Quality and Readability of Online Information on Keratoconus in Portugal

Qualidade e Legibilidade da Informação *Online* sobre Queratocone em Portugal

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ABSTRACT

INTRODUCTION: Keratoconus is the most common primary corneal ectasia. Nowadays, patients try to look on the Internet for answers to their expectations in diagnosis, treatment and prognosis. However, the webpages are not filtered or submitted to evaluation and quality control before getting published. We aim to evaluate the quality and readability of the online information available for the patients regarding keratoconus.

METHODS: Two independent ophthalmologists and one ophthalmologist supervisor evaluated 31 websites from a Google search by order of appearance with the word "Queratocone", using 2 quality scores: a quality index of consumer health information (DISCERN) and the Journal of the American Medical Association (JAMA) benchmark, as well as the presence of a quality seal. We also evaluated the readability, using 3 readability scores: FleschKincaid Reading Ease (FRE), FleschKincaid Grade (FKG) and Automated Readability Index (ARI).

RESULTS: We obtained 12 sites (38.70%) from private hospitals or clinics, 5 (16.13%) from online health platforms, 4 (12.90%) from spectacles/contact lenses companies, etc. The average score for each JAMA benchmark item was: 1: 0.48±0.51, 2: 0.32±0.48, 3: 0.03±0.18 and 4: 0.42±0.50; the average final score was: 1.26±1.24. The average score for each DISCERN section was: 1: 17.42±7.56, 2: 15.68±5.68 and 3: 2.45±1.21; the average final score was 35.55±13.63. The mean FRE score was 32.23±12.98, which corresponds to "difficult to read" and to college school level, as well as a concordant mean FKG of 14.72±3.24; the mean ARI was 14.81±4.09, which denotes "professor" level needed to understand the text. Eleven sites (35.48%) exhibited some kind of quality seal and did not show statistically significant better readability or quality scores than sites without quality seal. There was no apparent strong correlation between google ranking and quality and readability scores.

CONCLUSION: The information on keratoconus that is available online to Portuguese speaking patients is, overall, of poor quality and difficult to interpret. Physicians need to be aware that some patients might fully trust their own online research. Ophthalmologists have a shared responsibility to tackle this challenge through multifold efforts, cooperating with different entities and resources to improve the information that is available online and educating our patients on how to find reputable web sites that can help them navigate their life with keratoconus.

KEYWORDS: Comprehension; Consumer Health Information; Information Sources; Internet; Keratoconus/therapy; Reading.

RESUMO

INTRODUÇÃO: O queratocone é a ectasia corneana primária mais comum. Atualmente, os doentes procuram na Internet respostas às suas expectativas em termos de diagnóstico, tratamento e prognóstico. Porém, os *sites* não são filtrados nem submetidos a avaliação e controlo de qualidade antes de serem publicados. O nosso objetivo é avaliar a qualidade e a legibilidade das informações *online* sobre queratocone disponíveis para os doentes.

MÉTODOS: Dois oftalmologistas independentes e um supervisor avaliaram 31 *sites* de uma pesquisa no Google por ordem de aparecimento da palavra "Queratocone", usando 2 *scores* de qualidade: um de qualidade de informações sobre saúde do consumidor (DISCERN), e o *Journal of the American Medical Association* (JAMA) *benchmark*, bem como a presença de um selo de qualidade. Também foi avaliada a legibilidade, com 3 *scores*: *FleschKincaid Reading Ease* (FRE), *FleschKincaid Grade* (FKG) e Índice de Legibilidade Automatizado (ARI).

