Minimally Invasive Repair of Pectus Excavatum

Zuidema, W.P.

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Chapter 2

The quality of websites health information on minimally invasive repair of pectus excavatum using the DISCERN instrument

WP Zuidema,
MJ Graumans,
JWA Oosterhuis,
AFW van der Steeg,
LWE van Heurn

Abstract

Introduction

The Internet is a frequently used tool for patients with pectus excavatum (PE) to get information about symptoms and treatment options. In addition it is used by both health care providers as a marketing tool and support group systems. The internet health information varies in precision, quality, and reliability. The study purpose was to determine the quality of information on the PE websites using the DISCERN instrument, including information about operation and potential complications after a Nuss bar procedure.

Materials and Methods

Four search engines; Google, Yahoo, Ask, and Bing, were used to explore seven key terms concerning PE. Search language was English. The DISCERN quality instrument was used to evaluate the websites. Also information on possible complications was scored per website.

Results

560 websites were assessed in March 2019. Excluded were 139 websites. There were 333 duplicates, leaving 88 unique websites. Of these 58.1% were hospital related information websites, 28.4% medical information websites and 3.4% patient forum sites. Interactive multimedia was used on 21.6% of the sites. Pain post-operatively was mentioned on 64.8% of the sites, while only 9.1% mentioned the mortality risk of the surgical correction of PE for Nuss bar placement. The quality of the unique websites showed a mean DISCERN score of 42.5 (SD 12.2).

Medical information websites, encyclopedia and government sponsored sites had higher DISCERN scores. Hospital related information sites, medical companies and lay persons sites, had lower total scores.

Conclusion

The overall quality of pectus excavatum websites is low to moderate, with serious shortcomings.

Introduction

The internet has become a very important source for information in almost every area of life, including information about health and health care services [1,2]. In December 2018 there were 4.1 billion internet users in the world [3]. Approximately 35% of adults engage in web use for symptom appraisal and health information, but this proportion varies between 23% and 75% depending on sociodemographic and disease-related factors [4, 5]. Health seeking individuals report 'anonymity and fast and easy access to health information' on the internet as reasons that they prefer the internet above direct face to face contact with a health care professional [6]. Despite efforts to create a standard for health information web sites, there are however concerns about the quality of health information on the internet. [7]. At present the information remains very variable in quality and objectivity [8].

There are good reasons to improve the quality of health information. Especially for would-be-surgical patients, the information can lead to a better shared decision making, and possibly to a reduced level of anxiety for the procedure and the post-operative period. There may also be an effect on outcome in favor of better informed patients [9].

This is especially true for, mostly adolescent, patients with a pectus excavatum (PE) [10]. They frequently use the internet to learn more about their condition and possible treatment options. However, the online information about PE may not be accurate. Patients sometimes take the website information as credible, and do not discuss the information acquired from websites with their physician. Without minimal quality requirements for health information, the patients can be misled by the information found and incapable of making sound informed decisions about possible surgical procedures [11].

Accessible health information is increasing at such a fast pace, that health information seekers can choose from an overwhelming selection of health related web sites. This selection is constantly changing more in number than in content. In particular there is little attention for the outcome from systematic reviews or evidence based medicine. And there is no focus on patient reported outcomes or complications [12,13].

One of the criteria that determine the value of health related information on the internet is the competency of patients to critically assess the provided

information. Are they capable of differentiating between low and high quality websites, can they recognize bias in the information? Another possible obstacle for interpreting health information can be the language used on the websites which can be difficult to read for a wide public [14].

The availability of free appraisal tools could help the health information consumer to find trustworthy websites [15].

To help patients with PE to find the correct and good quality information on the web, health related websites should be assessed for quality of health information shown on their pages. The DISCERN questionnaire was developed in order to assess websites and their content in an objective way. Before, the content of the websites was sometimes checked by medical professionals but this did not always lead to acceptable results. The advises for adhering to an ethical code, computer induced filtering of web-based information or scoring the content of websites by health consumers, did also not lead to improvement [16,17,18]. The DISCERN questionnaire is a validated instrument for analyzing health information. It is used as a tool to critically evaluate health care information aimed at health care consumers [19].

