying who should be screened for BE, have poor knowledge on screening guidelines, and competing clinical issues makes it challenging to implement BE screning.[13] Respondents in this study had limited understanding of risk factors that warrant screening. Despite this, two-thirds of respondents were worried about getting BE/EAC and were interested in prioritizing screening endoscopy to lower their concern. These data suggest that patients will be engaged in disease prevention if their providers refer them for screening, especially among this cohort where nearly 90% had completed a test for colon cancer screening, suggesting they are highly motivated to take care of their health.

A major impetus for our study is the increasing focus on the patient centered experience and using a model for shared decision-making in clinical practice. These themes and approaches have been incorporated into liver and colon cancer screening programs[23–25] and are becoming a focus for BE treatment algorithms. Most of the literature to date evaluating the patient perspective for esophageal cancer comes from studies looking at preferences and experience of patients with BE in surveillance endoscopy programs.[26] Patients with BE tend to overestimate their risk of developing EAC and subsequently are more willing to accept risks of endoscopic therapy despite low yield of repeated examinations.[14, 15] The

present cohort was eligible for screening and seemed to have an appropriate perceived risk and concern about developing cancer, and felt that screening endoscopy would reduce that concern. Research demonstrates that patient reported discomfort and perceived burden of cancer screening and surveillance testing must be addressed for a program to be successful.[27] In this survey, 20% of respondents reported fear of discomfort with endoscopy as a barrier to completing screening. These and prior data[28] are particularly important as we refine screening algorithms to include the use of non-endoscopic modalities for screening[29] as recently endorsed by the ACG (conditional recommendation, very low quality of evidence).[6] A quantitative and qualitative systematic review of 19 studies with 15,249 participants similarly emphasized the general public's high level of interest in EAC screening and provided complementary results to our survey showing strong preference for minimally invasive and highly accurate screening tests.[21] These unique insights still need to be tested in a US population.

BE screening guidelines to date have taken an oversimplified approach and identified a narrow demographic of white males as the high-risk target. Although these recommendations have in theory assigned race as a big part of screening, they have in effect completely failed to account for risk among other racial or ethnic groups.[12] The epidemiology of EAC has changed in more recent years with analysis of SEER data showing stabilization of EAC mortality in non-Hispanic Whites with continued rising EAC mortality in non-Hispanic Blacks.[30] Therefore, our secondary goal was to describe how racial differences impact patient attitudes and barriers to BE/EAC screening. Our findings are compelling and demonstrate that the GI societies and guideline perception of who is at risk for BE/EAC does not align with how patients perceive and experience their health. Black respondents, who are typically not recommended for BE screening unless they have multiple other risk factors, were in fact most worried about BE/EAC. We found racial minorities are most interested in screening but also face the most barriers. Similar findings have been reported in hepatocellular carcinoma[31] and colorectal cancer.[32] Additional research with more granular data to understand the specific drivers for these barriers on a patient, provider, and system level can inform future intervention trials to address these disparities. Future BE/EAC screening guidelines should address the current racial categories which may be inappropriate and potentially propagating health inequities.[12]

There are several strengths to our study. This is the first study to evaluate patient attitudes and barriers to BE screening using rigorously developed surveys with multiple domains and refined after direct interviews with patients. Our study design and sampling strategy recruited a demographically and geographically diverse group of patients from different socioeconomic backgrounds. We identified important barriers and facilitators that can be used to inform future intervention trials and screening guidelines.

There are also limitations to our study. We identified eligible patients using ICD-10 codes which may lack specificity for GERD, and therefore we may have inadvertently included people without true GERD. However, since contemporary guidelines require GERD for BE/EAC screening, providers would likely target a similar mixed group when implementing screening, making this approach relevant for generalizability. We also acknowledge that GERD is frequently absent in EAC and therefore responses from a non-GERD cohort

would be potentially interesting, but this was not pursued due to the continued inclusion of GERD as entry criteria in screening guidelines and should be the focus of future research. Since the cohort was primarily comprised of non-Hispanic White individuals, the study was underpowered to detect differences by ethnicity or sex. Additionally, we used self-reported race and ethnicity, which may be prone to misclassification bias. However, we found high concordance between self-reported answers per surveys and recorded race and ethnicity in electronic medical records. Finally, our response rate for the survey was relatively low at 22.6%, which may have been impacted by the by timing in relation to the COVID-19 pandemic.

Overall, the success of a BE/EAC screening program in the US will depend on its effectiveness, feasibility, cost, and patient acceptability; it must cater to the individuals undergoing screening. Additionally, we must partner with and educate our primary care colleagues and wider community of gastroenterologists to reach those patients with risk factors who are eligible for screening. Although our study only focused only on upper endoscopy for screening, future efforts are underway to understand patients' preferences for alternative options such as minimally invasive non-endoscopic cell collection techniques. Our results underscore the importance of considering patient preferences and health perceptions as we develop interventions to improve BE screening implementation with a goal of reducing EAC morbidity and mortality.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS:

BE	Barrett's esophagus
EAC	esophageal adenocarcinoma
GERD	gastro-esophageal reflux disease
PCP	primary care physician

