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Total Thyroidectomy and the Readability and Reliability of Information on the World Wide Web

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ABSTRACT

Introduction: Thyroidectomy is a complex procedure with significant risks and life long consequences. As a result of its complexity, many patients use the internet as a 'quasi-second opinion' to gain more information about the procedure. Thus, information on the internet regarding thyroidectomy should be high quality and easy to read. Our aim is to assess the quality and readability of healthcare information regarding total thyroidectomy on the internet.

Methods: Thyroidectomy related websites were assessed using Google, Yahoo and Bing search engines. After removing duplicates, 34 unique websites were assessed using the DISCERN score and JAMA benchmark to assess quality of information. Readability was assessed using the Flesch Reading Ease Score, the Gunning Fog Index and the overall reading level of each website. The presence or absence of the HON code was also noted.

Results: The average DISCERN score was 36.24 +/- 10.02, putting the quality of available material into the poor category. Only 4 websites had a FRES score greater than the recommended 65 points and 14 websites] (41.17%) had a reading level of grade 10 of higher, making them accessible to college level graduates only. No significant difference was found in the difference between DISCERN scores (p=0.34) or FRES scores based on whether the HON code was present or absent. The average reading level was 9.2 +/- 2.2. The reading grade level was shown to be significantly too high when compared to the sixth-grade standard (P<0.001, CI=2.4-4).

Conclusion: The overall standard of information of the internet regarding thyroidectomy is of poor quality. Serious deficiencies were noted especially in terms of discussing alternative treatments, undertaking no treatment at all and encouraging shared care. Furthermore, only three websites met the criteria of a sixth grade reading level, meaning that the majority of the websites (91%) were inaccessible to patients with lower levels of education.

Keywords: Thyroidectomy, Internet, DISCERN, Readability

List of Abbreviations: HON code: Health on the Net code; FRES: Flesch Reading Ease Score; GFI: Gunning Fog Index; RGL: Reading Grade Level

INTRODUCTION

The World Wide Web came into being in 1990 and over the last three decades, it has become an extraordinarily valuable tool which has transformed modern life. The internet has the capacity to disseminate data across populations and nations, and while this presents unique opportunities, it also poses significant threats in terms of health care and the regulation of the information available to patients [1,2].

Traditionally, healthcare professionals have been the primary source of information for patients. However, recent studies suggest that 72-80% of Americans have sought health information on line within the last year [2,3]. Studies have shown that patients may develop perceptions and expectations about their diagnosis and treatment from the information available on the internet and this may impact on the patient-clinician rapport and interactions if the physician has to spend a significant amount of the consultation re-educating the patient

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and dispelling false information [1-4]. This means the internet has become a 'quasi-second opinion' for patients and presents significant challenges of the information available is poor quality and not credible [4].

Furthermore, patient education forms a crucial part of not only decision making but is also important for medication adherence and disease self-management. Thus, information needs to not only be accurate but it must also be accessible to patients. Guidelines have previously shown that for accessibility to the general public, information should be at a 6th grade reading level [5,6]. Previous studies have shown the online healthcare information is often above this reading level, rendering it inaccessible.

Thyroidectomy: The thyroid gland is located in the neck and is associated with the endocrine function of metabolism. Initially, thyroidectomy was considered 'butchery' due to the number of associated adverse events and it was banned by medical society until the 19th century when advances in technology and aseptic technique led to improved outcomes [7,8]. Theodor Kocher, whose own mortality rate for thyroidectomy dropped to 1%, was awarded the 1909 Nobel Prize for his advancement of thyroid surgery [9]. The indications for thyroidectomy include malignancy, refractory Graves Disease and compression symptoms [10,11].

