Is Dr. Google® trustworthy? Reliability of the online medical information on pediatric inflammatory bowel diseases☆

¿Se puede confiar en el doctor Google®? Fiabilidad de la información médica *online* sobre la enfermedad inflamatoria intestinal pediátrica

Dear Editor:

Adherence to medication in paediatric inflammatory bowel disease (pIBD) is determined by patient motivation, which in turn is influenced by disease- and treatment-related information. Access to the right information can improve patient engagement in self-care and management. In fact, individuals with inflammatory bowel disease that participate in their own care and in shared decision-making have appreciably better outcomes compared to those who do not.[1,2] The use of the internet as a source of medical data is widespread among patients with p-IBD and their families, who typically read the first 10-results page. However, online content may be of questionable quality, and valuable content may be hard to find, sometimes depending on the skills or educational attainment of the user.[3-5] The DISCERN instrument[6] is a validated 16-points questionnaire that provides a valid and reliable means to assess the quality of written information on treatment choices for a health problem. In our study, we aimed to use the DISCERN score to (a) determine the average quality of online information on p-IBD and (b) assess whether the quality depended on the source of the information.

We performed a Google search on the October 28th, 2019 with the keywords: ''Crohn's disease'', ''ulcerative colitis'', ''Inflammatory Bowel Disease'', ''colonoscopy'' and ''endoscopy'', all of them combined with the terms ''pediatric'' and ''children''. We recorded the first 10 results for each search and excluded scientific papers, advertisements, videos and subscription-only sites. We classified websites by type of source as hospital, professional society, government agency, health press or patient organization.

We assessed the quality of the written information using the DISCERN instrument (possible total score, 16–80). Evaluators rated each item by assigning 1–5 points (Table 1) in addition to providing a detailed explanation for each, including examples. We categorized DISCERN total scores as excellent (68–80), good (55–67), fair (42–54), poor (29–41) or very poor (16–28). In order to minimize subjectivity, four evaluators assessed the quality of the content, after which the mean total score was calculated for each selected website. We compared the proportion of websites with a rating

Table 1 DISCERN instrument items.

DISCERN items
1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?
5. Is it clear when the information used or reported in the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?
9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment is used?
13. Does it describe how the treatment choices affect overall quality of life?
14. Is it clear that there may be more than one possible treatment choice?
15. Does it provide support for shared decision-making?
16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

of excellent or good in each category using the Fisher exact test. We performed the statistical analyses with the software SPSS version 20.

The search yielded 100 websites, of which 65 met all the inclusion criteria. Table 2 presents the distribution by type of authorship and the DISCERN scores. The median DISCERN score for the total sample was 40.8 (interquartile range, IQR 10.5). Only 5 websites had an excellent or good score. The proportion of websites with excellent or good scores was significantly higher in websites from government agencies and professional societies compared to those from hospitals or the health press (33.3% and 30% vs 2% and 0%; $P < .05$). None of the health press websites received an excellent or good score. Surprisingly, the search did not yield any websites from patient organizations.

The quality of online information on pIBD is highly variable. Most of the easily found websites are from hospitals, but professional societies and government agencies provide information of higher quality. Despite a rapid growth in the provision of health information, the overall quality remains poor and valuable resources may not be easy to find. However, it is time to face this fact: patients with pIBD and their families are consulting or even following the advice available online. One of our responsibilities is to inform about and protect against unreliable sources of information about treatment choices, and the DISCERN instrument can be used as a guide to the standard that users are entitled to expect. Facilitating patient-engaged care in a safe and reasonable way does more than just empower patients, it also leads to better outcomes.

Table 2 Sources and quality of online medical information.

DISCERN	Hospitals (n = 50)	Professional societies (n = 10)	Government agencies (n = 3)	Health press (n = 2)	Patient organizations (n = 0)
Median DISCERN scores [IQR]	40.1 [7.7]	45.9 [26.3]	46.3 [33.8]	49 [-]	- [-]
Excellent or good	1 (2%)	3 (30%)	1 (33.3%)	0 (0%)	0
Fair, poor or very poor	49 (98%)	7 (70%)	2 (66.7%)	2 (100%)	0

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