



Contents lists available at ScienceDirect

Journal of Pediatric Surgery

journal homepage: www.sciencedirect.com/journal/journal-of-pediatric-surgery

Esophageal Surveillance Practices in Esophageal Atresia Patients: A Survey by the Eastern Pediatric Surgery Network

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ARTICLE INFO

Article history:

Received 26 January 2023

Accepted 10 February 2023

Keywords:

Esophageal atresia

Surveillance

Esophageal disease

ABSTRACT

Introduction: Endoscopic surveillance guidelines for patients with repaired esophageal atresia (EA) rely primarily on expert opinion. Prior to embarking on a prospective EA surveillance registry, we sought to understand EA surveillance practices within the Eastern Pediatric Surgery Network (EPSN).

Methods: An anonymous, 23-question Qualtrics survey was emailed to 181 physicians (surgeons and gastroenterologists) at 19 member institutions. Likert scale questions gauged agreement with international EA surveillance guideline-derived statements. Multiple-choice questions assessed individual and institutional practices.

Results: The response rate was 77%. Most respondents (80%) strongly agree or agree that EA surveillance endoscopy should follow a set schedule, while only 36% claimed to perform routine upper GI endoscopy regardless of symptoms. Many institutions (77%) have an aerodigestive clinic, even if some lack a multi-disciplinary EA team. Most physicians (72%) expressed strong interest in helping develop evidence-based guidelines.

Conclusions: Our survey reveals physician agreement with current guidelines but weak adherence. Surveillance methods vary greatly, underscoring the lack of evidence-based data to guide EA care. Aerodigestive clinics may help implement surveillance schedules. Respondents support evidence-based protocols, which bodes well for care standardization. Results will inform the first multi-institutional EA databases in the United States (US), which will be essential for evidence-based care.

Level of Evidence: This is a prognosis study with level 4 evidence.

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Abbreviations: EA, Esophageal Atresia; EPSN, Eastern Pediatric Surgery Network; ESPGHAN, European Society for Paediatric Gastroenterology, Hepatology and Nutrition; GERD, Gastroesophageal reflux disease; GI, Gastrointestinal; IRB, Institutional Review Board; NASPGHAN, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition.

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<https://doi.org/10.1016/j.jpedsurg.2023.02.030>

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Please cite this article as: Hamilton-Hall III MN et al., Esophageal Surveillance Practices in Esophageal Atresia Patients: A Survey by the Eastern Pediatric Surgery Network, Journal of Pediatric Surgery, <https://doi.org/10.1016/j.jpedsurg.2023.02.030>

1. Introduction

Esophageal atresia (EA) is the most common congenital esophageal anomaly now with excellent survival rates after surgical repair allowing patients to survive well into adulthood [1,2]. Yet patients with EA have several long-term disease related morbidities. They face a high incidence of Gastroesophageal Reflux Disease (GERD), which can lead to esophagitis and even esophageal cancer if untreated [3–5]. Asymptomatic esophageal disease is also prevalent [3]. One study performing routine surveillance found esophagitis or metaplasia in 40% of EA patients under age three [6]. More research is needed to determine the best approach for early detection and treatment of esophageal disease.

In order to address this silent progression of esophageal disease, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN/NASPGHAN) proposed a surveillance schedule for EA patients that begins endoscopic screening as early as one year of age [7]. However, data to support this recommendation is limited. Guidelines are based largely on gastroenterology expert opinion with little surgeon input. Pediatric surgeons play a significant role in the endoscopic surveillance of EA patients, especially in the first few years after surgical repair. We hypothesized that the ESPGHAN/NASPGHAN guidelines may be less well known outside the field of gastroenterology and are inconsistently implemented across pediatric institutions in the US.

Without strong backing data, it is unknown whether current standards are adequate to detect early disease or place patients at undue risk/burden secondary to unnecessary surveillance. To better understand practice patterns and preferences of providers treating EA patients, we surveyed pediatric surgeons and gastroenterologists at EPSN member institutions. Survey results will guide development of standardized protocols across EPSN member institutions, contributing to the development of evidence-based guidelines for both short- and long-term surveillance after EA repair.