However, despite the advances in thyroid surgery, complications still exist and must be explained to patients fully before surgery is undertaken. Injury to the recurrent laryngeal nerve can yield vocal cord paralysis, resulting in post-operative hoarseness, dysphasia and aspiration of liquids [11,12]. Bilateral vocal cord paralysis, a complication of total thyroidectomy, can yield devasting post-operative complications of airway obstruction, biphasic stridor and respiratory distress. Neck haematoma is a rare but dangerous complication of thyroidectomy, which can lead to airway compromise and asphyxiation. Thyrotoxic storm is a rare complication of thyroidectomy seen in patients with refractory Grave's disease and are associated with gland manipulation; symptoms include tachycardia, hyperthermia, and altered mental state and cardiac arrythmias [12]. Rates of transient hypocalcaemia vary in the literature between 5-50 percent with patients often requiring supplementation post operatively. In approximately 0.5-2 percent of individuals this may require lifelong supplementation [12].

The complexity of this surgery and its long-term complications can be difficult for patients to comprehend while undertaking consultation with their physician and often patients will consult the internet to supplement their knowledge or to seek answers to questions they may have felt too embarrassed to ask their physician. It is thus important that the information available is reliable and credible [1,3]. However, a number of studies have demonstrated that many healthcare websites contain inaccurate and misleading information and that many may be inaccessible to patients from an educational point of view [1-6]. The reliability and readability of healthcare data on the internet pertaining to the thyroidectomy has not been explored previously in the literature. Our aim is to assess the quality of the information available to patients on the internet regarding thyroidectomy and to determine the accessibility of this information by examining its readability.

Quality Assessment Instruments: Three key tools can be used to address the issues of accuracy and reliability of online health information; the DISCERN instrument, the Health of the Internet (HON) code and the JAMA benchmarks [1,3,4,13-15]. The DISCERN is a valid and reliable questionnaire; composed of 16 questions. It is used to test written consumer health information [13]. The JAMA benchmarks provide a qualitative assessment of the authorship, attribution, currency and disclosure for each website [1,3]. The HON code certification is an ethical standard created to encourage the dissemination of quality health information for patients and medical professionals [1,3,14].

METHODS

This study used the DISCERN instrument and JAMA benchmark to critically appraised the online health information related to total thyroidectomy. On the 25/04/2020, the three most popular search engines (Google, Bing and Yahoo!) were examined using the search term total thyroidectomy. The total number of returned hits is shown in **Table 1**.

Table 1. Total search results for Total Thyroidectomy for each of the search engines used.

Search Engine	Results Total
Google	1770000
Bing	37200
Yahoo!	108000

The first three pages of websites encountered on each search engine were reviewed, for a total of 93 websites. The limit for assessing hits was based on previous studies which showed that individuals typically examine the firstthree pages of a search engine, which contain on average 8-11 hits [1]. The returned sites were examined for duplications, which were removed. Websites which were entirely visual in nature or required a password were considered inaccessible and also removed. Medical journals were removed as it was felt that these would be beyond the capacity and understanding of most patients without a medical background. Once this had been performed, 34 websites remained; these are listed in **Appendix 1**. This methodology is summarized in **Figure 1**.

