The Quality and Readability of Online Consumer Information about Gynaecological Cancer

Abstract

Objective: The Internet has become an important source of health-related information for consumers, among whom younger women constitute a notable group. The aims of this study were: (1) to evaluate the quality and readability of online information about gynaecological cancer using validated instruments; and (2) to relate the quality of information to its readability.

Methods: Using the Alexa Rank we obtained a list of 35 webpages providing information about 7 gynaecological malignancies. These were assessed using the HON seal of approval, the JAMA benchmarks, and the DISCERN instrument. Flesch readability score was calculated for sections related to symptoms and signs, and treatment.

Results: Less than 30% of the webpages displayed the HON seal or achieved all JAMA benchmarks. The majority of the treatment sections were of moderate to high quality according to the DISCERN. There was no significant relationship between the presence of the HON seal and readability. Webpages achieving all JAMA benchmarks were significantly more difficult to read and understand than webpages that missed any of the JAMA benchmarks. Treatment-related content of moderate to high quality as assessed by the DISCERN had a significantly better readability score than the low quality content.

Conclusions: The online information about gynaecological cancer provided by the most frequently visited webpages is of variable quality and in general difficult to read and understand. The relationship between the quality and readability remains unclear. Healthcare providers should direct their patients to reliable material online since patients consider the Internet as an important source of information.

Introduction

With the gradual departure from the paternalistic model of physician-patient relationship and the introduction of the patient-centered model of care, access to reliable and understandable medical information enables patients to participate in the process of decision-making concerning their course of treatment [1], improves patient health outcomes [2], and also gives the patients a sense of control over their illness [3]. Over the last decade, the Internet has become an important source of health-related information for cancer patients and their carers [4]. Women, especially those who are younger, constitute a group who most frequently searches the Internet for health-related information [5, 6], including cancer [7].

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Information needs of cancer patients vary depending on the time point in cancer trajectory. According to Rutten et al. [8]'s systematic review on information needs of cancer patients, cancer-specific and treatment-related content as well as information on prognosis are most valuable to patients at the time of their diagnosis or treatment. At post-treatment, treatment-related and prognosis information stay among the most important, while the interest from cancer-specific content tends to shift towards the rehabilitation aspects. For women who were diagnosed with cancer during their reproductive years, resolving their fertility issues might be a salient part of the rehabilitation process [9, 10].

In view of the existing literature, we decided to assess the quality and readability of the content of frequently accessed gynaecological cancer-related webpages. We concentrated mainly on information about symptoms and signs, treatment, and fertility issues related to gynaecological cancer. To assess the quality of information, we chose three instruments that have been widely used for this purpose in the existing literature: the Health on the Net (HON) seal of approval (www.hon.ch/HONcode/), the Journal of the American Medical Association (JAMA) benchmarks [11] and the DISCERN instrument [12]. To evaluate the readability of information, we calculated the Flesch Reading Ease Score of the textual content [13]. We also explored the associations between the quality of online information and its readability. To do that, we compared the readability scores of the webpages that (1) displayed the HON seal versus those that did not; (2) achieved all JAMA benchmarks versus those that missed any of the benchmarks; (3) scored 3 to 5 on the last DISCERN item (indicating moderate to high quality webpages) versus those that scored 1 to 3 on the last DISCERN item (indicating low quality webpages).

Materials and methods

We planned to assess the quality of online health information on gynecological cancers that is most frequently accessed globally. To do this, we used the Alexa Rank, a database providing different sorts of information about webpages accessible around the world, including visiting statistics based on measures of user traffic. Alexa Rank has already proved to be a good source of Web traffic data [14].

Sixty-seven webpages about gynecological cancers were identified on January 15th, 2013, of which 27 were on ovarian cancer, 13 on cervical cancer, 5 on endometrial cancer, 3 on fallopian tube cancer, 4 on gestational trophoblastic tumors, 5 on uterine sarcoma, 3 on vaginal cancer, 3 on vulvar cancer, and the other 4 not belonging to any of the distinguished categories. We examined the quality of information provided by top

ten webpages on ovarian cancer, top 5 on cervical cancer, and all other webpages about specific types of cancers giving us in total 35 websites.

The websites were initially categorized adopting the classification Ni Riordain and McCreary [15] used to assess the accuracy and content of online information on head and neck cancer.

Three instruments were used to assess the quality of information: the HON seal of approval, the Journal of the American Medical Association (JAMA) benchmarks [11] and the DISCERN instrument [12]. We also assessed the readability of sections of the webpages related to the symptoms and signs, treatment, and fertility issues using the Flesch Reading Ease Score [13]. For further information on the instruments please see Supplemental Digital Content 1.

Of the thirty-five webpages, some belonged to the same website (e.g., www.nhs.uk was one of the most frequently consulted websites concerning both ovarian and vaginal cancer). The initial quality screening process revealed the differences in quality scores between the webpages belonging to the same website; therefore, we decided to assess each particular webpage with both JAMA benchmarks and the HON seal.