2. Methods

An anonymous, 10-min, online questionnaire was distributed via email to 181 pediatric surgeons and gastroenterologists within the EPSN network, a surgical research consortium composed of 19 tertiary care children's hospitals located in 13 states and the District of Columbia. The survey was hosted on the Qualtrics (Qualtrics, Provo, UT) platform and received local Institutional Review Board (IRB) approval #20–050. A lead EPSN surgeon was identified at each institution to assist in project development and execution. All other practicing pediatric surgeons ($n = 138$) were identified at these institutions through an EPSN membership list, facilitated by lead surgeons and public directories. We then identified 21 lead pediatric gastroenterologists that manage EA patients at each institution. Responses were accepted during a continuous 5-week period with 3 reminder emails. Questions were not modified during this time. Physicians were allowed to skip question(s) and still submit responses.

Lead physicians were asked for the number of new cases (surgeon) or total patients (gastroenterology) managed annually at their institution. All physicians reported their experience, i. e. years in practice and if they currently manage EA. If they do not manage EA, they were redirected to skip management questions but received Likert questions and questions to assess interest in future evidence-based guidelines. The six Likert scale questions (five-point scale, ranging from “strongly agree” to “strongly disagree”)

were intended to gauge respondent agreement with various EA pathology and surveillance statements stemming from existing ESPGHAN/NASPGHAN guidelines. We then requested information regarding institutional EA surveillance recommendations and schedules, individual practices, and other facets of EA management at both the individual and organizational level.

3. Results

139 surveys were completed after 5 weeks of submissions. The overall response rate was 77%, including 79% ($n = 19$) of gastroenterologists, 100% ($n = 19$) of lead EPSN surgeons, and 73% ($n = 101$) of non-lead pediatric surgeons. A negligible percent of surveys was excluded from analysis ($n = 3$) if the participant did not complete at least 70% of the survey. Institutional response rates ranged from 29% to 100% with a median institutional response rate of 80%. Data was exported from Qualtrics and analyzed in Microsoft Excel 2018 (Microsoft Corporation, Redmond, WA). Some questions did not receive the same number of responses, given that respondents were not required to answer every question in order to submit a questionnaire.

Physicians as a whole reported a wide range of years in practice; 26.6% ($n = 37$) have been in practice less than 5 years, 25.9% ($n = 36$) in practice 5–10 years, 15.1% ($n = 21$) practicing 11–15 years, 6.5% ($n = 9$) practicing 16–20 years, and 25.9% ($n = 36$) practicing over 20 years. The majority of lead surgeons (57.8%) report that their institution manages between 10 and 20 new EA cases annually, while the majority of gastroenterologists (57%) see between 10 and 40 clinic EA patients annually. However, some (26.3%, $n = 5$) report managing less than 10, while others (10.5%, $n = 2$) report managing over 100 new EA patients annually.

3.1. EA surveillance schedule

Over 75% of respondents agreed or strongly agreed with each listed ESPGHAN/NASPGHAN based guideline statement (Fig. 1.). In a sub analysis, no gastroenterologists disagreed with a guideline statement. Most surgeons (77%) and gastroenterologists (95%) agreed that endoscopy should be performed on a scheduled basis for EA patients, but 6% of surgeons disagree.

Only 37% ($n = 47$) of participants report that their EA patients have predetermined, outpatient clinic follow-up schedules. 36% ($n = 44$) stated their patients follow set surveillance schedules. Approximately 9% ($n = 12$) of participants were unsure if their patients have a standardized outpatient follow-up schedule, and 17% ($n = 21$) were uncertain if their patients receive scheduled esophageal surveillance. Surprisingly, only 24% ($n = 30$) of respondents claim that upper endoscopy follows a set schedule, while (22%, $n = 27$) were uncertain.

