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ORIGINAL ARTICLE

Disparity in online health information in pediatric vs. adult surgical conditions

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Abstract

Background Although the quality of online health information (OHI) for adult surgical conditions is well described, the availability of quality OHI for pediatric surgical conditions, and the comparison to that of adult surgical OHI, remains undefined.

Methods Medical and lay terms for 15 pediatric and 15 adult surgical conditions were searched using Google in English. The Health on the Net Foundation, a non-governmental OHI accreditation body, designates approval for quality websites. We compared the role of patient population while controlling for disease incidence (pediatric vs. adult), term complexity (medical vs. lay), and order (earlier vs. later listing of websites) on availability of quality OHI among the first 100 websites for each term.

Results Among the first 100 websites, the adjusted mean number of quality websites was 11.80 for pediatric vs. 17.92 for adult medical search terms, and 13.27 for pediatric vs. 18.20 for adult lay search terms ($P < 0.05$ for all). Term complexity did not affect quality, and earlier appearing results were more likely to be of high quality.

Conclusion Availability of quality pediatric surgical OHI lags behind that of adult surgical OHI, even when controlling for disease incidence. These findings highlight the potential need for increased quality OHI in pediatric surgery.

Keywords Pediatric surgery · Internet · General surgery · eHealth

Introduction

The Internet is a fast-growing and pervasive tool that has revolutionized how billions of people seek information. Close to half the world's population (3.8 billion) used the Internet as of January 2018 [1]. In 2011, 80% of Americans sought health information online [2]. Many use the Internet as their initial source of health information and may be influenced by this knowledge before consulting health professionals [3, 4]. Others use the internet to improve confidence in advice given by their healthcare providers [5]. The internet provides a means through which patients can continue to take charge of their own health decisions; indeed, patients are increasingly equipped with knowledge about their conditions, thereby diminishing the exclusivity of health information held by healthcare professionals [3]. As the amount of information on the internet continues to grow, and as patients and caregivers—with varying degrees of health literacy—turn to the internet as a source of information that may influence actions that affect their health, the internet will continue to be a means through which education about one's own health may be modified both positive and negatively. Thus, quality of online health information (OHI) is of critical importance in ensuring responsible education of the public [5].

Parents of pediatric patients with surgical conditions make use of the Internet as a key source of health information. Multiple studies in pediatric tertiary care centers have found 70–80% of parents have looked or intend to look to the Internet for information about their child's surgical condition [6, 7]. However, the quality of available OHI is variable,

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with potentially misleading results [8]; biases and incorrect information could potentially increase the likelihood of suboptimal outcomes [9].

Given the importance of OHI to patients [10], myriad studies have examined the quality of OHI across a range of conditions [4, 11, 12]. Studies in adult surgical OHI have found widespread variability in quality as a function of language [11, 13], geographic location [14], anatomical location [13], disease incidence [15], and search term [16]. Although online resources play a key role in information distribution in pediatric surgery [17], the majority of the aforementioned studies are in adult conditions. The studies in pediatric surgical OHI are limited in number, and show general variability in quality of OHI [18], with common topics achieving higher quality OHI compared with uncommon topics [19]. This discrepancy may be due to the assumption that results in the adult literature are generalizable to the pediatric patient. To our knowledge, no study has compared the availability of quality OHI for pediatric surgical topics to adult surgical topics.

In contrast to the adult literature, data are lacking in the pediatric surgery literature on search strategies, including search term complexity and the order in which sites appear in search results. Our study seeks to characterize these important parameters of OHI in pediatric surgery. We hypothesize that search terms for adult conditions will yield more high-quality results compared to search terms for pediatric conditions, that increasing the complexity of the search term (medicalizing) would positively affect the availability of quality information, and that earlier appearing websites would be more likely to be of high quality.