GI Gastroenterology

References

1. Kolb JM, Han S, Scott FI, et al. Early-Onset Esophageal Adenocarcinoma Presents With Advanced-Stage Disease But Has Improved Survival Compared With Older Individuals. Gastroenterology 2020;159:2238–2240 e4. [PubMed: 32777286]
2. Domper Arnal MJ, Ferrández Arenas Á, Lanas Arbeloa Á. Esophageal cancer: Risk factors, screening and endoscopic treatment in Western and Eastern countries. World J Gastroenterol 2015;21:7933–43. [PubMed: 26185366]
3. Kolb JM, Fox C, Friedman C, et al. Prognostic Impact of the Presence of Barrett's Esophagus and Intestinal Metaplasia on Esophageal Adenocarcinoma Survival. Foregut;0:26345161211033277.
4. Shaheen NJ, Falk GW, Iyer PG, et al. ACG Clinical Guideline: Diagnosis and Management of Barrett's Esophagus. Am J Gastroenterol 2016;111:30–50; quiz 51. [PubMed: 26526079]
5. Asge Standards Of Practice C, Qumseya B, Sultan S, et al. ASGE guideline on screening and surveillance of Barrett's esophagus. Gastrointest Endosc 2019;90:335–359 e2. [PubMed: 31439127]
6. Shaheen NJ, Falk GW, Iyer PG, et al. Diagnosis and Management of Barrett's Esophagus: An Updated ACG Guideline. Am J Gastroenterol 2022;117:559–587. [PubMed: 35354777]
7. Dulai GS, Guha S, Kahn KL, et al. Preoperative prevalence of Barrett's esophagus in esophageal adenocarcinoma: a systematic review. Gastroenterology 2002;122:26–33. [PubMed: 11781277]
8. Bhat SK, McManus DT, Coleman HG, et al. Oesophageal adenocarcinoma and prior diagnosis of Barrett's oesophagus: a population-based study. Gut 2015;64:20–5. [PubMed: 24700439]
9. Lagergren J, Bergström R, Lindgren A, et al. Symptomatic gastroesophageal reflux as a risk factor for esophageal adenocarcinoma. N Engl J Med 1999;340:825–31. [PubMed: 10080844]
10. Eusebi LH, Telese A, Cirota GG, et al. Systematic review with meta-analysis: risk factors for Barrett's oesophagus in individuals with gastro-oesophageal reflux symptoms. Aliment Pharmacol Ther 2021;53:968–976. [PubMed: 33705573]
11. Ronkainen J, Aro P, Storskrubb T, et al. Prevalence of Barrett's esophagus in the general population: an endoscopic study. Gastroenterology 2005;129:1825–31. [PubMed: 16344051]
12. Siddique SM, May FP. Race-Based Clinical Recommendations in Gastroenterology. Gastroenterology 2022;162:408–414.e2. [PubMed: 34890599]
13. Kolb JM, Chen M, Tavakkoli A, et al. UNDERSTANDING COMPLIANCE, PRACTICE PATTERNS AND BARRIERS AMONG GASTROENTEROLOGISTS AND PRIMARY CARE PRROVIDERS IS CRUCIAL FOR DEVELOPING STRATEGIES TO IMPROVE SCREENING FOR BARRETT'S ESOPHAGUS. Gastroenterology 2022.
14. Stier MW, Lodhia N, Jacobs J, et al. Perceptions of risk and therapy among patients with Barrett's esophagus: a patient survey study. Dis Esophagus 2018;31.
15. Shaheen NJ, Green B, Medapalli RK, et al. The perception of cancer risk in patients with prevalent Barrett's esophagus enrolled in an endoscopic surveillance program. Gastroenterology 2005;129:429–36. [PubMed: 16083700]
16. Bandura A.Health promotion by social cognitive means. Health Educ Behav 2004;31:143–64. [PubMed: 15090118]
17. Michels TC, Taplin SM, Carter WB, et al. Barriers to screening: the theory of reasoned action applied to mammography use in a military beneficiary population. Mil Med 1995;160:431–7. [PubMed: 7478025]
18. Simmons OL, Feng Y, Parikh ND, et al. Primary Care Provider Practice Patterns and Barriers to Hepatocellular Carcinoma Surveillance. Clin Gastroenterol Hepatol 2019;17:766–773. [PubMed: 30056183]
19. Singal AG, Tiro JA, Murphy CC, et al. Patient-Reported Barriers Are Associated With Receipt of Hepatocellular Carcinoma Surveillance in a Multicenter Cohort of Patients With Cirrhosis. Clin Gastroenterol Hepatol 2021;19:987–995 e1. [PubMed: 32629122]
20. Robb KA. The integrated screening action model (I-SAM): A theory-based approach to inform intervention development. Prev Med Rep 2021;23:101427. [PubMed: 34189020]