RESULTADOS: Obtivemos 12 *sites* (38,70%) de hospitais ou clínicas privadas, 5 (16,13%) de plataformas de saúde *online*, 4 (12,90%) de empresas de óculos/lentes de contato, etc. A pontuação média para cada secção do JAMA *benchmark* foi: 1: 0,48±0,51, 2: 0,32±0,48, 3: 0,03±0,18 e 4: 0,42±0,50; a pontuação média final foi: 1,26±1,24. A pontuação média para cada secção do DISCERN foi: 1: 17,42±7,56, 2: 15,68±5,68 e 3: 2,45±1,21; a pontuação média final foi 35,55±13,63. A pontuação média do FRE foi 32,23±12,98, o que corresponde a "difícil de ler" e ao nível de ensino superior, bem como uma média concordante de FKG de 14,72±3,24; o ARI médio foi de 14,81±4,09, o que denota nível de "professor" necessário para compreensão do texto. Onze *sites* (35,48%) tinham selo de qualidade e não mostraram melhor legibilidade ou índices de qualidade significativamente melhores do que *sites* sem selo de qualidade. Não houve uma aparente correlação entre o *ranking* no Google e os *scores* de qualidade e legibilidade.

CONCLUSÃO: A informação sobre queratocone disponível *online* para doentes de língua portuguesa é, em geral, de baixa qualidade e difícil de interpretar. Os médicos precisam de estar cientes de que alguns doentes confiam plenamente nas pesquisas *online*, tendo os oftalmologistas a responsabilidade partilhada de enfrentar este desafio através de esforços múltiplos, cooperando com diferentes entidades e recursos para melhorar a informação disponível *online* e educar os doentes sobre como encontrar websites fidedignos que os possam auxiliar a gerir a doença.

PALAVRAS-CHAVE: Compreensão; Informação de Saúde ao Consumidor; Fontes de Informação; Internet; Leitura; Queratocone.

INTRODUCTION

Keratoconus is an ophthalmological disorder characterized by corneal ectasia with a conical shape protrusion and concurrent thinning of the stroma. It is considered to be the most common primary corneal ectasia.[1] Its prevalence and incidence vary widely through the world, ranging from 0.2 to 4.790 per 100 000 persons and from 1.5 to 25 per 100 000 persons/year, respectively.[2] Clinically, quality of vision can be severely compromised, with progressive myopia and irregular astigmatism, that are poorly rehabilitated with spectacles. The typical age of emergence is the adolescence, and it tends to stabilize in the third or fourth decade of life. Its precise etiology is not fully understood, however there is strong evidence of the important role of both genetic, although with incomplete penetrance, and environmental factors, such as atopy, mechanical trauma, chronic eye rubbing, contact lens wear and even ultraviolet radiation,[1,2] although the last 2 may not play an important role.[3]

Concerning management, two important things must be done: control and arrest progression and improve vision. The best strategy can range from optical correction to corneal transplantation, depending on the severity of keratoconus.[4] At the very beginning, spectacles and soft contact lenses may be enough to improve vision quality, although with the development of irregular astigmatism, rigid gas-permeable contact lenses may become part of the treatment. Mindful vigilance of at-risk patients is mandatory to control disease progression, usually through serial corneal topographies. On those patients that do present with clinically meaningful progression, corneal collagen cross-linking is currently the gold-standard to halt – and hopefully ameliorate – said progression. On patients with severe advanced disease, ocular surgery is often mandatory. Common techniques include the intrastromal corneal ring segments, phakic intraocular lens or even lamellar or penetrating keratoplasty in extremely advanced cases.[1,2,4]

There has been an apparently increasing incidence in keratoconus diagnosis, although this could be attributed to the increasing numbers of patients wanting to perform re-

fractive surgery, therefore conducting preoperative ectasia screening.[5] Additionally, we now have much more sensitive complementary diagnostic tools, such as very precise corneal tomographers and great diagnostic algorithms.[6] Of note, these patients are, commonly very young, leading active lives. As soon as they are diagnosed, it is only normal that reasonable questions arise: how will this disease affect me? What can I expect in the future? What are my treatment options?

Patients often try to do this on the Internet, performing their own research or using social media to look for like-minded people. Surveys show that a huge part of the World-Wide-Web users regularly use the Internet to search for health information and, of note, e-health has become an important supplement to traditional health resources.[7] The Internet is used by patients, relatives and even ophthalmologists to get health information on keratoconus. However, the way physicians and patients search online – how and where – is vastly different. For example, a systematic review on the overall online health information showed that 70% of web sites were not of high enough accuracy, completeness, readability, design disclosures and references.[8]

With all of this in mind, it is crucial to promote research to check the reliability and quality of the information published because it will allow us to better understand the knowledge, attitudes and options of our patients. With better online information quality, patients may be legitimately involved in the decision-making process and improve the doctor patient relationship. This acknowledgment has led to a continued effort to assess for health information online in the English-speaking world.[9–11] To the best of our knowledge, there is no study yet on this topic, on Portuguese-speaking websites. Therefore, with this work, we want to report the overall quality and readability of online sources of information for Portuguese-speaking patients trying to seek knowledge about keratoconus on the Internet.