Some physicians (36%, $n = 45$) perform routine surveillance endoscopy regardless of patient symptoms. However, many (46%, $n = 57$) report performing endoscopy only if symptoms are present. Although 82% ($n = 102$) of participants state their patients generally receive upper endoscopy as part of their care (all indications), only 44% of endoscopies are performed according to a routine schedule. Endoscopy frequency varies among those who perform surveillance endoscopy (Fig. 2.), with only 22% ($n = 26$) doing so three times during childhood/adolescence. First endoscopy is performed at one year of age by 35% ($n = 42$) of respondents, but some (45%, $n = 54$) do so only if and when symptoms develop.

3.2. EA surveillance methods

Although 72% ($n = 68$) report personally performing some form of postoperative esophageal surveillance, surveillance modalities

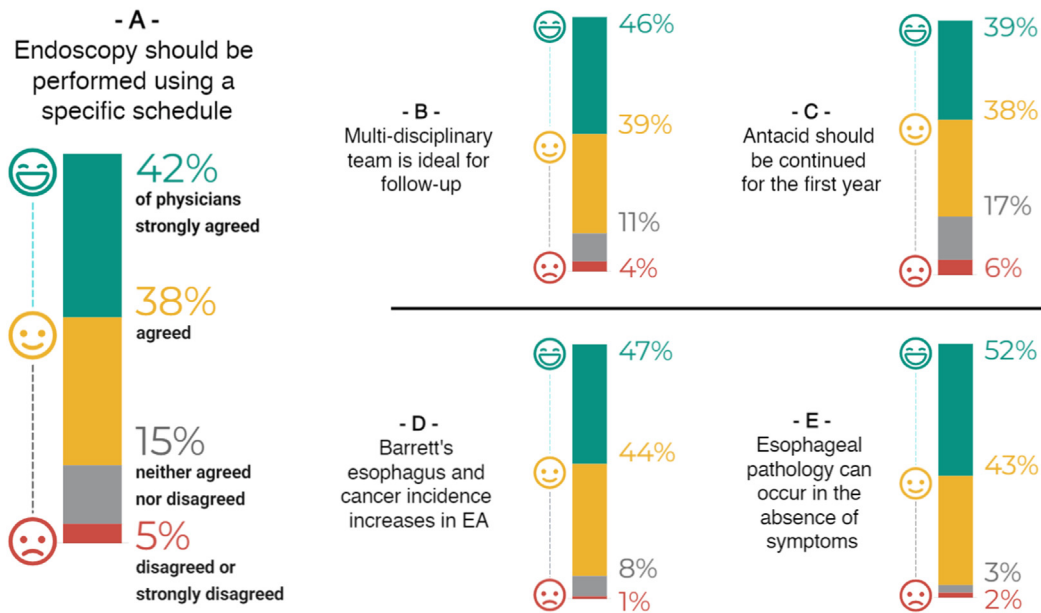


Fig. 1. Physician (pediatric surgeons & gastroenterologists) level of agreement with NASPGHAN based esophageal atresia care guidelines. Most physicians recognize esophageal disease in EA patients is a long-term problem that requires surveillance. (A) Endoscopy of the upper gastrointestinal tract should be performed in EA patients in childhood & adolescence according to a schedule. (B) EA patients should be followed by a multi-disciplinary team. (C) EA patients need to remain on an antacid for the first year of life. (D) EA patients are at increased risk of developing Barrett's esophagus & potentially esophageal cancer. (E) EA patients may have esophageal pathology in the absence of symptoms.

vary (Fig. 3.) and range from clinical review of systems to endoscopy with or without routine biopsy. Surprisingly, 16 physicians (7.5%) responded they do not utilize “clinical review of symptoms” for EA surveillance. A majority (66.7%, n = 10) of this subgroup state they perform a patient’s first upper endoscopy “only when and if symptoms develop.”

