

Research Paper
 Cleft Lip and Palate

Clefts of the lip and palate: is the Internet a trustworthy source of information for patients?

G. A. Karamitros¹, N. A. Kitsos²

¹Medical School, Aristotle University of Thessaloniki, Greece; ²Faculty of Medicine, University of Southampton, Southampton, UK

G. A. Karamitros, N. A. Kitsos: *Clefts of the lip and palate: is the Internet a trustworthy source of information for patients?*. *Int. J. Oral Maxillofac. Surg.* 2018; xxx: xxx–xxx. © 2018 International Association of Oral and Maxillofacial Surgeons. Published by Elsevier Ltd. All rights reserved.

Abstract. Great numbers of patients use the Internet to obtain information and familiarize themselves with medical conditions. However, the quality of Internet-based information on clefts of the lip and palate has not yet been examined. The goal of this study was to assess the quality of Internet-based patient information on orofacial clefts. Websites were evaluated based on the modified Ensuring Quality Information for Patients (EQIP) instrument (36 items). Three hundred websites were identified using the most popular search engines. Of these, 146 were assessed after the exclusion of duplicates, irrelevant sites, and web pages in languages other than English. Thirty-four (23.2%) web pages, designed mostly by academic centres and hospitals, covered more than 22 items and were classified as high-score websites. The EQIP score achieved by websites ranged between 4 and 30, out of a total possible 36 points; the median score was 19 points. The top five high-scoring web pages are highlighted. The overall quality of Internet-based patient information on orofacial clefts is low. Also, the majority of web pages created by medical practitioners have a marketing perspective and in order to attract more patients/customers avoid mentioning the risks of the reconstructive procedures needed.

Key words: patient information; quality; Internet; cleft palate; cleft lip.

Accepted for publication 7 March 2018

Cleft palate with or without a cleft lip is one of the most commonly observed congenital anomalies. The incidence is estimated at about 3.4–22.9 per 10,000 births, although this varies geographically¹. Clefts of the lip and palate are also one of the most heterogeneous orofacial malformations². The most well-known classi-

fication system, which is still used for the registration of cleft lip and palate by the American Cleft Palate–Craniofacial Association, was proposed by Kriens in 1975 – the ‘LAHSHAL code’³. Due to the increased frequency of these orofacial anomalies (the occurrence has been estimated at 1 in 600 to 1 in 700 births in the

USA⁴), there has been an increase in the number of parents/guardians of affected patients who are knowingly searching the Web to obtain information and familiarize themselves with the medical condition before seeking the help of a doctor⁵. However, with the plethora of health information available on the Internet⁶, it has

2 Karamitros and Kitsos

become a real challenge to acquire objective and reliable health information⁷. Because Internet health information is not always reviewed by a medical specialist or a specific scientific group, the information provided might mislead the Internet user/patient and could prove to be dangerous⁸⁻¹⁰.

Taking this into consideration, it is understandable that there is ever-increasing concern about the scientific accuracy of the health information that is available on the Internet¹¹⁻¹⁴.

In order to maintain high quality health information on the Internet, international guidelines referring to the development of new decision aids in health care have been established by the International Patient Decision Aids Standards (IPDAS) collaboration^{15,16}. Apart from the 44 items of the IPDAS checklist¹⁷, there are many other tools to assess the quality of health information on the Internet¹⁸⁻²⁰. One reliable and validated method for the critical assessment of the quality of health information is the modified Ensuring Quality Information for Patients (EQIP) instrument^{20,21}. The EQIP instrument has been used in several previous studies to evaluate the quality of information for different medical conditions²²⁻³⁰. However, it appears that no study to date has assessed the quality of Internet health information on the subject of clefts of the lip and palate. Additionally, the use of a validated tool on the information available for these conditions has not been reported.

Consequently, the aims of this study were (1) to perform an objective evaluation of the health information on clefts of the lip and palate that is openly accessible on the Internet, and (2) to perform a systematic analysis to determine whether the Internet provides high-quality information on the subject.