Material and Methods

Search strategy
The primary search terms were obtained from the medical literature. These terms included pectus excavatum, Nuss bar, pectus excavatum surgery, pectus excavatum information, pectus excavatum procedure, pectus excavatum treatment, MIRPE. The keywords were entered into four different search engines (Google, Yahoo, Ask, and Bing). The first 20 links reported by each search engine per keyword were evaluated using the DISCERN questionnaire [20].

Inclusion/exclusion criteria
Included were websites that gave information based on the seven search terms about the treatment options for patients with PE. Websites that were not about pectus excavatum or only provided a list of website links were removed. So were advertisements for books about the subject, congress companies or sites with name overlap.

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Data abstraction
The following items were taken for evaluation of the websites in the search: type of website, certification mark, multimedia use, different surgical options discussed, complementary surgery for removal implant discussed, non-operative treatment discussed, minimal age for treatment, pain, recurrences rates, total complication rates, mortality rates, and additional scientific publications.

The websites reporting these items or lacking them were documented. The websites were also scored on quality, as specified by the DISCERN score. Overall and characteristic specific average DISCERN scores were calculated. and presented. Two reviewers (WZ, MG) performed the search individually and scored the specific items and the DISCERN score. Each reviewer independently assessed the same list of websites and generated a DISCERN score. In case of disagreement a third reviewer (AS) was acting as referee.

The DISCERN scoring
The DISCERN questionnaire was the first developed standardized index of quality of consumer health information. It is directed on the evaluation of written information about treatment choices. The instrument was validated in 1998 as part of a British national project to establish quality thresholds for written information on treatment choices provided by charities, National Health Service (NHS) organizations, self-help groups, pharmaceutical industry and other sources of consumer health information [21]. It consists of 16 questions with a Likert scale of 1 to 5, in which 1 is no, 2-4 stands for partially and 5 for yes. The 16 questions are divided into three sections. Section 1 (questions 1 to 8) assesses reliability, dependability and trustworthiness of a website; Section 2 (questions 9 to 15) focuses on the quality of information about treatment choices; and Section 3 (question 16), evaluates overall quality rating on a Likert scale for websites (1 = Low to 5 = High). The rating of question 16 is performed independently of the rating for the other previous 15 questions [20].

Statistical analysis
Data analyses were conducted using IBM SPSS 23 software (SPSS Inc. Chicago, IL, USA). Descriptive statistics for variables of interest in this study are presented as percentage, means and SDs. Website characteristics were reported independently.