3.3. Multi-disciplinary team management

Roughly half of participants (47%, n = 60) report a multi-disciplinary team follows their EA patients, with an additional 19% (n = 24) noting their institution is working to develop this follow-up structure. Approximately one third (30%, n = 38) of all surveyed

physicians are members of a multi-disciplinary team for EA patients. Most respondents (78%, n = 99) state their institutions have a multi-disciplinary aerodigestive clinic with an additional 7% (n = 9) working to develop one. Those who reported that their institution lacks a multi-disciplinary EA team often note their hospital system does have an aerodigestive clinic (Fig. 4.).

3.4. Physician readiness for standardization & evidence-based guidelines

When asked if their institution’s current practices and resources meet a desirable standard of care, nearly 10% (n = 13) of physicians disagreed; 18% (n = 25) neither agreed or disagreed. The majority of

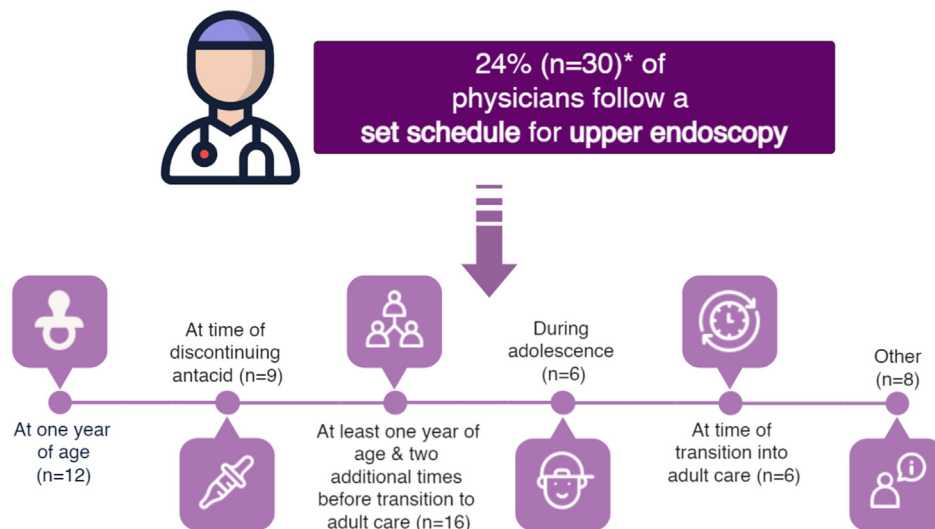


Fig. 2. Schedule for upper endoscopy for esophageal atresia surveillance. Most physicians do not follow a set schedule for upper endoscopy for esophageal atresia surveillance and those that do have variable timing of surveillance. *note this survey question allowed respondents to select more than one option.