21. Sijben J, Peters Y, van der Velden K, et al. Public acceptance and uptake of oesophageal adenocarcinoma screening strategies: A mixed-methods systematic review. EClinicalMedicine 2022;46:101367. [PubMed: 35399814]
22. Vajravelu RK, Kolb JM, Gellad WF, et al. Patient Factors Associated with Gastroesophageal Reflux Disease Diagnostic Evaluation Strategies: A Retrospective Cohort Study Using Real-World Evidence from a Large U.S. Medical Claims Database. Gastro Hep Advances 2022.
23. Woolen SA, Singal AG, Davenport MS, et al. Patient Preferences for Hepatocellular Carcinoma Surveillance Parameters. Clin Gastroenterol Hepatol 2022;20:204–215 e6. [PubMed: 33618022]
24. Singal AG, Volk ML, Rakoski MO, et al. Patient involvement in healthcare is associated with higher rates of surveillance for hepatocellular carcinoma. J Clin Gastroenterol 2011;45:727–32. [PubMed: 21602704]
25. Schroy PC, 3rd, Duhovic E, Chen CA, et al. Risk Stratification and Shared Decision Making for Colorectal Cancer Screening: A Randomized Controlled Trial. Med Decis Making 2016;36:526–35. [PubMed: 26785715]
26. Arney J, Hinojosa-Lindsey M, Street RL, Jr., et al. Patient experiences with surveillance endoscopy: a qualitative study. Dig Dis Sci 2014;59:1378–85. [PubMed: 24500449]
27. Essink-Bot ML, Kruijshaar ME, Bac DJ, et al. Different perceptions of the burden of upper GI endoscopy: an empirical study in three patient groups. Qual Life Res 2007;16:1309–18. [PubMed: 17634755]
28. Gupta M, Beebe TJ, Dunagan KT, et al. Screening for Barrett's esophagus: results from a population-based survey. Dig Dis Sci 2014;59:1831–50. [PubMed: 24652109]
29. Kolb JM, Wani S. A Paradigm Shift in Screening for Barrett's Esophagus: The BEST Is Yet to Come. Gastroenterology 2021;160:467–469. [PubMed: 33229292]
30. Corona E, Yang L, Esrailian E, et al. Trends in Esophageal Cancer Mortality and Stage at Diagnosis by Race and Ethnicity in the United States. Cancer Causes Control 2021;32:883–894. [PubMed: 34003396]
31. Schoenberger H, Rich NE, Jones P, et al. Racial and Ethnic Disparities in Barriers to Care in Patients with Hepatocellular Carcinoma. Clin Gastroenterol Hepatol 2021.
32. Warren Andersen S, Blot WJ, Lipworth L, et al. Association of Race and Socioeconomic Status With Colorectal Cancer Screening, Colorectal Cancer Risk, and Mortality in Southern US Adults. JAMA Netw Open 2019;2:e1917995.

Study Highlights

WHAT IS KNOWN

- Esophageal cancer is deadly and associated with a poor 5-year survival rate
- Screening for Barrett's esophagus and esophageal cancer is recommended, but uptake is poor

WHAT IS NEW HERE

- At-risk patients are rarely recommended for or had screening endoscopy
- Patients have poor knowledge about screening indications
- Minorities are most worried about developing disease but have the highest barriers to completing screening