Materials and methods

Selection of medical and lay terms

We selected 15 pediatric and 15 adult surgical conditions that represent a wide range of diseases involving the following organ systems: hepatobiliary, respiratory, cardiac, genitourinary, gastrointestinal, central nervous system, and reproductive. Two authors independently generated lay terms that fit each condition. Lay terms were generated using descriptive, largely non-medical language with the goal of simulating how patients and caregivers may phrase search queries for a patient's condition; names of organs were included, e.g., "brain" and "heart," whereas names of pathological processes were replaced, e.g., "volvulus" and "endocarditis" with "twisted" and "infection." These terms were then pooled. At least four lay terms were generated for each medical term, with a maximum of four words in each lay term. Each candidate lay term was searched on Google. For each condition, the candidate lay term with the greatest number of Google search results was selected for further analysis (Fig. 1, Supplementary Table 1). We included a total of 60 English medical and lay terms in the analysis (Table 1).

Incidence data

Supplementary Table 2 lists the sources used to collect United States (US) incidence data for the conditions included in the analysis. As no single source provided incidence data for all the conditions, primary texts, Centers for Disease Control and Prevention statistics, and other sources were used. If a percentage was reported, and not a numerical incidence, the incidence was calculated with the assumption of a US birth rate of 4,000,000 live births per year [20] and a US population of 320,000,000 [21].

Website search

We searched the 60 terms using the English Google search engine in February 2018. The first 100 websites of each search were assessed for quality, yielding a total of 6000 websites.

Assessment of quality by Health On the Net (HON)

We evaluated websites using the Health On the Net (HON) Foundation HONcode tool. The Health On the Net (HON) Foundation is a World Health Organization-supported accreditation body for health websites that designates HONcode approval based on the key principles of authority, complementarity, confidentiality, attribution, justifiability, transparency of authorship, transparency of sponsorship, and honesty in advertising and editorial policy (Table 2) [22, 23]. To gain HONcode accreditation, websites are assessed by HON medical experts for adherence to the HON principles [23]. The presence of the HONcode accreditation, therefore, denotes a website's compliance with the HON principles; many studies have used HONcode accreditation as a tool for identifying quality OHI [11–13, 19, 24–26]. We [14] and others [11] have validated HONcode accreditation by re-assessing websites using HON principles by hand; over 90% of non-HONcode-accredited websites were found to not meet HONcode criteria [11]. Furthermore, HONcode has been shown to be a significant predictor of scientific information quality [27]. We thus defined HONcode-accredited websites as 'high quality.'

Statistical analysis

We used the Student's *T* test to compare mean numbers and percentages of high-quality sites of pediatric and adult surgical terms. Analysis of covariance (ANCOVA)