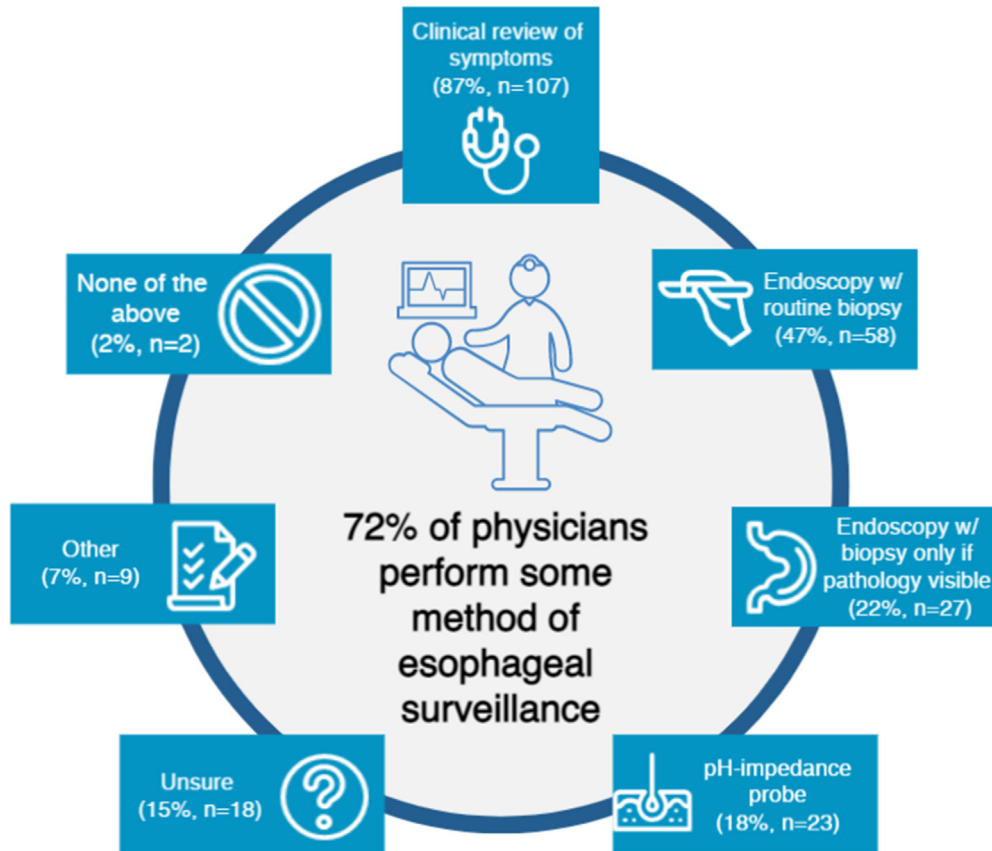


Fig. 3. Method(s) of post-operative esophageal surveillance that physicians utilize for esophageal atresia patients. Clinical review of symptoms and endoscopy (with or without routine biopsy) are the most common methods of surveillance, followed by pH-impedance and “other” which ranged from airway exam or feeding evaluation to “aerodigestive team determines surveillance”.

physicians (95%, $n = 125$) are willing or potentially willing to incorporate new evidence-based guidelines into their practice. Respondents expressed support for developing multi-disciplinary EA surveillance practices and evidence-based practice guidelines, with 71% ($n = 93$) expressing strong interest and 19% ($n = 25$) expressing potential interest in doing so.

4. Discussion

We report practice trends/beliefs of pediatric surgeons and gastroenterologists regarding EA management and surveillance across EPSN institutions, including discrepancies between stated beliefs and practices. The high response rate and satisfactory median institutional response rate indicates that results are likely representative of current practice patterns. Results may be extrapolated to all EA-treating pediatric surgeons and gastroenterologists within the EPSN and potentially beyond. Most participating institutions manage a substantial number of EA cases annually and a multi-institutional effort is key to generate the power to develop evidence-based surveillance guidelines.

4.1. Agreement with EA management guidelines

The majority of respondents agree with the NASPGHAN based statements for EA management. Our study yielded greater agreement levels than others, including a survey of mostly European EA healthcare professionals (13% American), which found a median of 69% agreement [2]. A survey distributed at Canadian Association of Pediatric Surgeons conference (60% practicing in US) found that

only 12% of providers perform routine endoscopy [8]. We did not directly test for awareness of NASPGHAN guidelines by name as we did not want to influence responses with social desirability bias. Agreement with EA management statements bodes well for future multi-disciplinary, multi-institutional standardization of EA management and surveillance within the EPSN.

4.2. Adherence to EA surveillance guidelines

Interestingly, self-reported clinical practice reveals low concordance with ESPGHAN/NASPGHAN guidelines when compared to physicians' stated guideline agreement. Although the majority of respondents claimed their patients receive postoperative surveillance of some form, only 36% reported a predetermined EA surveillance schedule. Some were unsure if set follow-up or surveillance schedules exist at their institution. For instance, 20% of respondents were unsure if their patients followed a predetermined schedule for surveillance (any method) or if a specific schedule is followed for upper endoscopy. This may indicate either that institutions do not have protocols for EA care, lack of surgeon involvement and/or prospective data in creating existing guidelines, or that physicians are unaware of formal follow-up recommendations. Additionally, EA patients may be lost to follow-up by their original surgeon over time or be followed by a physician that is not aware of the essential need for esophageal surveillance. Rather than discovering departures from standard of care, our findings highlight the complexity of longitudinal EA management and lack of strong data to guide practice patterns, as well as reveal opportunities for further research and education.