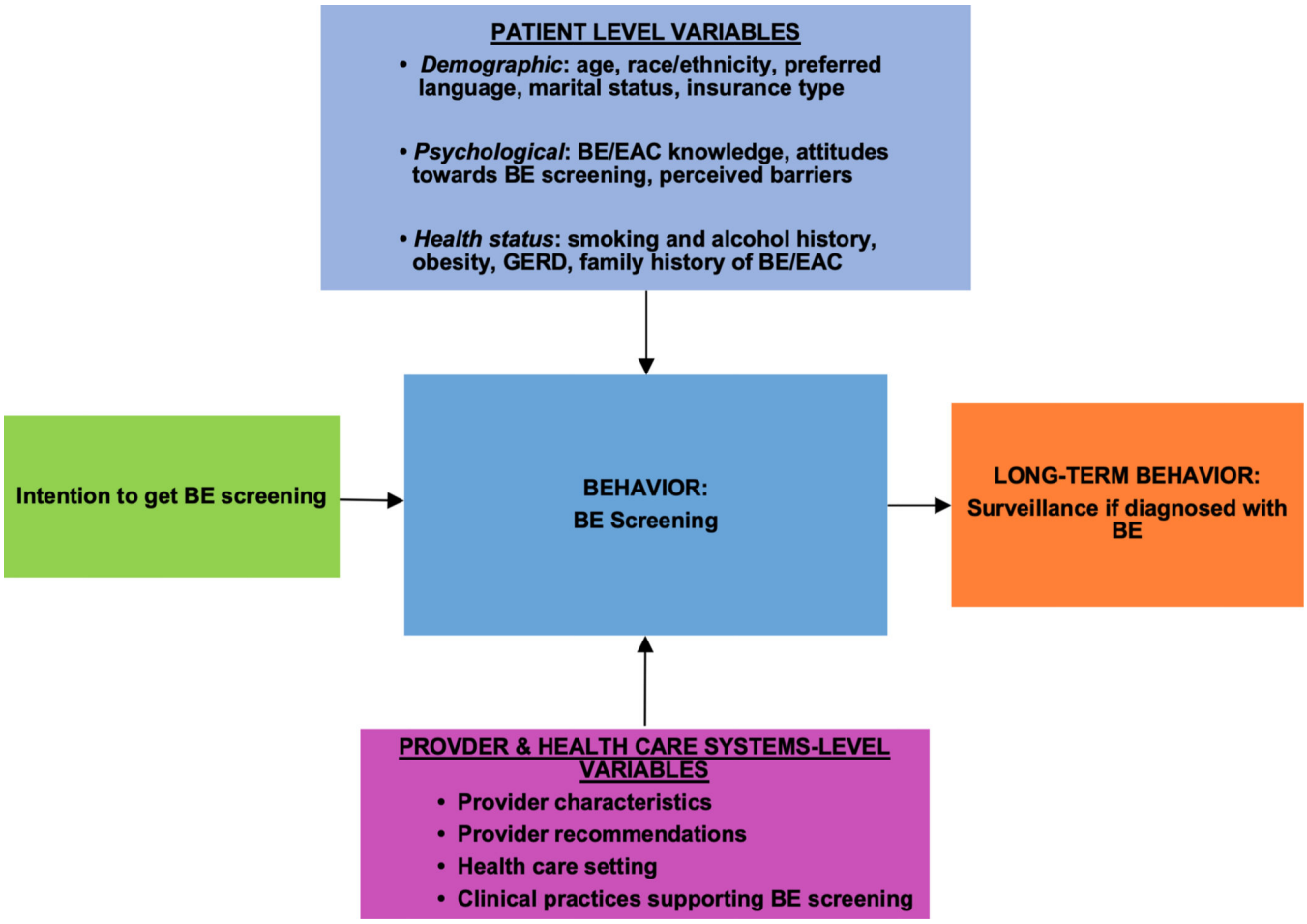

Figure 1.
Conceptual Model for Patient Barrett's Esophagus Screening

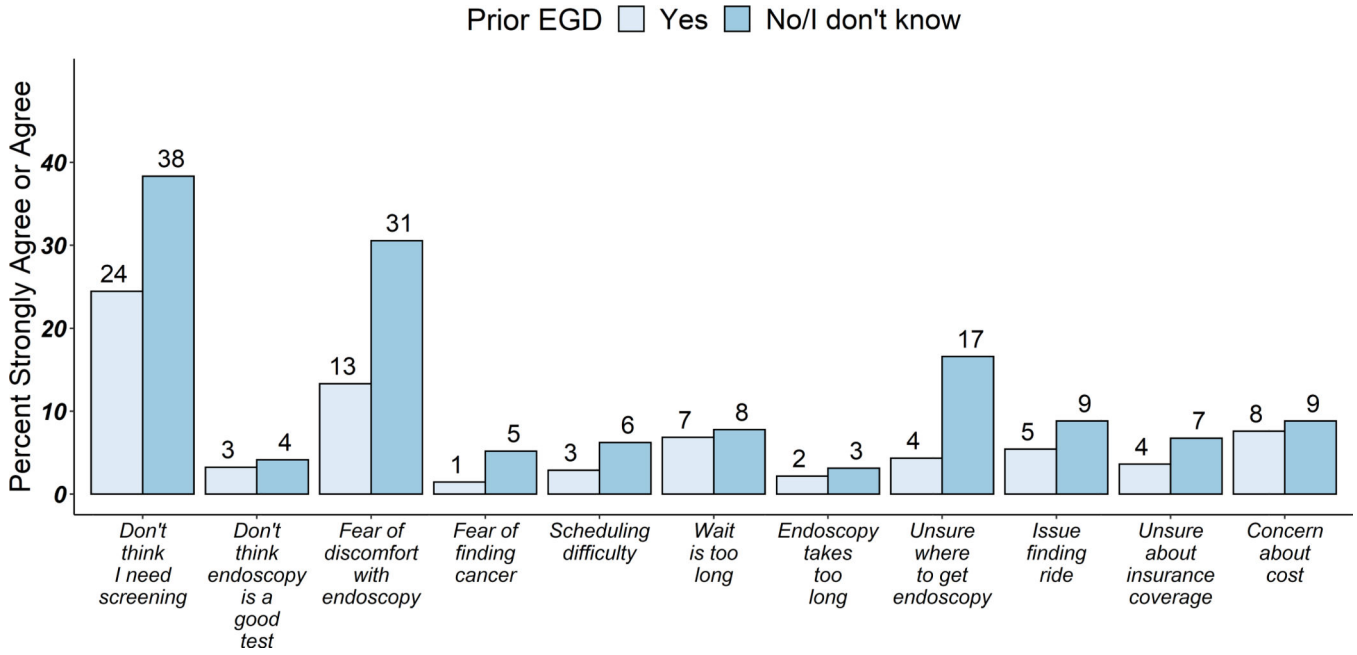

Figure 2. Patient reported barriers to Barrett's esophagus screening stratified by receipt of prior EGD