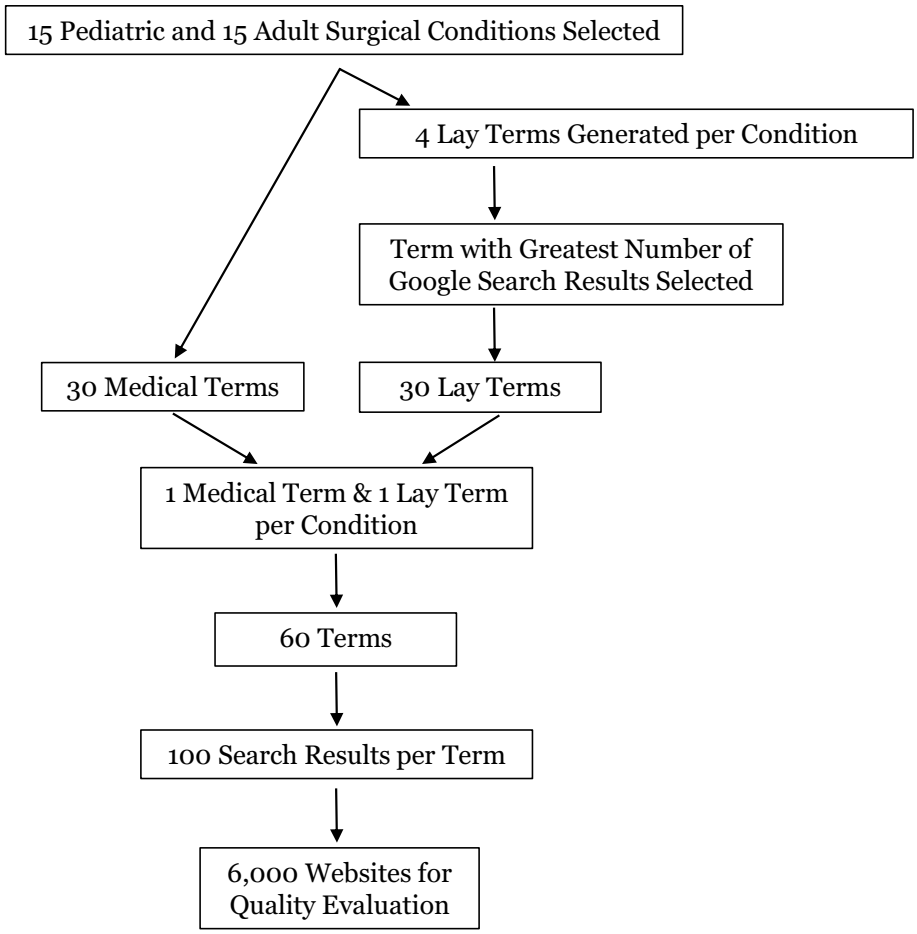

Fig. 1 Search term generation schematic

Table 1 Search terms included in the analysis

	Pediatric		Adult	
	Medical	Lay	Medical	Lay
Hepatobiliary	Hepatoblastoma	Baby liver cancer	Hepatocellular carcinoma	Liver cancer
	Biliary atresia	Baby bile duct block	Cholecystitis	Gallbladder infection
Thoracic (non-cardiac)	Congenital diaphragmatic hernia	Child diaphragm hole	Lung adenocarcinoma	Lung cancer
	Esophageal atresia	Blocked food pipe baby	Esophageal adenocarcinoma	Esophagus tumor
Cardiac	Tetralogy of Fallot	Blue baby heart	Mitral valve prolapse	Heart prolapse
	Atrioventricular septal defect	Heart wall defect	Infective endocarditis	Heart infection
Renal	Wilms tumor	Baby kidney cancer	Renal cell carcinoma	Kidney cancer
Gastrointestinal	Malrotation and volvulus	Baby twisted gut	Colorectal cancer	Colon cancer
	Gastroschisis	Baby abdomen hole	Diverticulitis	Intestine pouch disease
	Necrotizing enterocolitis	Baby intestine infection deadly	Ulcerative colitis	Colon inflammation
	Pyloric stenosis	Blocked stomach baby	Sigmoid volvulus	Adult twisted left bowel
CNS	Pediatric glioma	Child brain mass	Meningioma	Brain layer tumor
	Congenital hydrocephalus	Water in brain	Glioblastoma	Aggressive brain cancer
GU	Cryptorchidism	Baby testicle in belly	Benign prostatic hyperplasia	Large prostate
	Hypospadias	Baby penis bottom open	Testicular cancer	Man genital cancer

Search terms were selected to cover a wide range of organ systems

Table 2 HONcode key principles

Principle 1	Authority	Give qualifications of authors
Principle 2	Complementarity	Information to support, not replace
Principle 3	Confidentiality	Respect the privacy of site users
Principle 4	Attribution	Cite the sources and dates of medical information
Principle 5	Justifiability	Justification of claims/balanced and objective claims
Principle 6	Transparency	Accessibility, provide valid contact details
Principle 7	Financial disclosure	Provide details of funding
Principle 8	Advertising	Clearly distinguish advertising from editorial content

Health On the Net Foundation Code of Conduct (HONcode) accreditation is granted to websites that adhere to the HONcode key principles as a benchmark of reliability and credibility

was used to control for different disease incidences among conditions. To assess whether or not complexity of the term would change the mean numbers and percentages of high-quality sites, Student's *T* tests were used to compare medical vs. lay terms for corresponding conditions. We reported odds ratios and logistic regression to assess the likelihoods that websites would be of high quality based on search result order, separated into bins of ten websites for each page of search results. Analyses were conducted using SAS Studio (Cary, NC, USA). All *P* values are two sided and statistical significance was considered for $P < 0.05$.