METHODS

Two independent ophthalmologists (CS and RS) were the evaluators and reviewed the web sites, while another ophthalmologist (JG) checked the reliability of the evaluation and was responsible for solving disagreements between the evaluators.

SEARCHING STRATEGY

We performed a search in Google chrome using merely the search engine tool Google, as it is the most frequently used search engine all over the world.[12] The term used was "Queratocone", as we wanted to obtain data related not just to treatment, but also about diagnosis, management and prognosis, as patients trying to obtain a full range of information. Additionally, we checked in Google ad words the keratoconus-related keywords that are more frequently searched in Portugal, and the results are shown in Table 1.

We used the filters "Country: Portugal" and "written in Portuguese". Historical and cached data and cookies were erased, as well as location sharing was disabled, and an incognito tab on google chrome was used to avoid any interference from past searches or location-specific materials. The first 31 hits from the search were included, by order of appearance. We excluded duplicate, commercial or advertisement, videos and news, to focus on just written lay content and avoid the noise in health information. We did not exclude scientific documents that addressed general aspects of keratoconus, having in mind that patients are increasingly literate and capable of reading scientific research; we just excluded scientific works too specific for one particular point of keratoconus or too complex.

Table 1. Average monthly searches by keratoconus-related keywords in Portugal.

Keyword	Average monthly searches
Queratocone	100-1000
Queratocone sintomas	10-100
Queratocone causas	10-100
Queratocone tratamento	10-100
Queratocone cirurgia	10-100

QUALITY ASSESSMENT

Regarding quality, we used Journal of the American Medical Association (JAMA) benchmark criteria, which assesses the presence of four core elements: authorship, attribution, disclosure, and currency; if the answer is positive to any item, it scores 1 point, and originates a final score from 0 to 4 (Table 2).[13]

Table 2. JAMA benchmark score.

Authorship	Authors and contributors, their affiliations, and relevant credentials should be provided
Attribution	References and sources for all content should be listed clearly, and all relevant copyright information should be noted
Disclosure	Website "ownership" should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest
Currency	Dates when content was posted and updated should be indicated

We also used the DISCERN tool, that consists of 16 items, each one categorized from 1 to 5 (so the final score ranges from 16 to 80), divided in 3 sections: 1: "What is investigated? Is the publication reliable?", with 8 items, 2: "How good is the quality of information regarding treatment choices?", with 7 items, and 3: "Overall rating of the publication", with 1 item (Table 3).[14]

Finally, we also recorded whether the webpage has some kind of independent quality seal, such as an attributed reward or prize, which could help the patient better evaluate the site.

Table 3. DISCERN score.

Question Number	What is investigated?	Question Rating				
		No Partially				Yes
Section 1	**Is the publication reliable?**					
1	Are the aims clear?	1	2	3	4	5
2	Does it achieve its aims?	1	2	3	4	5
3	Is it relevant?	1	2	3	4	5
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	2	3	4	5
5	Is it clear when the information used or reported in the publication was produced?	1	2	3	4	5
6	Is it balanced and unbiased?	1	2	3	4	5
7	Does it provide details of additional sources of support and information?	1	2	3	4	5
8	Does it refer to areas of uncertainty?	1	2	3	4	5
Section 2	**How good is the quality of information regarding treatment choices?**					
9	Does it describe how each treatment works?	1	2	3	4	5
10	Does it describe the benefits of each treatment?	1	2	3	4	5
11	Does it describe the risks of each treatment?	1	2	3	4	5
12	Does it describe what would happen if no treatment is used?	1	2	3	4	5
13	Does it describe how the treatment choices affect overall quality of life?	1	2	3	4	5
14	Is it clear that there may be more than 1 possible treatment choice?	1	2	3	4	5
15	Does it provide support for shared decision making?	1	2	3	4	5
Section 3	**Overall rating of the publication**					
16	Based on the answers to all of these questions, rate the overall quality of the publication as a source of information about treatment choices	1, 2, 3 **Low Moderate**			4, 5 **High**	