Footnote: all p values are significant

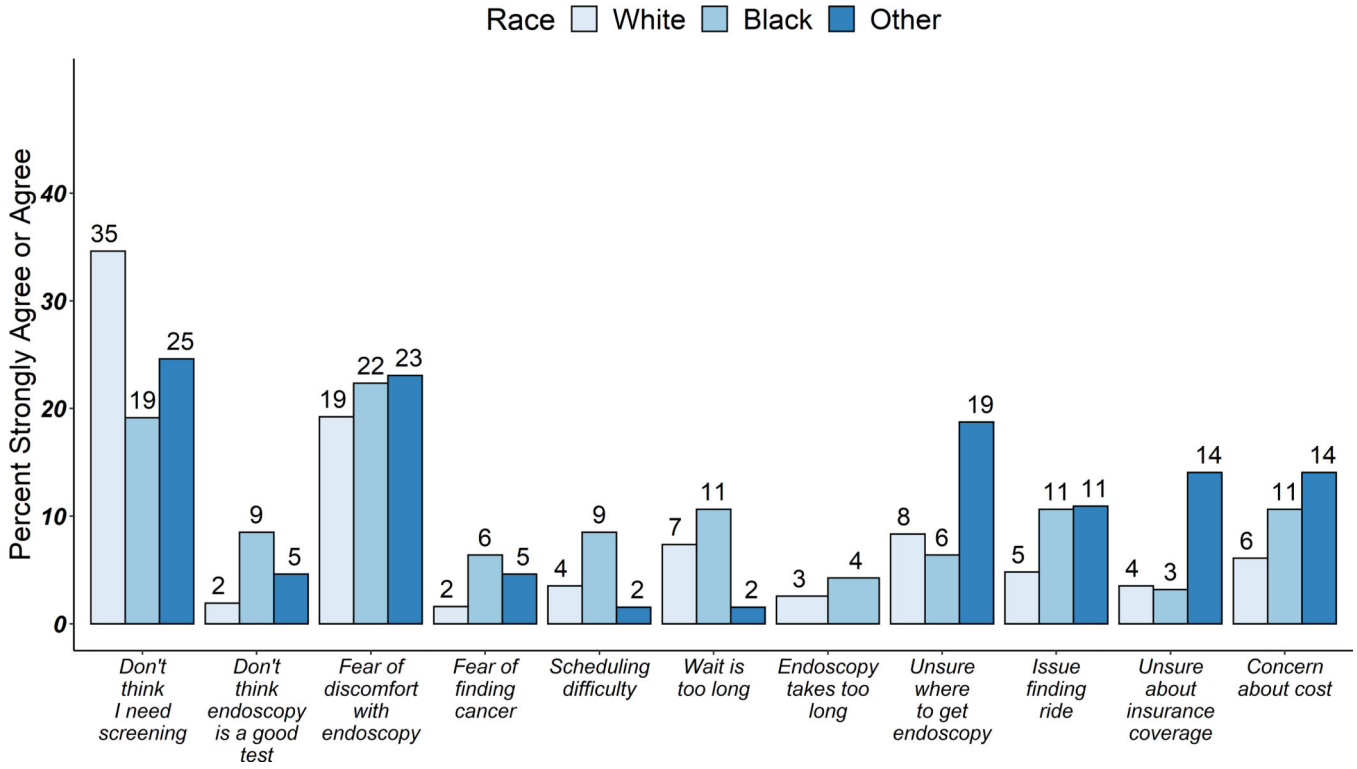

Figure 3. Patient reported barriers to Barrett's esophagus screening stratified by race.
Footnote: *p value<0.5

Table 1.

Characteristics of patient respondents

Patient Characteristic n (%)	Colorado (n=184)	Penn (n=114)	Texas (n=174)	Overall (n=472)
Sex				
Male	145 (78.8)	75 (66.4)	128 (74.4)	348 (74.2)
Female	39 (21.2)	38 (33.6)	44 (25.6)	121 (25.8)
Race/ethnicity				
White	145 (78.8)	61 (54.0)	106 (61.6)	312 (66.5)
African American	15 (8.2)	41 (36.3)	38 (22.1)	94 (20.0)
Asian	5 (2.7)	2 (1.8)	8 (4.7)	15 (3.2)
Other	19 (10.3)	3 (2.7)	16 (9.3)	38 (8.1)
Prefer not to specify	0 (0.0)	6 (5.3)	4 (2.3)	10 (2.1)
Ethnicity				
Hispanic/Latino	20 (11.4)	2 (1.9)	10 (5.8)	32 (7.1)
Age, mean (SD)	65.95 (7.67)	66.41 (7.70)	70.97 (8.76)	67.90 (8.41)
Rating of current overall health status				
Excellent	20 (10.9)	7 (6.2)	9 (5.2)	36 (7.7)
Very good	43 (23.4)	33 (29.2)	53 (30.8)	129 (27.5)
Good	63 (34.2)	40 (35.4)	68 (39.5)	171 (36.5)
Fair	44 (23.9)	28 (24.8)	31 (18.0)	103 (22.0)
Poor	14 (7.6)	4 (3.5)	10 (5.8)	28 (6.0)
Prefer not to specify	0 (0.0)	1 (0.9)	1 (0.6)	2 (0.4)
Type of insurance				
Employer provided	54 (29.3)	53 (46.5)	47 (27.0)	154 (32.6)
Individually insured	25 (13.6)	11 (9.6)	67 (38.5)	103 (21.8)
Medicare	117 (63.6)	61 (53.5)	112 (64.4)	290 (61.4)
Medicaid	20 (10.9)	14 (12.3)	4 (2.3)	38 (8.1)
Not insured	0 (0.0)	0 (0.0)	1 (0.6)	1 (0.2)
Unknown	0 (0.0)	1 (0.9)	1 (0.6)	2 (0.4)
Highest level of education				
Advanced degree	67 (36.4)	53 (46.9)	61 (35.5)	181 (38.6)
Bachelor’s degree	50 (27.2)	19 (16.8)	43 (25.0)	112 (23.9)
Some college	51 (27.7)	21 (18.6)	38 (22.1)	110 (23.5)
High school	15 (8.2)	17 (15.0)	30 (17.4)	62 (13.2)
Did not attend high school	1 (0.5)	1 (0.9)	0 (0.0)	2 (0.4)
Prefer not to specify	0 (0.0)	2 (1.8)	0 (0.0)	2 (0.4)
Employment status				
Full-time	63 (37.1)	39 (35.1)	41 (24.4)	143 (31.8)
Part-time	7 (4.1)	6 (5.4)	8 (4.8)	21 (4.7)
Retired	85 (50.0)	52 (46.8)	110 (65.5)	247 (55.0)
Homemaker	1 (0.6)	0 (0.0)	1 (0.6)	2 (0.4)
Disability	12 (7.1)	13 (11.7)	7 (4.2)	32 (7.1)
Prefer not to specify	2 (1.2)	1 (0.9)	1 (0.6)	4 (0.9)
Living situation				
Living with relatives/non-relatives	138 (75.4)	75 (66.4)	132 (76.7)	345 (73.7)
Alone	41 (22.4)	34 (30.1)	36 (20.9)	111 (23.7)
Homeless	1 (0.5)	0 (0.0)	0 (0.0)	1 (0.2)
Prefer not to specify	3 (1.6)	4 (3.5)	4 (2.3)	11 (2.4)
Household income				
>$100,000 per year	68 (37.0)	33 (29.2)	51 (29.7)	152 (32.4)
$75,000–100,000 per year	27 (14.7)	9 (8.0)	17 (9.9)	53 (11.3)
$50,000–75,000 per year	15 (8.2)	5 (4.4)	16 (9.3)	36 (7.7)
$25,000–50,000 per year	11 (6.0)	11 (9.7)	15 (8.7)	37 (7.9)
$10,000–25,000 per year	14 (7.6)	8 (7.1)	7 (4.1)	29 (6.2)
<$10,000 per year	13 (7.1)	3 (2.7)	5 (2.9)	21 (4.5)
Prefer not to specify	36 (19.6)	44 (38.9)	61 (35.5)	141 (30.1)