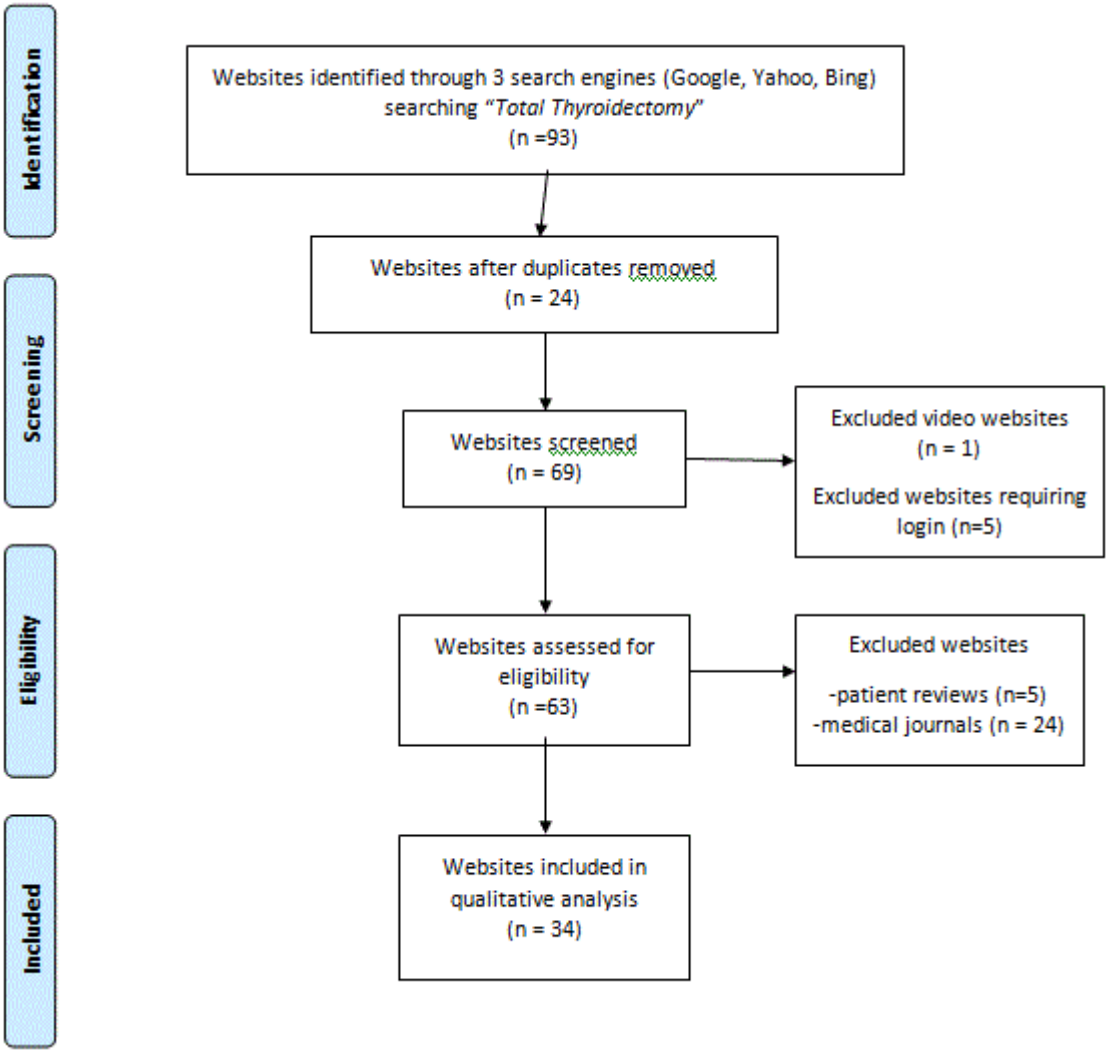

Figure 1. Internet search flow diagram, based on the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) statement.

The next phase of the methodology involved classifying the websites into categories. We categorized sites as academic, physician, non-physician, commercial, non-profit, media, and discussion groups/social media and unspecified. These classifications were developed based on those described in previous studies. Academic websites included those affiliated with a university or medical societies. Websites were considered non-physician if they were created by allied healthcare professionals or alternative medicine providers while commercial websites were defined as those who displayed advertisements or had products for sale. Physician websites included professional sites for individual physicians as well as practitioner groups not affiliated with an academic institution. Media websites were non-medical news-oriented sites. Any website that did not fit the preceding categories was classed as unspecified.

Once classified, websites were assessed for quality and validity using the DISCERN score and the JAMA benchmark criteria. They were also assessed for the presence or absence of the HON code certification.

DISCERN tool: The DISCERN tool is a reliable means of assessing written consumer health information. Developed by an expert group in the United Kingdom, it is the first standardised quality index of consumer health information that can be used to critically appraise health information [13]. The DISCERN instrument consists of 16 questions; the first 8 determine the reliability of the publication and the subsequent seven questions address specific details regarding treatment choices. The last question is an overall rating of the quality of the website. Each question of the DISCERN tool is rated on a scale of 1-5 with 1 providing a definite NO and 5 conveying a complete and satisfactory answer to the proposed question. Scores between 2-4 suggest that some of the necessary information is provided but key elements may be missing.