Results

In March 2019, a total of 560 websites was reviewed on four search engines (Google, Yahoo, Ask, and Bing). A total of 421 websites was eligible for examination after application of the exclusion criteria (Figure 1, Table 1). Removal of 333 duplicate websites left a total of 88 unique sites. The evaluation of the scored items of the unique websites is shown in Table 2. It shows clearly that among the websites, the majority were hospital related websites. Non-operative management of PE was discussed in less than half of the websites. Scientific publications as basis for information were reported in less than a third. Complications, recurrence rates and minimal age were also only mentioned on 27 – 40 percent of the websites. The risk of mortality of surgical correction of a PE is only mentioned in 9.1% of the health information websites. Very few of the websites had a certification mark.
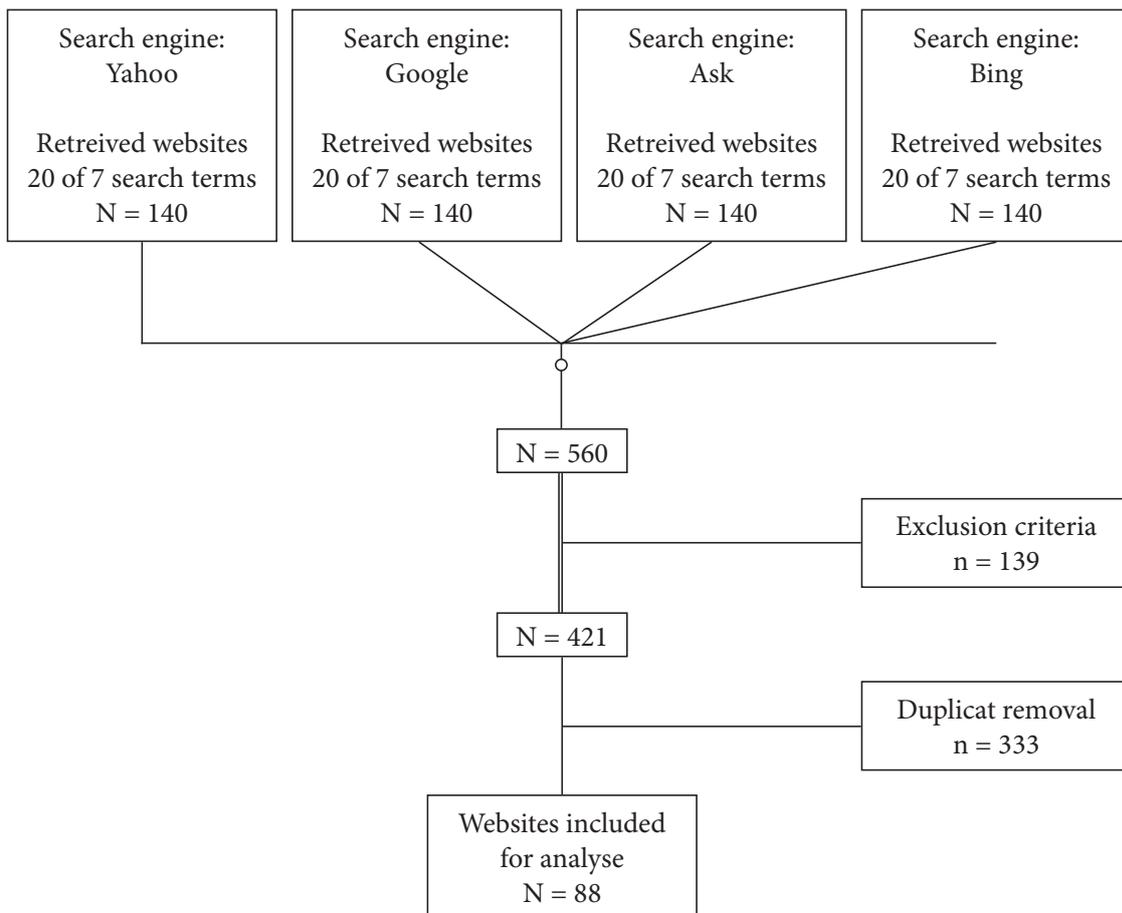

Figure 1. Consort diagram of websites included in the study.

The DISCERN score on reliability (question 1-8) of the information provided by the websites had an average of 2.81 (max. 5), which is between low and moderate for trustworthiness of the websites. For quality of treatment choices mentioned on the websites the DISCERN score was on average 2.43 (max. 5), which is comparable with low to moderate quality of health information. The overall mean score for DISCERN (question 16) was 2.17 (SD 0.85) which reflects low to moderate quality of health information of the websites on pectus excavatum. The agreement percentage of the two reviewers on the overall DISCERN score was 94.3 %.

Table 1. Number and sort of excluded sites

Excluded site	number
Scientific articles	75
Bookseller sites	2
Insurance site	3
Trialregister	3
Pass on sites	4
Dictionary sites	6
Travel sites	8
Only images	15
Surnames	8
General companies	11
Animal site	1
No longer existing site	1
Private website	2

Total mean DISCERN scores for different websites showed for a single encyclopedia 61.0 and government sites 53.3 (SD 17.0). The medical information sites 49.2 (SD 13.4), hospital related sites 38.9 (SD 9.9) and lay persons sites 37.4 (SD 8.9). The DISCERN mean total score for the 88 websites was 42.5 (maximum 80) with a SD of 12.2.