Patient Characteristic n (%)	Colorado (n=184)	Penn (n=114)	Texas (n=174)	Overall (n=472)
Endoscopy History	**UCH (n=184)**	**UPenn (n=114)**	**UTSW (n=174)**	**Overall (n=472)**
Have you ever had an upper endoscopy for any reason in the past?	97 (52.7)	83 (72.8)	98 (56.6)	278 (59.0)
Yes	83 (45.1)	29 (25.4)	59 (34.1)	171 (36.3)
No	4 (2.2)	2 (1.8)	16 (9.2)	22 (4.7)
I don’t know				
If yes, what were the reasons why you had an upper endoscopy? (select all that apply)	55 (29.9)	61 (53.5)	66 (37.9)	182 (38.6)
Heartburn/reflux	33 (17.9)	6 (5.3)	10 (5.7)	49 (10.4)
Difficulty swallowing	3 (1.6)	4 (3.5)	3 (1.7)	10 (2.1)
Weight loss	16 (8.7)	14 (12.3)	14 (8.0)	44 (9.3)
Abdominal pain	5 (2.7)	3 (2.6)	6 (3.4)	14 (3.0)
Suspected blood loss	7 (3.8)	10 (8.8)	8 (4.6)	25 (5.3)
Screening for BE	6 (3.3)	3 (2.6)	7 (4.0)	16 (3.4)
I don’t know	17 (9.2)	13 (11.4)	23 (13.2)	53 (11.2)
Other				
When did you have your upper endoscopy?				
Less than 1 year ago	10 (10.3)	10 (12.0)	17 (17.3)	37 (13.3) 102 (36.7)
1 to 5 years ago	36 (37.1)	35 (42.2)	31 (31.6)	129 (46.4)
Greater than 5 years ago	50 (51.5)	32 (38.6)	47 (48.0)	10 (3.6)
I don’t recall	1 (1.0)	6 (7.2)	3 (3.1)	
Has a doctor ever recommended screening for BE for you?	21 (11.4)	21 (18.4)	20 (11.6)	62 (13.2)
Yes	140 (76.1)	79 (69.3)	136 (78.6)	355 (75.4)
No	23 (12.5)	14 (12.3)	17 (9.8)	54 (11.5)
I don’t know				
Have you completed a test for colon cancer screening?				
Yes	163 (88.6)	98 (86.0)	157 (90.8)	418 (88.7)
No	21 (11.4)	16 (14.0)	16 (9.2)	53 (11.3)
Which of the following tests have you used for colon cancer screening (select all that apply)?	29 (15.8)	8 (7.0)	16 (9.2)	53 (11.2)
Stool based testing (FIT, Cologuard)	152 (82.6)	97 (85.1)	152 (87.4)	401 (85.0)
Colonoscopy				

Table 2.