JAMA Benchmark: The JAMA benchmarks are a series of four core criteria established by the Journal of the American Medical Association which allow readers to determine whether what they are reading was credible, reasonable or useful. Initially described by Silberg [15], these criteria assess authorship, attribution, disclosure and currency. The authorship criterion requires the website to provide details of the authors and contributors, their affiliations and relevant credentials [1,15]. Attribution refers to

effective reference of content presented throughout a website. Currency refers to the provision of dates when the content was posted and updated. Finally, disclosure requires the 'owner' of the website to highlight any potential conflicts of interest [1,15].

HON Code: The Health on the Net Foundation is a non-profit, non-governmental organisation which seeks to establish ethical standards for publishing medical and health-related information on the internet [14]. The Health On the Net code (HON code) seal accredits the websites with a list of standards to which they must comply and they must publish transparent health related information [1,3,14]. For each website we checked for the presence of the HON code seal.

Readability: Using an online analysis tool (WEB FX)[16], the readability of each website was evaluated for two validated scores: the Flesch Reading Ease Score (FRES) and Gunning Fog Index (GFI) [5-6,16].

The FRES gives the website a mark between 0-100, with higher score indicating that the material is easier to read [5,16]. Magazines such as Reader's Digest and The Huffington post have scores of approximately 65 while articles in Harvard Law Review usually score in the low thirties [16]. It has been suggested in previous studies that for accessibility, medical websites should have a score over 65 [16]. A full breakdown of the FRES is shown in **Table 2**.

Table 2. Breakdown of the Flesch Reading Ease Score system. A score of 65 or greater is concerned to be easily accessible to all reading levels.

Score	School level	Notes
100.00-0.00	5th grade	Very easy to read. Easily understood by an average 11 year old student.
90.0-80.0	6th grade	Easy to read. Conversational English for consumers.
80.0-70.0	7th grade	Fairly easy to read.
70.0-60.0	8th& 9th grade	Plain English. Easily understood by 13 to 15 year old students.
60.0-50.0	10th to 12th grade	Fairly difficult to read.
50.0-30.0	College	Difficult to read.
30.0-0.0	College graduate	Very difficult to read. Best understood by university graduates.

In linguistics, the GFI is a readability test which estimates the years of formal education a person would need to understand the text on first reading. Texts for near universal understanding require an index less than 8 [5-6,16]. However, it must also be acknowledged that some common words are not considered complex despite their syllable count.

The reading grade level (RGL) of each of the websites was also assessed. Health care related information of the internet should be available at a reading level equivalent to the sixth grade or a primary school leaver [17]. This ensures accessibility of the text across the majority of the population.

Statistical Analysis: Descriptive and inferential statistical analysis was performed using SPSS version 26 (SPSS, Chicago, IL). The level of significance as set at 5%. To determine whether HON code certification predicted higher scores for reliability and readability, 2 sample t tests were used when data was normally distributed and the Mann-Whitney U test was used when it was not. To determine the difference between categories, ANOVA testing was performed. RGL was compared to the 6th grade standard by one-way t-test.

RESULTS

A total of 34 unique websites were assessed as part as part of the investigation. **Table 3** shows the breakdown of the websites according to type. Ten were HONcodeaccredited (29.41%). The majority of the websites reviewed were academic (n=17;50%).

Table 3. Breakdown of the websites included in the final analysis by type.

Website type	Total websites (N)
Academic	17
Physician	3
Non- physician	2
Commercial	3
Non- profit	7
Unspecified	2
Total	34

DISCERN Score: The mean DISCERN score for all websites was 36.24 +/- 10.02 of a maximum score of 80. The range was 17 to 62. The highest scoring site was an academic site. Only two websites out of 34 (5.88%) of websites achieved a score of 60 or higher, representing excellent quality with minimal shortcomings. The non-profit website type had the highest overall DISCERN scores. However, the differences in DISCERN score were not significantly different between website types (P=0.65). Statistical testing also illustrated no difference between mean DISCERN scores in those websites which were HON code certified and those that were not (P=0.341).