Results

Pediatric vs. adult

The 60 terms yielded a total of 6000 websites for analysis (Supplementary Table 3). For medical search terms, the mean number of high-quality sites among the first ten search results was 3.67 (36.7%) for pediatric and 5.47 (54.7%) for adult conditions (two-tailed *T* test $P = 0.009$). The mean numbers of high-quality sites among the first 20, the first 50, and the first 100 pediatric surgical sites were significantly lower than the mean numbers of high-quality sites among the first 20, the first 50, and the first 100 adult surgical sites (two-tailed *T* test $P < 0.01$ for all). For lay search terms, the mean number of high-quality sites among the first ten search results was 3.13 (31.3%) for pediatric and 6.53 (65.3%) for adult conditions (two-tailed *T* test $P < 0.0001$). The mean numbers of high-quality sites among the first 20, first 50, and first 100 lay pediatric surgical sites were also significantly lower than those of the lay adult surgical sites (two-tailed *T* test $P < 0.05$ for all, Fig. 2). All comparisons between pediatric and adult search terms remained significant when adjusting for disease incidence (ANCOVA $P < 0.05$ for all, Supplementary Table 4).

Medical vs. lay

For medical vs. lay terms, we found no significant differences in the number of high-quality sites within the pediatric and adult groups among the first 10, 20, 50, and 100 search results ($P \geq 0.10$ for all, Table 3).

Order and organ group

For pediatric medical terms, the odds of a high-quality site among the first ten search results were greater than the second ten results and were statistically significant (OR 2.32, 95% CI 1.38–3.90, $P = 0.0015$); the same held true for pediatric lay (OR 1.21, 95% CI 0.74–2.00, $P = 0.45$), adult medical (OR 2.34, 95% CI 1.47–3.73, $P = 0.0004$), and adult lay terms (OR 3.55, 95% CI 2.21–5.71, $P < 0.0001$), but was only statistically significant for adult medical and adult lay terms. The odds that websites in later pages of search results (each page with ten search results) were of high quality were lower in later pages compared to the first page of results (Table 4). Logistic regression demonstrated diminishing probability of high-quality sites with later appearing search results for pediatric medical, pediatric lay, adult medical, and adult lay terms (Wald Chi square and likelihood ratio Chi square $P < 0.0001$ for all, Fig. 3). The odds of a website being of high quality decreased by the following factors for each subsequent page of results: 0.780 (95% CI 0.732–0.829) for pediatric medical terms, 0.720 (0.675–0.767) for pediatric lay terms, 0.694 (0.653–0.735) for adult medical terms, and 0.665 (0.624–0.706) for adult lay search terms. Fifty percent of the high-quality sites occurred within the first 20 sites returned. When the six organ groups with greater than one term (hepatobiliary, thoracic non-cardiac, cardiac, gastrointestinal, CNS, and GU) were compared on ANOVA analysis (adult, pediatric, medical, and lay considered together), there were no significant differences in mean number of high-quality websites among the first 10, 20, 50, and 100 search results ($P \geq 0.23$ for all).