READABILITY ASSESSMENT

Readability is an underestimated point, but it is very important, as it is a measure of how easy a piece of text is to read. We can have a very complete article, but, for example, if it is written with medical jargon or in a very exhausting way, patients would not understand it properly. Several readability scores are available to evaluate this point. A readability score is a computer-calculated score that tell us the level of education someone will need to be able to read a piece of text easily.[15,16]

In this work, three readability indexes were used. The FleschKincaid Reading Ease formula (FRE) calculates a score from 0 to 100 based on average sentence length and the average number of syllables per word, with 100 being the highest readability score (Table 4).[17] The FleschKincaid Grade (FKG) was originally created to be a United Stated school grade level and is similar in method but inversely proportional to the first one, as it ranges from 0 to 18 (or more) and the lowest values mean that low levels of education are needed to understand the text (Table 5).[18] Finally, the Automated Readability Index (ARI) ranges from 1 to 14 (or more) and also determines the grade level by calculating sentence length and character count, and low values also mean low grade level needed to understand the text (Table 6).[19] All these scores are now available in formulas adapted to Portuguese and in this work were used all together in "https://legibilidade.com/". More readability scores can be visualized in this webpage.

Table 4. FleschKincaid Reading Ease score and the correspondent description of style.

Reading Ease Score	Description of style
0-30	Very difficult
30-50	Difficult
50-60	Fairly difficult
60-70	Standard
70-80	Fairly easy
80-90	Easy
90-100	Very easy

Table 5. FleschKincaid Grade score and the correspondent school level and comprehension.

Flesch Kincaid score	School level	Comprehension
5.0-5.9	5th Grade	Very easy to read
6.0-6.9	6th Grade	Easy to read
7.0-7.9	7th Grade	Fairly easy to read
8.0-9.9	8th & 9th Grade	Conversational English
10.0-12.9	10th, 11th & 12th Grade	Fairly difficult to read
13.0-15.9	College	Difficult to read
16.0-17.9	College Graduate	Very difficult to read
18.0+	Professional	Extremely difficult to read

Table 6. Automated readability index and the correspondent school level and age.

Automated readability index	School level	Age
1	Kindergarten	5-6
2	1st & 2nd Grade	6-7
3	3rd Grade	7-9
4	4th Grade	9-10
5	5th Grade	10-11
6	6th Grade	11-12
7	7th Grade	12-13
8	8th Grade	13-14
9	9th Grade	14-15
10	10th Grade	15-16
11	11th Grade	16-17
12	12th Grade	17-18
13	College Student	18-24
14+	Professor	24+

POPULARITY ASSESSMENT

Popularity was estimated through the order of appearance in "Google.pt". Google ranks search results and its relevancy is determined by hundreds of factors, that include complex algorithms, with many factors, so we avoided the personalized ones, as we described in "searching strategy".

STATISTICAL ANALYSIS

The normality of the distribution was first checked by the Kolmogorov-Smirnov test. We then used parametric tests un such cases, like the students t-test, or nonparametric tests, such as the MannWhitney U test, to access for differences between sites in different situations. Correlation between scores was searched using Spearman's rank correlation coefficient. Analyses were performed using SPSS Statistics and Microsoft Excel. Statistical significance was defined as $p < 0.05$.

RESULTS

The search in the described conditions achieved 2340 results. We excluded 4 news, 3 advertisements, 1 very complex scientific article (addressing some specific particularities of corneal cross-linking), 1 in maintenance and 3 unsuitable for being submitted to scores (for example online dictionaries with the definition of keratoconus and nothing else) till we achieved 31 sites in our chosen conditions.