There were three questions that websites consistently performed well on; these questions involved explaining the basics of the procedure as well as relevant information pertaining to the outcomes and risks of thyroidectomy. Conversely, websites regularly failed to mention other treatment options that may be

available instead of thyroidectomy or what potential consequences existed if the patient chose not to undertake treatment. Furthermore, very few websites encouraged shared decision making. **Figure 2** shows the breakdown of the mean DISCERN scores for each question while **Figure 3** shows the DISCERN scores according to category.

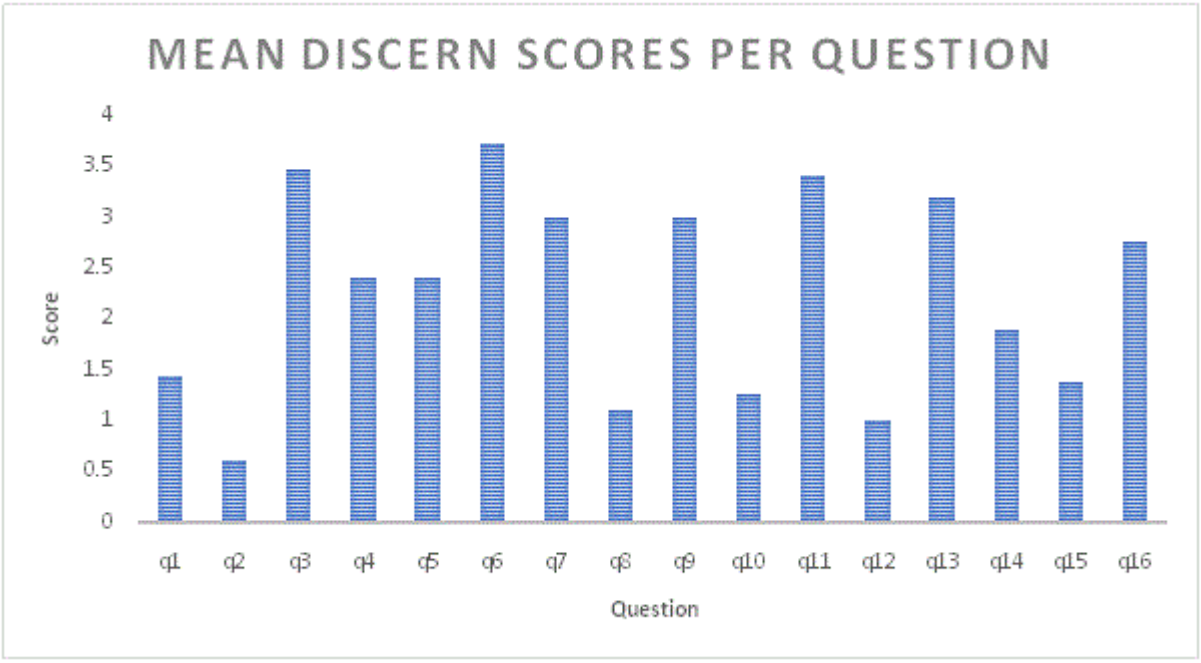

Figure 2. DISCERN score mean figure for each question.

JAMA: The mean JAMA benchmark criteria score was 1.65 +/- 1.2. Only three sites achieved maximal scores of 4 (8.82%). While most websites fulfilled the criteria of authorship, the majority of websites were found to be lacking in the categories of currency, attribution and disclosure (**Table 4**). Figure 3 shows the breakdown of the JAMA scores by category.

Table 4. JAMA benchmark criteria which was met by each website.