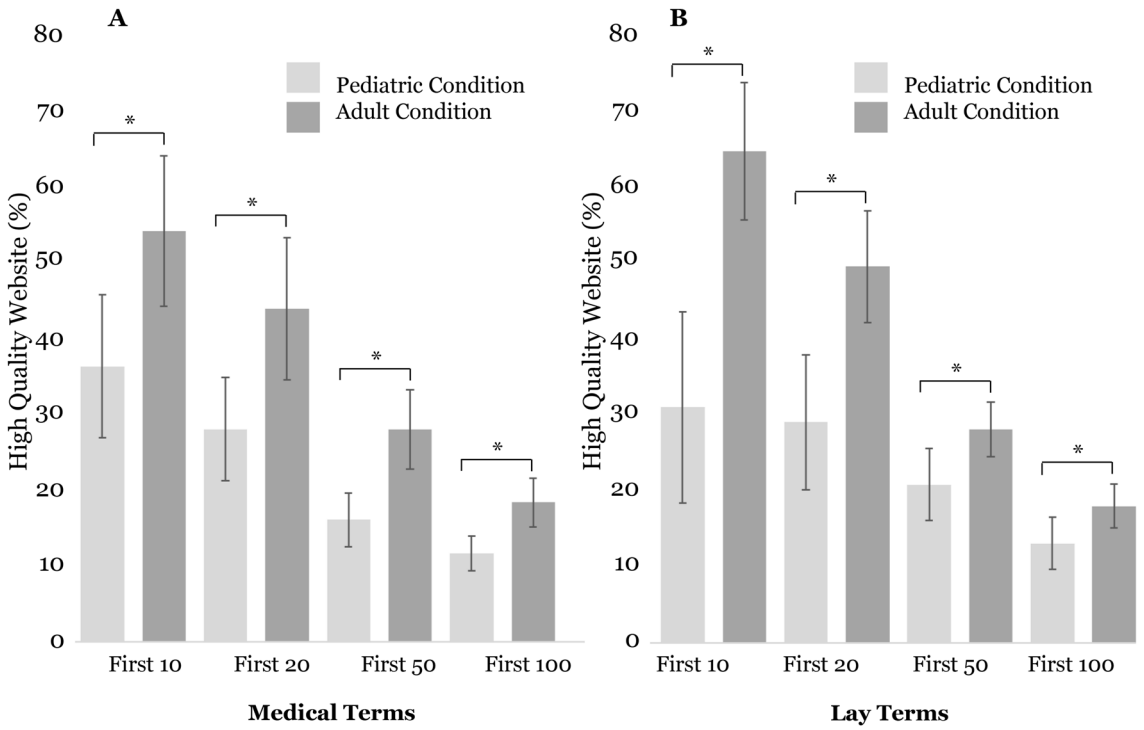

Fig. 2 Comparison of percent HONcode-accredited sites between pediatric and adult surgical online health information (OHI) using medical search terms (**a**) and lay search terms (**b**) (asterisk indicates statistically significant Student's *T* test at $P < 0.05$)

Table 3 Quality comparison of medical vs. lay term OHI

	Pediatric surgical conditions			Adult surgical conditions		
	Medical mean	Lay mean	*T* test *P* value	Medical mean	Lay mean	*T* test *P* value
First 10	3.67	3.13	0.48	5.47	6.53	0.10
First 20	5.67	5.87	0.85	8.87	10.00	0.32
First 50	8.13	10.53	0.098	14.13	14.20	0.96
First 100	11.80	13.27	0.46	17.93	18.20	0.90

Comparison between medical and lay terminologies for the same conditions. Student's *T* test is considered significant at $P < 0.05$

Discussion

To our knowledge, this study is the first to highlight the disparate availability of quality OHI for pediatric surgical compared to adult surgical conditions using both medical and lay search terms. Many studies have assessed the quality of adult surgical OHI in a wide array of topics [4, 11–13, 25, 28–30] and have found the quality to be variable. In contrast, only a limited number have analyzed pediatric surgical OHI [18, 19], perhaps owing to an assumed generalizability of the adult surgical OHI quality findings to pediatric surgical conditions, or the lower incidence of pediatric surgical disease. However, the true degree of difference in availability of high-quality OHI for pediatric compared to adult surgical conditions has remained undefined. This study demonstrates a deficit in high-quality pediatric surgical OHI compared to adult surgical OHI and raises important questions about the knowledge our patients access online.

The deficit in high-quality OHI between pediatric and adult surgical search terms persisted for the first 10, first 20, first 50, and first 100 search results, even when controlling for disease incidence, for both medical and lay terms. For example, the search term "hepatoblastoma" yielded only one high-quality site among the first ten results, and the term "baby liver cancer" yielded none. In contrast, the term "hepatocellular carcinoma" yielded five high-quality websites, and the term "liver cancer" yielded seven. As parents of children with rare conditions were shown to