We obtained 12 sites (38.70%) from private hospitals or clinics, 5 sites (16.13%) from online health platforms, 4 (12.90%) sites from spectacles or contact lenses companies, 2 sites (6.45%) from blogs, 2 sites (6.45%) from master's degree thesis, 2 sites (6.45%) from orthoptist practitioners, 1 site (3.23%) from an online flyer, 1 site (3.23%) from one scientific journal, 1 site (3.23%) from one online encyclopedia and 1 site (3.23%) from one online presentation. This information is displayed in Fig. 1.

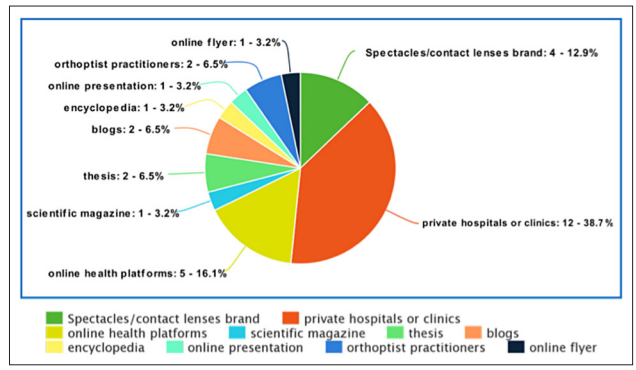

Figure 1. Distribution of the origin of the sites.

QUALITY ASSESSMENT

The average score for each JAMA benchmark item was: 1: 0.48±0.51, 2: 0.32±0.48, 3: 0.03±0.18 and 4: 0.42±0.50; the average final score was: 1.26±1.24, 12 sites (38.72%) reaching 0, 7 sites (22.58%) reaching 1, 4 sites (12.90%) reaching 2, 8 sites (25.80%) reaching 3 and no site reaching the maximum JAMA benchmark score.

The average score for each DISCERN section was: 1: 17.42±7.56, 2: 15.68±5.68 and 3: 2.45±1.21; the average final score was 35.55±13.63. "https://revistas.rcaap.pt/oftalmologia" scored the highest in section 1, followed by https://pt.wikipedia.org., the same situation happening in section 2. In section 3, "https://revistas.rcaap.pt/oftalmologia" scored the highest, followed by https://www.hospitaldaluz.pt/, https://www.saudebemestar.pt/, https://pedipedia.org/, https://ubibliorum.ubi.pt/, https://repositorio.ul.pt/ and https://pt.wikipedia.org/. Overall results are explicit in Table 7.

There is an evident positive correlation between JAMA benchmark score and DISCERN full score (r=0.867, p<0.001), as well as with section 1 (r=0.8592, p<0.001). A not so strong positive correlation was noted between JAMA benchmark score and DISCERN section 2 (r=0.6559, p<0.001) and DISCERN section 3 (r=0.6428, p<0.001), but still statistically significant.

Eleven sites (35.48%) exhibited some kind of quality seal. This included, for example, industry awards, accreditations attributed by international commissions, quality certifications attributed by health agencies, newspapers recognitions, patients recognitions, etc. Sites with quality seal attributed did not show a statistically significant difference versus sites without quality seal in terms of DISCERN full score (mean scores – 39.09 and 33.60, respectively, p=0.20). The same happened in terms of JAMA score (mean scores – 1.36 and 1.25, respectively, p=0.48).

READABILITY ASSESSMENT

The mean FRE score was 32.23±12.98, which corresponds to "difficult to read" and to college school level,

Table 7. Google rank, DISCERN score, JAMA score, presence of quality seal and readability scores.