Table 2. Scores on items mentioned on website

Item	Percentage of the 88 websites
Website type: hospital related	59.1
medical information sites	28.4
lay person	5.7
government related	4.5
different surgical options	58.0
non-operative treatment	46.6
minimal age for treatment	27.3
scientific publications	33.0
certification mark	2.3
multimedia use	21.6
pain	64.8
recurrences rates	37.5
total complication rates	39.8
mortality rates.	9.1
material removal/ re-operation	54.5
costs of treatment	3.4

Discussion

The internet has developed into a very important tool to bring fast information to patients and health care professionals or organizations. It enables a two way direction of communication where potential patients can ask their questions in anonymity. Questions remain however about the trustworthiness of the presented health information on the internet. [22, 23]. Oxman et al. looked for a way to select trustworthy health information. In their study they tried to identify and evaluate free sources of internet health information for patients and the public, which provide information about effects of treatments based on systematic reviews. They found only two websites to be trustworthy on treatment effects for patients [24]. One important improvement for the health information on the internet could be a guideline concerning the minimal requirements for objective information. In order to assess the quality of online health information in this study in an uniform and consistent way, the DISCERN questionnaire was used. The DISCERN mean score for the 88 websites was 42.5 (maximum 80) with a SD of 12.2. Such a score suggests information of low to moderate quality, with potentially important shortcomings [24]. There was a difference in total score between the different website types. It is acknowledged that PE patients are

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mostly adolescents and have a different search behavior on the internet compared to older persons. They frequently use incorrect spelling, scan only the first hits, do not look at source of information and scan pages randomly [25,26].

Parents of patients using the internet for health information are also sensitive for incorrect information. Though they usually have a better functional literacy, critical literacy and interactive literacy, they are still depending on basis accurate health information [27].

In our study about the information provided for patients with a pectus excavatum on the internet who consider surgery, we found most websites lacked substantial information needed to take a weighted decision. The majority of websites had a bias with a preference for surgical treatment, especially towards the Minimally Invasive Repair of Pectus Excavatum (MIRPE) technique. Even without evidence of the superiority of this operation method [28]. Serious complications were frequently not addressed and even if there were scientific publications cited, these were frequently one sided. The benefits of treatment were declared more often than the risks of the treatment.

The results suggest that patients should be critical on the health information that is provided on the internet, especially on information provided by websites linked to hospitals, medical device companies or personal sites. A better start for their search would be a digital encyclopedia or government sponsored evidence base sites. Hopefully the results of this study have an impact on the way patients with pectus excavatum are informed. Patients can be more critical on the health information they find at the internet. It may also stimulate the providers of the content to adjust their website information. Especially from the ethical aspect that the target audience consists of children under the age of 18 years. The patients have a wish to understand their symptoms or disorder better and wish to be informed about the possible treatment options to weigh their decision [4]. This is the first study that analyzes PE websites using the highly reliable DISCERN tool and also provides novel insight into the variability of quality scores when examining online websites. Previous studies using the DISCERN tool have reported nearly the same finding, that websites on the internet are at best of moderate quality [29,30].

Shortcomings:
Only the top 20 websites were investigated for each PE search term. Although this number seems limited, most patients with a PE are adolescents and their search strategy on the internet is usually limited to the first page or hits.

The Web provides continuing change and new websites all the time, so the quality of websites may change in the future. However, since there are hardly any high quality websites about this subject, improvement cannot be expected to come by itself. The DISCERN instrument is an effective tool for assessing the quality of online information directed towards treatment, but may be less effective in evaluating other areas of website information.

Conclusion

The overall quality of PE websites is low to moderate, with extensive shortcomings that need to be addressed. Patients with a pectus excavatum, which are mostly adolescents, need good quality evidence based information so they can make an informed decisions about their treatment. Since the available health information at this moment on the internet cannot provide this, it becomes the task of the consulted physician or medical societies to provide unbiased good quality information.

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