Table 4 Order of search results and quality

Website number	Odds ratios of high-quality websites per page compared to first page of search results											
	Pediatric medical			Pediatric lay			Adult medical			Adult lay		
	OR	95% CI	*P* value	OR	95% CI	*P* value	OR	95% CI	*P* value	OR	95% CI	*P* value
1–10	1	–	–	1	–	–	1	–	–	1	–	–
11–20	0.43	0.26–0.73	0.0015	0.82	0.50–1.36	0.4470	0.43	0.27–0.68	0.0004	0.28	0.18–0.45	< 0.0001
21–30	0.31	0.18–0.54	< 0.0001	0.67	0.40–1.11	0.1211	0.23	0.14–0.39	< 0.0001	0.14	0.086–0.24	< 0.0001
31–40	0.072	0.030–0.17	< 0.0001	0.42	0.24–0.73	0.0021	0.17	0.097–0.28	< 0.0001	0.068	0.037–0.12	< 0.0001
41–50	0.097	0.044–0.21	< 0.0001	0.17	0.086–0.35	< 0.0001	0.14	0.077–0.24	< 0.0001	0.055	0.029–0.10	< 0.0001
51–60	0.21	0.11–0.38	< 0.0001	0.17	0.086–0.35	< 0.0001	0.12	0.067–0.21	< 0.0001	0.059	0.031–0.11	< 0.0001
61–70	0.15	0.076–0.30	< 0.0001	0.21	0.11–0.40	< 0.0001	0.079	0.041–0.15	< 0.0001	0.072	0.040–0.13	< 0.0001
71–80	0.047	0.017–0.13	< 0.0001	0.17	0.086–0.35	< 0.0001	0.066	0.033–0.13	< 0.0001	0.063	0.034–0.12	< 0.0001
81–90	0.12	0.060–0.25	< 0.0001	0.030	0.0070–0.12	< 0.0001	0.047	0.021–0.10	< 0.0001	0.030	0.014–0.066	< 0.0001
91–100	0.16	0.085–0.32	< 0.0001	0.060	0.021–0.17	< 0.0001	0.035	0.014–0.083	< 0.0001	0.011	0.0033–0.036	< 0.0001

Odds ratios comparing likelihoods of websites being of high-quality based on the order of appearance in search results (in bins of ten websites), using first ten websites (first page of results) as baseline. Odds ratios are considered significant at $P < 0.05$

be impacted by OHI [31], this lack may be a cause for concern.

In contrast to our hypothesis, we found that for both pediatric and adult searches, lay terminology did not result in fewer high-quality sites than medical terms. Therefore, providing patients with the proper medical name for a condition or suggesting an OHI search using lay terminology may not increase the availability of high-quality OHI. These results are consistent with Lawrentschuk et al. [11] who found no difference using lay and medical terms for certain malignancies. Within pediatrics, Fabricant et al. [16] demonstrated that using a similar but distinct word pair (i.e., hip dysplasia vs. hip dislocation) yields differing results, but the effect of common vs. lay search strategies has remained unknown. Our data indicate that disparities in OHI cannot be skirted by strategies focusing on using the "right" or "ideal" search term. Therefore, surgeons must play a more active role—indeed more than simply recommending a search term—in directing patients to quality OHI. Ideally, we should work to ensure high-quality resources are accessed by our patients. For example, surgeons can suggest that patients seek the HON seal of approval as patients seek OHI, as this has been repeatedly validated as a marker of high-quality OHI [11, 14, 27]. Patients can also be pointed towards databases such as the HON-accredited MedlinePlus (https://medlineplus.gov/), which offers curated medical information run by the US National Library of Medicine. Though the purpose of this study was not to evaluate the best individual website for each surgical condition, databases such as MedlinePlus, academic pediatric hospitals, and academic associations such as the American Pediatric Surgical Association consistently had high-quality information. Finally, surgeons can provide direct links to self-validated high-quality OHI when possible; given that in a recent study as little as 2% of parents were directed to a particular website by their child's surgeon [32], it is our hope that more surgeons incorporate quality OHI in their practice.

Notably, although our study focuses on the availability of quality information rather than types of websites, our review of the search results yielded few to no support group websites among the first 100 sites returned. For example, no support groups for "congenital diaphragmatic hernia" and "hepatoblastoma" were returned among the first 100 sites for each term. As support groups are important for patients and parents [33], it is important to direct patients towards hospital-based support groups (often linked within pediatric hospital websites) or to social media-based support groups easily accessed by searching "condition + support group."