Criteria	Number of websites which contained criteria	Percentage
Authorship	20	58.82%
Currency	16	47.05%
Attribution	12	35.29%
Disclosure	9	26.47%

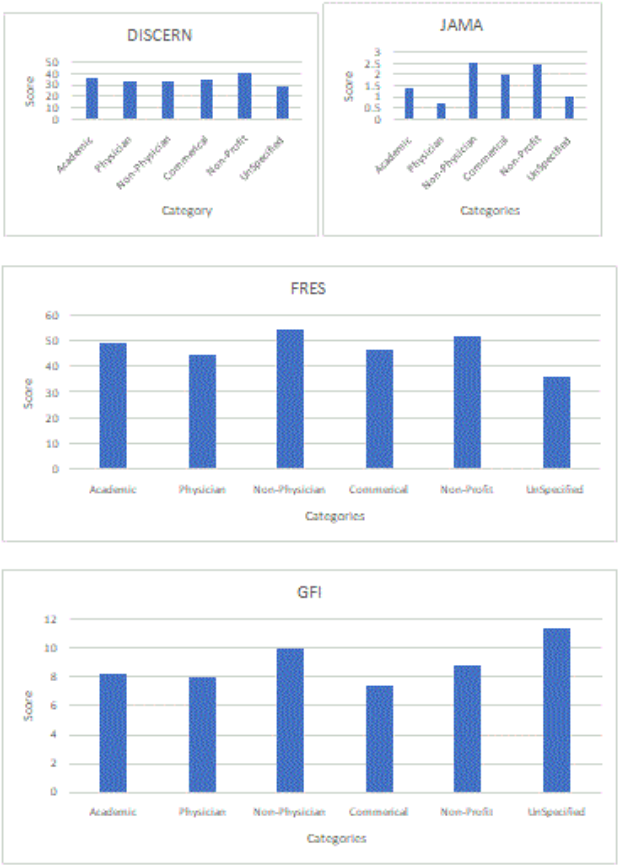

Figure 3. Quality and Readability scores based on Website type.

Statistically, no difference was found between the JAMA scores for each category (P=0.25). However, the presence or absence of the HON code was found to be statistically significant (P=0.015)

Readability: For this investigation, the Flesch Reading ease score, the Gunning Fog Index and the estimated RGL were examined. A FRES score of 65 and above is considered to be easy to read and accessible to the majority of people. The acceptable reading level as recommended in previous studies was to a sixth-grade level (primary school leaver).

The mean FRES score was 48.8 +/- 17.6. Only four of the 34 websites reviewed met the target of a FRES score equal to or above 65 (11.76%). 9 websites (26.47%) scored between 30-50 points, meaning these were classed as fairly difficult to read. Five websites (14.71%) achieved a FRES score less than 30, putting them in the category of extremely difficult to read, at a level considered appropriate for college students. Statistical testing showed no statistically significant differences between the FRES scores for each category (P=0.9) and for FRES scores from websites with HON codes (P=0.6).

The mean GFI was 8.5 +/- 2.5. This means that on average 8.5 years of formal education would be needed to understand the materials provided. Figure 3 shows the breakdown of the FRES and GFI scores according to category.

The average RGL was 9.2 +/- 2.2, meaning that a high school level education would be needed to read most sites. 14 websites (41.17%) were found to have a reading level grade which was ten or higher, meaning they were considered extremely difficult to read. Only 3 websites (8.82%) met the recommended criteria of providing materials at a reading level equivalent to grade six. The average RGL exceeded the 6th grade level by an average of 3.2 grade levels ($p<0.001$, CI=2.4-4).

DISCUSSION

The internet provides patients with readily available access to boundless informationon any topic, including health [1]. However, unlike traditional media, the internet remains largely unregulated, making finding credible health information websites more challenging [3]. Information seeking is an important step for patients in the understanding of their treatment options and encouraging adherence to post-operative therapy [5].

As shown in previous studies [1-4], over 70% of people use the internet at least once a month in regards to a health-related query, especially when preparing for a complex operation such as thyroidectomy which carries significant risks and may prove difficult for the patient to understand. It is therefore imperative that the information online related to this operation is high quality and up to date. The three most common search engines utilized are Google, Bing and Yahoo [1,3].