Knowledge and beliefs about BE and EAC

	Total (n=472)	Prior EGD (n=278)	No Prior EGD (n=193)	p-value
Having GERD increases risk for developing Barrett's esophagus and esophageal cancer				**0.001***
Strongly agree or agree	314 (66.5)	203 (73.0)	110 (57.0)	
Neither agree nor disagree	144 (30.5)	69 (24.8)	75 (38.9)	
Strongly disagree or disagree	14 (3.0)	6 (2.2)	8 (4.1)	
Having GERD for a longer time increases the risk for developing BE				**0.003***
Strongly agree or agree	329 (69.7)	210 (75.5)	118 (61.1)	
Neither agree nor disagree	134 (28.4)	65 (23.4)	69 (35.8)	
Strongly disagree or disagree	9 (1.9)	3 (1.1)	6 (3.1)	
Being overweight increases the risk for developing BE				0.754
Strongly agree or agree	256 (54.2)	154 (55.4)	102 (52.8)	
Neither agree nor disagree	186 (39.4)	106 (38.1)	80 (41.5)	
Strongly disagree or disagree	30 (6.4)	18 (6.5)	11 (5.7)	
Smoking increases the risk for developing BE				0.259
Strongly agree or agree	302 (64.0)	179 (64.4)	122 (63.2)	
Neither agree nor disagree	150 (31.8)	84 (30.2)	66 (34.2)	
Strongly disagree or disagree	20 (4.2)	15 (5.4)	5 (2.6)	
If GERD is well controlled on acid lowering medications, screening for BE is not needed				**0.008***
Strongly agree or agree	92 (19.5)	50 (18.0)	42 (21.8)	
Neither agree nor disagree	144 (30.6)	73 (26.3)	71 (36.8)	
Strongly disagree or disagree	235 (49.9)	155 (55.8)	80 (41.5)	
The earlier esophageal cancer is diagnosed, the more likely it can be cured				0.285
Strongly agree or agree	417 (88.5)	248 (89.2)	169 (87.6)	
Neither agree nor disagree	45 (9.6)	23 (8.3)	22 (11.4)	
Strongly disagree or disagree	9 (1.9)	7 (2.5)	2 (1.0)	
Knowledge Score % Correct (95% CI)		68.9 (66.6–71.1)	60.5 (57.7–63.3)	<0.001*
Screening for BE with upper endoscopy is a one-time procedure and does not need to be repeated				**<0.001***
Strongly agree or agree	80 (16.9)	40 (14.4)	40 (20.7)	
Neither agree nor disagree	155 (32.8)	62 (22.3)	93 (48.2)	
Strongly disagree or disagree	237 (50.2)	176 (63.3)	60 (31.1)	
Screening for BE should only be done if I am having trouble swallowing or losing weight (or both)				**<0.001***
Strongly agree or agree	90 (19.1)	45 (16.2)	45 (23.3)	
Neither agree nor disagree	144 (30.6)	72 (25.9)	72 (37.3)	
Strongly disagree or disagree	237 (50.3)	161 (57.9)	76 (39.4)	
Esophageal cancer is deadly if not treated				**0.045***
Strongly agree or agree	381 (80.9)	234 (84.2)	147 (76.2)	
Neither agree nor disagree	74 (15.7)	34 (12.2)	40 (20.7)	
Strongly disagree or disagree	16 (3.4)	10 (3.6)	6 (3.1)	

Table 3.

Perception of risk for BE/EAC

	Total (n=472)	Prior EGD (n=278)	No Prior EGD (n=193)	p-value
How likely or unlikely do you think you are to get BE in your lifetime?				
Very likely or somewhat likely	150 (31.9)	101 (36.5)	49 (25.4)	**0.030** *
Neither likely nor unlikely	143 (30.4)	82 (29.6)	61 (31.6)	
Very unlikely or somewhat unlikely	177 (37.7)	94 (33.9)	83 (43.0)	
How likely or unlikely do you think you are to get esophageal cancer in your lifetime?				
Very likely or somewhat likely	95 (20.2)	61 (22.0)	34 (17.6)	0.234
Neither likely nor unlikely	160 (34.0)	98 (35.4)	62 (32.1)	
Very unlikely or somewhat unlikely	215 (45.7)	118 (42.6)	97 (50.3)	
How concerned are you about getting Barrett's esophagus?				
Extremely concerned	39 (8.3)	25 (9.0)	14 (7.3)	0.058
Moderately concerned	65 (13.8)	46 (16.6)	19 (9.8)	
Slightly concerned	114 (24.3)	71 (25.6)	43 (22.3)	
Somewhat concerned	109 (23.2)	63 (22.7)	46 (23.8)	
Not at all concerned	143 (30.4)	72 (26.0)	71 (36.8)	
How concerned are you about getting esophageal cancer?				
Extremely concerned	40 (8.5)	25 (9.0)	15 (7.8)	0.254
Moderately concerned	66 (14.0)	41 (14.8)	25 (13.0)	
Slightly concerned	120 (25.5)	71 (25.6)	49 (25.4)	
Somewhat concerned	106 (22.6)	69 (24.9)	37 (19.2)	
Not at all concerned	138 (29.4)	71 (25.6)	67 (34.7)	
Would getting an upper endoscopy reduce your concern about esophageal cancer?				
Yes	323 (68.7)	200 (72.2)	123 (63.7)	0.122
No	50 (10.6)	28 (10.1)	22 (11.4)	
I am not concerned	97 (20.6)	49 (17.7)	48 (24.9)	
Considering your overall health, how important is getting screened for Barrett's esophagus and esophageal cancer for you?				
Very or somewhat important	293 (62.3)	190 (68.6)	103 (53.4)	**0.003** *
Neither important nor unimportant	71 (15.1)	36 (13.0)	35 (18.1)	
Very or somewhat unimportant	106 (22.6)	51 (18.4)	55 (28.5)	

*Significant with Chi-squared test

Table 4.