While sophistication of the search term was not found to influence amount of OHI quality, the order of the results was found to play a significant role. Specifically, we found significantly higher probability of high-quality sites among earlier appearing search results compared to later appearing search

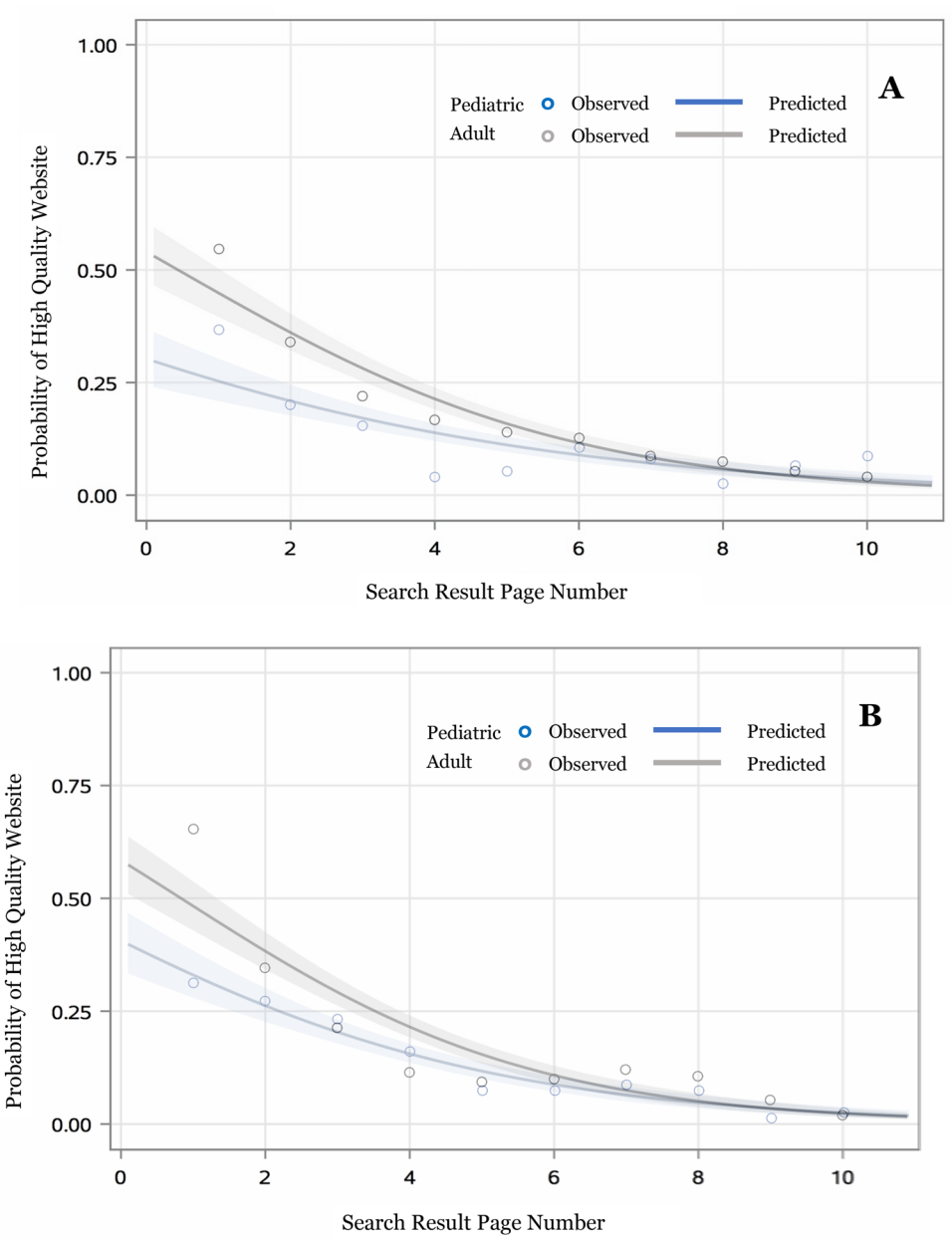

Fig. 3 Logistic regression demonstrating probability of returning high-quality websites vs. order of appearance when searched on the Google search engine, in bins of ten websites (number of websites per results page), for pediatric and adult medical search terms (**a**), and pediatric and adult lay search terms (**b**). Each page represents a bin of ten search results. Predicted probability curves are bound by 95% confidence limits. Likelihood ratio and Wald Chi square $P < 0.0001$ for all