The average DISCERN score was 36.24 for this study, well below the recommended DISCERN score of 65 which ensures that the health-related data on a website is of high quality [6,16]. These poor scores indicate that the majority of websites related to thyroidectomy are of poor quality with significant short comings. Unfortunately, thisdata is consistent with the findings of other studies that reviewed procedural based quality of information on websites [5,6]. While the mean DISCERN score was higher in websites with a HON code, consistent with previous studies [1,3], the difference was not significant (P=0.341).

As demonstrated above, further analysis of the DISCERN instrument shows key patterns related to the strengths and weaknesses of the healthcare websites. Nine websites failed to deal with the risks of thyroidectomy (26.47%) and 8 websites (23.53%) failed to deal with key lifelong outcomes such as the need to take thyroid hormone supplementation post operatively. Patients reading these websites would be misinformed about the significance of the operation they are undertaking and its consequences, resulting in significant anxiety when the physician endeavours to undertake informed consent [5].

Furthermore, 29 websites (85.29%) do not encourage any form of shared decision making. This is consistent with previous studies by Bruce which showed that 80% of websites regarding mastectomy did not encourage shared decision making [18]. All the websites reviewed failed to describe the consequences to the patient if no treatment was undertaken; this is a significant deficiency of these websites in an era of patient centred health care. In informed consent, capacity requires the patient to be able to understand the consequences and outcomes of both accepting and refusing treatment [1,5]. The standard of information on many websites fails to help in accomplishing this goal.

As stated in the results the average JAMA score is 1.65 +/- 1.2. Only three websites met all four JAMA benchmark criteria. Many websites failed to demonstrate appropriate citation of information, a finding which is consistent with previous studies. A failure to provide information of when the data was published and updated, which occurred in 18 websites (52.94%), means that those reading the information cannot determine if it is up to date and relevant. Similarly, providing information on conflict of interest allows for accountability. However, this did not occur in 24 of the reviewed websites (73.5%). JAMA criteria scores for website transparency and reliability were significantly higher in those with HONcode certification as would be expected (P=0.015).

In terms of the readability of these websites, it is worrying that the majority of websites (91.17%) are beyond the recommended sixth grade reading level with 14 websites (41.17%) rated at grade 10 or above, categorising them as difficult to read. Unfortunately, this data is consistent with previous studies by Jayaratne [6] who classified 87% of the websites they reviewed on dental implants as difficult to read and Neill [5] who classified only 13% of their reviewed arthroplasty websites at equal to or below the recommended reading level. This may make the data available on the internet inaccessible to patients, leaving them frustrated and anxious in regards to their surgery.

STRENGTH AND WEAKNESS

This is the first investigation to assess the quality and readability of medical information online pertaining to total thyroidectomy. This is a complex procedure which is frightening for patients

with life-long medication required afterwards. To ensure true consent for surgery and adherence to the medical regimes, good quality healthcare information is needed. Validated tools were used to assess the data for both parts of the research question, allowing us to provide more robust answers.

It must however be acknowledged that there are limitations to this investigation. Firstly, the internet is in constant flux and our search was conducted on one specific day; more high levels websites may have become available if the search had been repeated. The search may also not reflect the websites that the patient would have available to them at another point in time. Secondly, only the first three pages of websites from each of the three search engines were taken. Despite the evidence from previous papers that patients typically utilize no further than the first page of a search engine, this methodology may mean high quality websites may not have been assessed. The search was also confined to the English language.

CONCLUSIONS

The overall quality of the websites discussing thyroidectomy on the internet is low quality, inconsistent and overall, unreliable. The highest scoring websites were concise and patient orientated; describing the procedure, its risks and its outcomes, including the need to take life-long thyroid supplementation. However, these websites still failed to discuss the consequences of no treatment and few encouraged shared decision making. Many of the websites were not at an appropriate academic level to be accessed by patients, creating further barriers to information. Surgeons must therefore be aware of the information to which their patients are exposed and should be proactive in directing patients to more high quality, accessible websites where possible.

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