Site	Google rank	Sec 1	Sec 2	Sec 3	DISCERN Total	JAMA Total	Quality seal	FRE	FKG	ARI	Type
https://coopervision.pt/cuidados-de-visao-e-saude-ocular/o-que-e-queratocone	1	16	16	2	34	0	yes	42.4	13	12.8	Spectacles/contact lenses brand
https://www.cuf.pt/saude-a-z/queratocone	2	18	14	2	34	2	yes	36.3	13.7	13.6	Private hospital/clinic
https://www.hospitaldaluz.pt/pt/dicionario-de-saude/queratocone	3	24	22	4	50	2	yes	43.5	12	11.3	Private hospital/clinic
https://spoftalmologia.pt/wp-content/uploads/2015/10/Queratocone.pdf	4	13	16	3	32	1	no	29.8	15.3	15.2	Online flyer
https://www.imo.pt/cirurgias/queratocone/	5	10	11	1	22	0	yes	12.4	20.5	21.8	Private hospital/clinic
https://cpoftalmologia.pt/patologia/queratocone/	6	17	16	3	36	0	no	34.2	14.3	21.8	Private hospital/clinic
https://www.mymedfarma.com/pt/guia-da-saude/11-oftalmologia/1149-ceratocone-ou-queratocone	7	13	16	3	32	0	yes	30.9	12.2	10.7	Health platform
https://www.saudebemestar.pt/pt/clinica/oftalmologia/ceratocone/	8	19	24	4	47	2	no	35.4	13.7	12.9	Health platform
https://www.multiopticas.pt/saude-ocular/queratocone---causas--sintomas	9	11	12	1	24	0	no	55.9	10.3	10.1	Spectacles/contact lenses brand
https://revistas.rcaap.pt/oftalmologia/article/view/6154	10	38	30	5	73	3	yes	19.2	16.7	16.4	Scientific journal
https://www.trofasaude.pt/trofa/artigos/queratocone-como-se-manifesta-e-possiveis-tratamentos/	11	19	16	3	38	1	no	-0.1	24.8	26.5	Private hospital/clinic
https://pedipedia.org/artigo/queratocone	12	18	21	3	42	2	yes	37.7	13.6	13.5	Health platform
https://pedipedia.org/pro/artigo-profissional/queratocone	13	25	23	4	52	3	yes	24.3	16.5	16.8	Health platform
https://ubibliorum.ubi.pt/bitstream/10400.6/9992/1/5643_11712.pdf	14	25	24	4	53	3	no	43.1	11.4	10.6	Thesis
https://blog.uc.pt/conhecer-e-prevenir-o-queratocone/	15	12	17	2	31	1	no	35.6	13.6	12.5	Blog
https://www.drmsn.com/queratocone	16	10	13	1	24	0	no	33.7	15.3	15.2	Private hospital/clinic
https://repositorio.ul.pt/bitstream/10451/42779/1/AndreiaCViegas.pdf	17	29	22	4	55	3	no	40.8	13	13	Thesis
https://pt.wikipedia.org/wiki/Ceratocone	18	31	25	4	60	3	no	29	15.8	16	Encyclopedia
https://repositorio.hff.min-saude.pt/bitstream/10400.10/1321/1/QK%202.pdf	19	21	16	3	40	3	no	34	15.2	16.3	Online presentation
https://www.paulasepulveda.pt/queratocone.html	20	10	11	1	22	0	no	50.2	10.1	8.7	Private hospital/clinic
https://www.clinivis.pt/?patologias=queratocone	21	11	11	1	23	1	no	40.3	11.8	10.7	Private hospital/clinic
https://salgadoborges.com/tratamento-de-queratocone/	22	28	11	2	41	3	yes	41.6	12.8	12.3	Private hospital/clinic
https://www.rodolfomoura.pt/artigo/o-que-e-o-queratocone	23	8	8	1	17	1	no	21.3	15.2	14.4	Orthoptist
https://www.opticaparente.pt/queratocone-e-modificacoes-corneais	24	11	9	1	21	0	no	23.2	16.3	16.5	Spectacles/contact lenses brand
https://www.ricardobatistaortoptista.pt/queratocone	25	14	10	1	25	1	no	-3.5	22.4	23.4	Orthoptist
https://www.oftaline.pt/p5-queratocone-pt	26	13	13	3	29	0	yes	40	12.5	11.8	Private hospital/clinic
https://healthnews.pt/2021/11/09/oftalmologistas-de-coimbra-esclarecem-duvidas-no-dia-mundial-do-queratocone/	27	22	17	3	42	2	no	42.7	12.7	11.9	Health platform
https://www.bausch.com.pt/sua-saude/doencas-e-disturbios-oculares/queratocono/	28	11	10	1	22	0	no	36.2	14	13.9	Spectacles/contact lenses brand
https://co-rufino-ribeiro.pt/tratamento_queratocone/	29	10	10	2	22	0	no	38.8	14	14.3	Private hospital/clinic
https://www.clinsborges.pt/ceratocone/	30	10	9	2	21	0	yes	28.6	16.1	16.4	Private hospital/clinic
https://www.fciencias.com/2018/11/20/queratocone-espaco-saude/	31	23	13	2	38	3	no	21.7	17.5	17.7	Blog