results for pediatric medical, pediatric lay, adult medical, and adult lay terms. Moreover, over half of the high-quality sites occurred within the first 20 results of the searches we conducted. This is consistent with findings from other fields that demonstrate higher quality OHI in earlier search results [24]. As patients rarely read beyond the first page of results (usually ten sites) [10], this finding suggests that making a few more high-quality sites available to patients and parents may close the gap between pediatric and adult OHI, at least among the search results patients are likely to access. Furthermore, patients can also be counseled to focus on the first 10–20 results for a given search.

Our study sought to mirror what parents experience as they seek health information about their children. The role of the Internet in making healthcare decisions cannot be overstated, as parents were found to be significantly influenced by OHI when making decisions about their child's care [8, 32]. Indeed, almost 90% of parents of children with rare conditions were shown to be impacted by what they found online, citing "relevant and accurate" as key elements of quality OHI [31]. Since most parents tend to use their child's condition's formal medical name as the primary search term (as opposed to, say, the name of the surgical procedure) [34], our comparison of search results using formal disease names is not unrealistic. We used the Google search engine, which is most frequently used in the US and has been employed in other studies [13]. The use of Google is also consistent with the finding that patients

tend to use general search engines more than known reliable sites [35]. Implicit in this reliance upon OHI is another avenue to improve care. Since only 25% of parents discuss what they find on the Internet with their surgeon [34], it is essential that surgeons are aware of what OHI is available and take part in the decision of what is indeed "relevant and accurate." This study has thus shed light on the dearth of quality OHI available in particular to pediatric surgical patients and their caregivers.

One limitation of this study is the sample of conditions searched; it is possible that a different set of terms may have yielded different results. In seeking to create a representative sample of pediatric surgical conditions, in addition to common pediatric surgical conditions, we included several rare conditions that often require multidisciplinary care over longer periods of time, such as congenital diaphragmatic hernia and esophageal atresia. Parents of these children may be especially likely to seek out more extensive OHI through the duration of their child's care and after. Another limitation of our study was the necessity to use multiple sources for disease incidence data. Next, the lay terms generated did not constitute an exhaustive list of potential search terms; however, generating several lay terms and picking the one with most hits may replicate what patients' parents are most likely to search. Our quality analysis is reliant on the validity of the HONcode accreditation tool [23]. HONcode has been found to correlate with scientific information quality in numerous studies [14, 27, 36], with over 90% of non-HONcode sites not adhering to all the HON principles [11], and has been deemed an important metric for patients [11–13, 22, 24]. Furthermore, we [14] and others [11] have validated HONcode principles by evaluating websites by hand. Efforts to increase HONcode certification in pediatric OHI are, therefore, warranted. Furthermore, our study does not provide a list of quality websites; instead, we intend for this work to galvanize pediatric surgeons to address the demonstrated disparity in quality OHI, and play a greater role in keeping patients and their parents appropriately informed. Lastly, how Google and other search engines generate search results is unclear to most parents and physicians, thus further necessitating the role that surgeons can play in guiding patients and parents towards quality OHI.

The amount of quality pediatric surgical OHI lags behind that of adult surgical OHI, even when controlling for disease incidence. Notably, the use of formal medical language for pediatric surgical conditions did not increase the amount of quality OHI available to patients. These findings highlight the need for providers to make available high-quality information at the point of care as well as the need for increased efforts to bolster the amount of quality OHI in pediatric surgery. As more and more people look to the Internet as a source of health information—and as one that influences health decisions—directing patients to reliable sources of information and making OHI more reliable are essential components of patient-centered health care.

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Compliance with ethical standards

Conflict of interest Edward C. Dee declares that he has no conflict of interest. Nathan H. Varady declares that he has no conflict of interest. Jeffrey N. Katz declares that he has no conflict of interest. Terry L. Buchmiller declares that she has no conflict of interest.

Research involving human participants and/or animals This article does not contain any studies with human participants or animals performed by any of the authors.

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