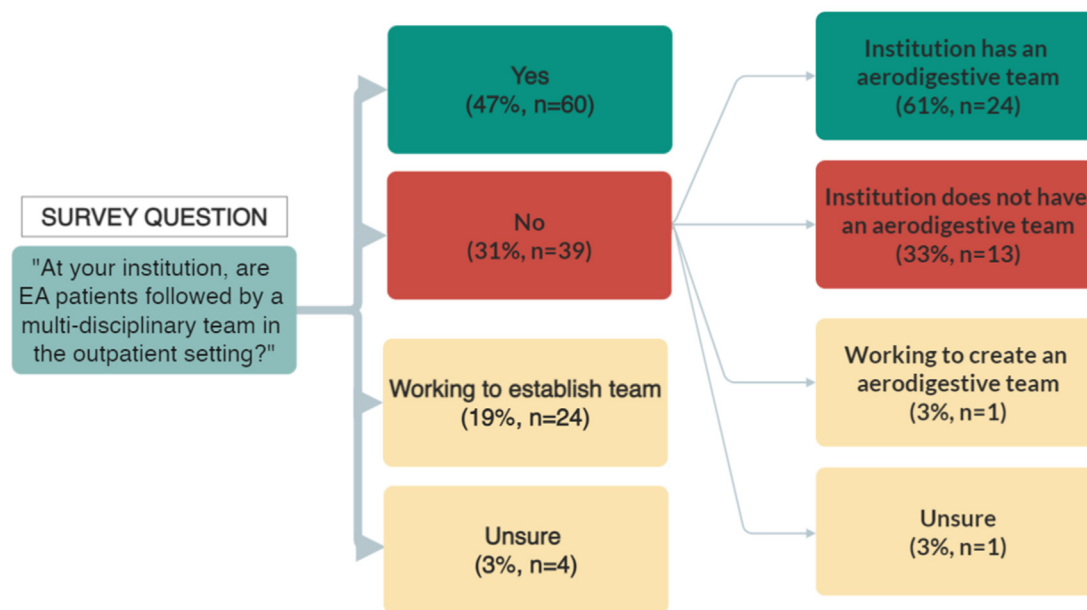


Fig. 4. Esophageal atresia patients cared for in a multi-disciplinary setting. A large portion of respondents note patients are followed by a multi-disciplinary team; where of those that are not, most have the infrastructure to develop a team. Of note, at least one physician from each institution stated the presence of an aerodigestive team at their institution.

Conversely, Dutch authors have proposed a formal follow-up schedule for EA patients including a swallow X-ray at five months, pH-monitoring beginning at six months of age, endoscopy with histology at 18 years of age, and quinquennial endoscopy after age eighteen [9]. Lifelong surveillance is crucial, as studies have discovered increases in the incidences of Barrett's esophagus (26-fold) and esophageal cancer (50-fold) in adult EA patients compared to the general population [10,11]. Documented long-term esophageal morbidity highlights the need for standardization of care across US institutions for EA patients.

NASPGHAN guidelines recommend performing endoscopy alongside routine biopsy three times (1 year of age, before age 10, and at transition to adulthood), regardless of symptoms [7]. Screening endoscopy has identified columnar metaplasia in 33% of EA patients by age 15, exposing pathologic injury to the esophagus in the absence of overt symptoms [3,12]. Yet endoscopy requires general anesthesia and thus carries risk for this patient population, which has a high incidence of comorbidities including cardiac anomalies [13]. There is little data to guide screening frequency due to limited late-stage follow-up [12,14]. Some question the ideal age for initial screening to improve outcomes, suggesting to delay routine endoscopic screening until 15 years of age [1,5,15]. Others have even proposed prioritizing alternative surveillance methods [16]. Clinical symptoms and endoscopy were the most preferred surveillance methods reported by EPSN physicians. About one third of our survey participants claimed to perform routine endoscopic surveillance regardless of symptoms, but nearly half only perform endoscopy if symptoms are present. Although screening can detect early or asymptomatic esophageal disease, further studies are necessary to identify the ideal screening method (with low risk profile and high detection rate) and timing (initiation and frequency).