Sec 1: section 1 of the DISCERN score, Sec 2: section 2 of the DISCERN score, Sec 3: section 3 of the DISCERN score, FRE: FleschKincaid Reading Ease, FKG: FleschKincaid Grade, ARI: automated readability index

as well as a concordant mean FKG of 14.72±3.24.[20] Accordingly, the mean ARI was 14.81±4.09, which denotes "professor" level needed to understand the text.[19]

Overall results are showed in Table 7.

Sites with a seal quality did not show statistically significant better FRE scores than sites without quality seal (mean scores – 32.44 and 32.12, respectively, *p*=0.49).

There was no correlation between FRE score and JAMA benchmark score (r=-0.0281, *p*=0.88). The same happened between the FRE score and the DISCERN full score (r=0.018, *p*=0.92).

POPULARITY ASSESSMENT

The "https://coopervision.pt" is the site that appears first in the search, followed by "https://www.cuf.pt/". The remaining searches can be consulted in Table 7, by order of appearance on Google.pt.

There was no apparent strong correlation between google ranking and DISCERN full score, r value suggesting only some tendency for the global quality to decrease, as sites show up later, but not in a statistically significant way (r=-0.3016, *p*=0.10). The same happened between google ranking and the JAMA score (r=-0.0147, *p*=0.94).

There was no apparent strong correlation between google ranking and FRE score (r=-0.0757, *p*=0.69).

Supplementary Table 1. Quality assessment (average data).

Quality score item	Average score
JAMA	
Section 1	0.48±0.51
Section 2	0.32±0.48
Section 3	0.03±0.18
Section 4	0.42±0.50
Final score	1.26±1.24
DISCERN	
Section 1	17.42±7.56
Section 2	15.68±5.68
Section 3	2.45±1.21
Final score	35.55±13.63

Supplementary Table 2. Readability assessment (average data).

Readability score item	Average score
FRE	32.23±12.98
FKG	14.72±3.24
ARI	14.81±4.09

FRE: FleschKincaid Reading Ease formula; FKG: FleschKincaid Grade; ARI: Automated Readability Index.

DISCUSSION

Nowadays, the line that divides our physical lives and our online lives is getting increasingly blurred. We can escape the influence that the Internet has, whether in politics or in medicine. Many patients rely very much on online sources and guide their attitudes and expectations on disease based on this. This is emphasized by the relatively young age of keratoconus patients. Because of this, it is extremely important to assure patients that they are getting good and useful information, or, on the contrary, they need to be careful with poor quality information. This can even compromise treatment and management recommended by the ophthalmologist. In Portugal, this kind of exploration, particularly in the fields of keratoconus and Ophthalmology, has never been done.

In terms of the type of online sources easily available for patients, some previous works immediately exclude scientific articles. However, we consider that not all scientific articles are of the same quality or are necessarily suitable or unsuitable for patients. Surprisingly, even some thesis scoring lower than other type of sites.

Sites from private hospitals or clinics were the most represented, followed by online health platforms and by spectacles/contact lenses brands. This reflects well on the importance that health providers have on providing information about diseases to their patients and to inform the public in general. On the other hand, some concern regarding commercial or financial interests could overshadow this.

The statistically significant positive correlation between the quality scores used in this work reinforce our confidence in the consistency of our results. The average score for each JAMA benchmark item (1: 0.48±0.51, 2: 0.32±0.48, 3: 0.03±0.18 and 4: 0.42±0.50), as well as the average final score (1.26±1.24), meaning that in any occasion the average score reached at least half of the maximum score, means that there is plenty work to do to improve the quality of the online information; the fact that 12 sites (38.72%) reached 0 and no site reached the maximum JAMA benchmark score is worrisome as well.