Materials and methods

Eligibility criteria, origins of information, and web page selection

Data were collected in June 2017 and July 2017 by the two investigators/reviewers of the websites. The data obtained were collected in a Microsoft Excel database. Any conflicts between the two investigators with regard to the results were discussed and resolved by consensus. The web pages were identified using the three largest search engines worldwide: Google, Yahoo, and Bing³¹. These search engines combined account for more than 99% of search engine traffic in Greece and 96% worldwide^{31,32}. A combination of the key

words “cleft palate”, “cleft lip”, cleft palate repair”, “cleft palate surgery”, “cleft lip repair”, and “cleft lip surgery” was used to identify the websites that contained the information about clefts of the lip and palate. The first 100 web pages from each search were isolated and included in this study, because it has been shown that users tend to limit their search to the first 100 links that the search engine provides²⁴.

Three hundred websites were initially included. These were then screened against the following exclusion criteria: duplicates, websites not relevant to the subject of clefts of the lip or the palate, and websites in languages other than English. After applying the exclusion criteria, 146 websites remained and were subjected to the evaluation and assessment process with the EQIP instrument.

The 146 websites included in the analysis were classified into the following categories: (1) hospital, (2) encyclopaedia, (3) professional society, (4) patient group, (5) practitioner, (6) news service (i.e., the press), (7) industry, and (8) academic centre/educational institution.

Data assessment tool

The 146 websites that fulfilled the eligibility criteria were screened and evaluated using the modified EQIP tool^{20,21}. This EQIP instrument is designed to assess documents, leaflets, or websites providing medical information based on three classifications: (1) content data, (2) identification data, and (3) structure data. The modified EQIP instrument consists of a 36-item checklist, and this was used to critically assess the content, structure, and identification data of the websites providing online information on clefts of the lip and palate (Table 1).

The EQIP tool was first developed as a 20-item system²¹. It was then reapproached, and 16 new items were added to create the 36-item assessment and evaluation instrument. This updated EQIP instrument was developed at the University Hospital of Geneva, Switzerland using 73 hospital documents that described medical procedures. The first 25 documents were used to determine the assessment rules and the remaining 48 documents were evaluated individually by two assessors. Based on this evaluation, it was found that the inter-rater reliability of the modified EQIP instrument was excellent (kappa coefficient = 0.84), while the inter-class correlation coefficient was 95%²⁰.

The EQIP tool has been used in previous studies²²⁻³⁰. The modified form using

the binary scale of ‘yes’ versus ‘no’ or ‘not applicable’ (i.e., no score) was used in the present study. The modified version of the EQIP instrument adopted does not include the answer ‘partially yes’, because this answer was previously found to be unreliable and not sufficiently objective in the evaluation of entire content³³.

Morbidity and mortality risks

Items 9 and 10 of the modified EQIP instrument were designed to evaluate the risks of the surgical interventions for clefts of the lip and palate (Table 1). Specifically item 9 was used to critically assess whether the websites adequately described the qualitative risks and complications related to the surgical procedures of palatoplasty and cheiloplasty (item 9, Table 1). In contrast, item 10 was used to determine whether the websites studied described the quantitative risk of each complication of the palatoplasty and cheiloplasty surgeries as a proportion (item 10, Table 1).

Statistical analysis

IBM SPSS Statistics version 21 for Mac (IBM Corp., Armonk, NY, USA) was used to perform the statistical analysis. Pearson’s χ^2 test or Fisher’s exact test was used to compare categorical variables. The Student *t*-test was used for numerical data whenever needed. The level of statistical significance was set at a *P*-value of <0.05; all tests were two-sided. The maximum number of points a web page could score was 36 and the minimum was 0. All items were scored equally, and an overall score was obtained for each website. High-score web pages were defined as those with an EQIP score above the 75th percentile; those with scores below the 75th percentile were defined as low-score web pages. This categorization has been used successfully in previous studies performed by Melloul et al.²⁴, Zuk et al.³⁰, and Karamitros et al.²⁹.

Results

Web pages presenting information on clefts of the lip and palate

Three hundred web pages containing a combination of the key words “cleft palate”, “cleft lip”, “cleft palate repair”, “cleft palate surgery”, “cleft lip repair”, and “cleft lip surgery” were found using the Google, Yahoo, and Bing Internet search engines. After the removal of duplicates, irrelevant pages, and those not in English, 146 web pages remained for qual-

Download English Version:

<https://daneshyari.com/en/article/8697733>

Download Persian Version:

<https://daneshyari.com/article/8697733>

[Daneshyari.com](https://daneshyari.com)