Knowledge, risk perception, and barriers to screening across racial groups

	White (n=312)	Black (n=94)	Other (n=66)	p-value
Knowledge Score, % Correct (95% CI)	66.0% (63.8–68.1)	63.5% (59.4–67.4)	66.0% (61.2–70.5)	0.54
Perception of risk for BE/EAC				
How likely or unlikely do you think you are to get Barrett's esophagus in your lifetime?				0.067
Very likely or somewhat likely	86 (27.6)	39 (41.5)	25 (39.1)	
Neither likely nor unlikely	100 (32.1)	27 (28.7)	16 (25.0)	
Very unlikely or somewhat unlikely	126 (40.4)	28 (29.8)	23 (35.9)	
How likely or unlikely do you think you are to get esophageal cancer in your lifetime?				0.077
Very likely or somewhat likely	54 (17.3)	27 (28.7)	14 (21.9)	
Neither likely nor unlikely	104 (33.3)	30 (31.9)	26 (40.6)	
Very unlikely or somewhat unlikely	154 (49.4)	37 (39.4)	24 (37.5)	
How concerned are you about getting Barrett's esophagus?				**<0.001** *
Extremely concerned	12 (3.8)	19 (20.2)	8 (12.5)	
Moderately concerned	39 (12.5)	16 (17.0)	10 (15.6)	
Slightly concerned	81 (26.0)	16 (17.0)	17 (26.6)	
Somewhat concerned	76 (24.4)	21 (22.3)	12 (18.8)	
Not at all concerned	104 (33.3)	22 (23.4)	17 (26.6)	
How concerned are you about getting esophageal cancer?				**0.007** *
Extremely concerned	16 (5.1)	16 (17.0)	8 (12.5)	
Moderately concerned	39 (12.5)	16 (17.0)	11 (17.2)	
Slightly concerned	81 (26.0)	21 (22.3)	18 (28.1)	
Somewhat concerned	73 (23.4)	22 (23.4)	11 (17.2)	
Not at all concerned	103 (33.0)	19 (20.2)	16 (25.0)	
Would getting an upper endoscopy reduce your concern about esophageal cancer?				0.412
Yes	211 (67.6)	64 (68.1)	48 (75.0)	
No	30 (9.6)	13 (13.8)	7 (10.9)	
I am not concerned	71 (22.8)	17 (18.1)	9 (14.1)	
Considering your overall health, how important is getting screened for Barrett's esophagus and esophageal cancer for you?				**<0.001** *
Very or somewhat important	160 (51.3)	82 (87.2)	51 (79.7)	
Neither important nor unimportant	59 (18.9)	6 (6.4)	6 (9.4)	
Very or somewhat unimportant	93 (29.8)	6 (6.4)	7 (10.9)	
Patient reported barriers to BE screening				
I don't think I need screening for Barrett's esophagus				<0.001 *
Strongly agree or agree	108 (34.6)	18 (19.1)	16 (24.6)	
Neither agree nor disagree	95 (30.4)	19 (20.2)	15 (23.1)	
Strongly disagree or disagree	109 (34.9)	57 (60.6)	34 (52.3)	
I am afraid that an upper endoscopy will be uncomfortable and painful				0.334
Strongly agree or agree	60 (19.2)	21 (22.3)	15 (23.1)	
Neither agree nor disagree	43 (13.8)	17 (18.1)	14 (21.5)	
Strongly disagree or disagree	209 (67.0)	56 (59.6)	36 (55.4)	
I do not want an upper endoscopy for screening because I am afraid it might show cancer				0.052
Strongly agree or agree	5 (1.6)	6 (6.4)	3 (4.6)	
Neither agree nor disagree	21 (6.7)	9 (9.6)	8 (12.3)	
Strongly disagree or disagree	286 (91.7)	79 (84.0)	54 (83.1)	

	White (n=312)	Black (n=94)	Other (n=66)	p-value
I do not think an upper endoscopy is a good test for screening for Barrett's esophagus				**0.042** *
Strongly agree or agree	6 (1.9)	8 (8.5)	3 (4.6)	
Neither agree nor disagree	105 (33.7)	28 (29.8)	18 (27.7)	
Strongly disagree or disagree	201 (64.4)	58 (61.7)	44 (67.7)	
Scheduling an appointment for an upper endoscopy is too difficult				**0.044** *
Strongly agree or agree	11 (3.5)	8 (8.5)	1 (1.5)	
Neither agree nor disagree	53 (17.0)	19 (20.2)	18 (27.7)	
Strongly disagree or disagree	248 (79.5)	67 (71.3)	46 (70.8)	
I have to wait too long before an upper endoscopy can be scheduled				0.293
Strongly agree or agree	23 (7.4)	10 (10.6)	1 (1.5)	
Neither agree nor disagree	91 (29.2)	25 (26.6)	21 (32.3)	
Strongly disagree or disagree	198 (63.5)	59 (62.8)	43 (66.2)	
An upper endoscopy takes too much time				0.299
Strongly agree or agree	8 (2.6)	4 (4.3)	0 (0.0)	
Neither agree nor disagree	65 (20.8)	21 (22.3)	19 (29.7)	
Strongly disagree or disagree	239 (76.6)	69 (73.4)	45 (70.3)	
I do not know where to have an upper endoscopy done				**0.017** *
Strongly agree or agree	26 (8.3)	6 (6.4)	12 (18.8)	
Neither agree nor disagree	24 (7.7)	11 (11.7)	9 (14.1)	
Strongly disagree or disagree	262 (84.0)	77 (81.9)	43 (67.2)	
I cannot arrange for a ride to have an upper endoscopy done				0.182
Strongly agree or agree	15 (4.8)	10 (10.6)	7 (10.9)	
Neither agree nor disagree	19 (6.1)	4 (4.3)	4 (6.2)	
Strongly disagree or disagree	278 (89.1)	80 (85.1)	53 (82.8)	
I do not think my insurance plan will cover an upper endoscopy				**0.004** *
Strongly agree or agree	11 (3.5)	3 (3.2)	9 (14.1)	
Neither agree nor disagree	83 (26.6)	29 (30.9)	20 (31.2)	
Strongly disagree or disagree	218 (69.9)	62 (66.0)	35 (54.7)	
I will have to pay too much out of pocket for an upper endoscopy				**0.002** *
Strongly agree or agree	19 (6.1)	10 (10.6)	9 (14.1)	
Neither agree nor disagree	80 (25.6)	20 (21.3)	27 (42.2)	
Strongly disagree or disagree	213 (68.3)	64 (68.1)	28 (43.8)	

* Significant w/ Fisher's exact test