The average score for each DISCERN section (1: 17.42±7.56, 2: 15.68±5.68 and 3: 2.45±1.21), as well as the average final score (35.55±13.63), corroborates the major impression when analyzing the JAMA score.

About the readability, in Portugal, as far as the authors are aware, there are no guidelines telling us what the ideal score for health information should be. However, the AMA recommends that it should be tailored to U.S. sixth grade.[21] Having that in mind, the mean FRE on the websites we analyzed was 32.23±12.98, which corresponds to "difficult to read" and to college school level, the mean FKG was 14.72±3.24, which is in accordance, and the mean ARI was 14.81±4.09, which denotes "professor" level needed to understand the text. This might imply there is plenty of work to do to make the information available to our patients more readable. As there was no correlation between FRE score and JAMA benchmark score or between the FRE score and the DISCERN full score, we cannot say that that the sites with best quality scores are the more readable ones, or vice versa. This may be explained by some complexity of the sites with better scores. It is important to note that one of important things that are taking into account by the readability scores is the number of not common words and as

information about keratoconus has obviously many words about treatment and diagnosis which are not common in the daily routine of a nonmedical population, we think this could be a handicap when scoring sites by this method.

Sites with some type quality seal did not show statistically significant better FRE scores than sites without quality seal, the same happening in terms of quality scores, showing that, when talking about quality and readability of the online information, these quality seals are only of relative importance.

Popularity seems to play a role in the quality of online information. As we scroll through the Internet sites to the less popular ones, there is a tendency for the quality to decrease, although this did not show a strong correlation nor a statistically significant association. Regarding readability, there was not even a tendency reported.

Our study is not without limitations. The fact that our research was focused only in Portuguese and written in Portuguese sites could lead us to a not fully representative idea of what Portuguese people obtain from the Internet. Plenty of Portuguese patients - young and old - know how to speak English and will search the web in English. Another important point is that we have many Brazilian sites that have potentially been consulted by our patients, and those sites were not considered in this study. Additionally, we know that online information can change significantly very quickly. We noticed that some sites did not have any information about the last update or even of the publication time, so they could be outdated. Also, we have to consider that the analysis of the sites, even when done by two ophthalmologists, is a subjective task, being submitted to all the limitations that this implies. We tried to manage this issue with a third evaluator, who confirmed the reliability of the evaluation and was responsible for solving disagreements between the evaluators.

In conclusion, the information on keratoconus that is available online to Portuguese speaking patients is, overall, of poor quality and difficult to interpret. Physicians need to be aware that some patients might trust their own online research as much (or more) than the information they receive through their ophthalmologist. These challenges of the Internet-age may be new but are likely now as important as our other challenges in diagnosis or treatment. Ophthalmologists have a shared responsibility to tackle this challenge through multifold efforts. On the one hand, to cooperate with different entities and resources to improve the information that is available online. And, on a daily basis, to educate our patients on how to find reputable web sites that can help them navigate their life with keratoconus.

CONTRIBUTORSHIP STATEMENT / DECLARAÇÃO DE CONTRIBUIÇÃO:

CC and RSO: Responsible for gathering the data, presenting the results, and writing the manuscript.

JG: Responsible for confirming the reliability of the evaluation and was responsible for solving disagreements between the evaluators, as well as supervising the evaluation.

EC, CT, AR, MJQ and JM: Concept and design of the study and revision of the manuscript. Supervised this project and contributed with their expertise to its conclusion.

All authors read and approved the final manuscript.

CC e RSO: Responsáveis pela recolha dos dados, apresentação dos resultados e redação do manuscrito.

JG: Responsável pela confirmação da fiabilidade da avaliação e foi responsável pela resolução de desacordos entre os avaliadores, bem como pela supervisão da avaliação.

EC, CT, AR, MJQ e JM: Conceito e desenho do estudo e revisão do manuscrito. Supervisionaram este projeto e contribuíram com os seus conhecimentos para a sua conclusão.

Todos os autores leram e aprovaram o manuscrito final.

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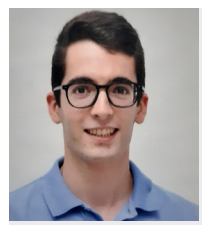

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