Furthermore, less than one quarter of EPSN physicians follow the endoscopic surveillance schedule proposed by NASPGHAN. It is not known how many patients may have asymptomatic esophageal disease in the absence of routine surveillance. This reveals an opportunity within EPSN institutions to standardize the management

of EA with a focus on esophageal surveillance and also to conduct longitudinal studies to quantify outcomes including rates of esophageal pathology and patient risk profiles.

4.3. Multi-disciplinary care for EA patients

A large percent of respondents note that their EA patients are followed by a multi-disciplinary team or are working to establish this level of care. Multi-disciplinary care (including surgery, gastroenterology and otolaryngology among others) is generally accepted as standard of care for EA patients [17]. The majority of institutions house aerodigestive clinics and this may be under-reported in our study as some physicians at each institution did report having such a team. Aerodigestive teams may provide the framework to develop formal, multi-disciplinary EA teams. EA clinic teams are an avenue for standardizing management to improve care quality and value as well as access in complex patients.

Most surveyed physicians are willing to incorporate evidence-based guidelines for EA management and surveillance into their practice. Many of these physicians are also interested in helping develop such guidelines. This broad support across EPSN institutions will enable efforts to standardize EA surveillance, and also create a longitudinal registry to generate data that develops evidence-based practice guidelines for EA surveillance.

5. Limitations

When performing an optional survey, the risk of selection bias is possible. Physicians who respond may be more interested in EA management and/or have different knowledge of protocols compared with non-respondents. Our high response rate provides confidence that results reflect the true opinions and practices of EPSN physicians. Questionnaires are also at risk of being unclear. For example, in reporting patient volume, surgeons were asked about annual new EA cases, but we did not specify if these were all operative cases versus referrals after initial surgical repair

elsewhere. Furthermore, when answering endoscopy questions, some may have misinterpreted the purpose/role of endoscopy such as for surveillance versus therapeutic benefit, although survey headers were used to clarify surveillance for relevant questions. Finally, the qualitative nature of this survey and imbalance in group sizes limited our ability to perform extensive statistical analysis. However, statistical group comparisons were not a goal of the survey and it was not designed to perform such analysis.

5.1. Study validity

Each question was answered by a majority of respondents. Thus, it is unlikely that any calculated percentages were skewed by nonresponse. The survey was anonymous; therefore, it is unlikely that social desirability bias influenced our results. Participants self-reported EA management methods at odds with ESPGHAN/NASPGHAN guidelines, even after reporting high levels of agreement with guideline statements. The Likert questions were also presented first in the questionnaire in an effort to minimize question order bias. Since some respondents still reported practices inconsistent with these guidelines despite the influence of order or social desirability, we are confident that results reflect the true opinions and management practices.

6. Conclusion

This survey is the first multi-institutional, multi-disciplinary study in the US to define current practice patterns for surveillance in patients with EA. Among EPSN institutions, we demonstrate broad physician agreement with previously published EA surveillance guidelines but less consistency in practice patterns. Variation in surveillance methods and frequency can improve with standardized care. We therefore aim to generate a balanced multi-disciplinary (near equal representation of lead pediatric surgeons and gastroenterologists), multi-institutional standardized protocol for EA surveillance within the EPSN. This would in turn generate longitudinal outcomes data such as disease pathology rates and potentially help identify high and low risk patient populations, which may each benefit from different screening frequencies. Our ultimate aim is to develop the much needed evidence-based practice guidelines for esophageal surveillance in our ever growing EA patient population.

Conflicts of interest

Author has no competing interests or financial conflicts. This study has institutional financial support only that has allowed access to research staff.

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