The DISCERN is only applicable to treatment-related information, therefore webpages that reported on treatment choices for gynaecological cancers were assessed with this instrument. The use of DISCERN instrument to assess the webpages implies some degree of subjectivity therefore each treatment section was assessed by both authors.

The Flesch Reading Ease Score was calculated for all the webpages, however only the scores for symptoms and signs, and treatment sections were used for further analyses.

The number of webpages evaluated with each instrument is outlined in Table 1 (see Supplemental Digital Content 2).

Data Analysis

We analyzed the data using SPSS/Windows version 19.0 (SPSS, Inc., Chicago, Illinois) and R (R Foundation for Statistical Computing, Vienna, Austria). Descriptive analysis was performed to characterize the webpages selected for the study. The Flesch Reading Ease Score was computed by software built in the Microsoft Office Word 2003. We calculated the inter-rater agreement for each DISCERN item. The Mann-Whitney U test was employed to test for the differences [16]. We chose a non-parametric test because the numbers of observations in groups of webpages assessed as high or low quality according to the HON seal,

JAMA benchmarks, and DISCERN were not equal. The significance level was set at $p < 0.05$ and the analyses were run using two-tailed significance tests.

Results

Most of the webpages we analyzed were affiliated with non-profit organizations and provided general health information, part of which related to some type of gynaecological cancer (see Table 2, Supplemental Digital Content 2). Out of all analyzed webpages, 74.3% provided information on signs and symptoms of gynecological cancers, 80% on treatment, and only 8.6% on fertility issues that cancer patients might face.

Only nine webpages achieved all 4 JAMA benchmarks (25.7%). The other nine achieved 3 benchmarks with the most achieving 2 benchmarks (34.3%) and the remaining 5 achieving 1 benchmark. Ten out of 35 webpages displayed the HON seal. Initially, eleven webpages were included in that group yet one webpage has proved to display a "false" seal with no details following the seal on the Health on the Net website.

Treatment-related sections were assessed with the DISCERN instrument by two raters coming from different professional backgrounds (medical background for rater 1 and psychological background for rater 2). The kappa values for the inter-rater agreement varied from -0.072 to 0.692. Eight results were in the range between 0.21 and 0.4; 3 in the range between 0.41 to 0.6 and 2 in the range between 0.61 and 0.8 (see Table 3, Supplemental Digital Content 2), showing that we reached a fair to substantial agreement on most of the DISCERN items [17].

The most important shortcomings of the treatment-related sections included the lack of clarity of the aims (item 1), the lack of sources of information used to compile the publication (item 4), the lack of information about what would happen if no treatment was used (item 12) and the lack of information related to the quality of life after treatment (item 13) (see Table 3, Supplemental Digital Content 2). The latter issue has also been reported in other studies using the DISCERN to assess cancer treatment related information [15, 18]. The overall quality score (item 16) for the webpages was on average moderate as assessed by both raters ($\kappa = 0.629$, $p < 0.001$). We computed the mean of the scores assigned by both raters for every webpage and used it to classify the information as low or moderate to high quality for further analysis.

The Flesch Reading Ease Score was calculated for 24 webpages that included symptoms and signs section and 27 that included treatment section. Over 80% of the symptoms and signs sections and all of the treatment sections have been classified as 'fairly difficult' to 'very difficult'. The mean values of Flesch Reading Ease Score for symptoms and signs sections, and treatment sections were 44.66 (SD = 15.08) and 41.18

(SD = 16.42), respectively and the difference between them tested with the *t*-test was statistically not significant. The KS two-sample test comparing the distributions of the scores for symptoms and signs, and treatment sections was also not significant. Therefore, we aggregated the data for the purpose of further analysis. We computed the mean values of Flesch Reading Ease Score for each webpage that had both signs and symptoms and treatment sections and if the page only contained one section (which in all the cases was the treatment section), we used this score for further analysis.

The webpages displaying the HON seal versus those that do not display the HON seal

We compared the median Flesch scores of pages that did (n = 9; Mdn = 41.4) and did not (n = 18, Mdn = 46.8) display the HON seal. The pages that displayed the HON seal did not significantly differ in terms of readability from those that did not display the seal. Nonetheless, the median Flesch scores for both groups can be categorized as 'difficult' [13] which indicates that to understand the text at least high school or some college/university education is required [19].

The webpages achieving all JAMA benchmarks versus those that missed any of the JAMA benchmarks

We compared the median Flesch scores of the webpages that achieved all four JAMA benchmarks (n = 8; Mdn = 31.05) to the webpages that achieved less than 4 JAMA benchmarks (n = 19; Mdn = 49.6). The Mann-Whitney *U* test showed a significant difference in readability between the two groups of webpages (Z = -2.60, *p* = 0.009) with webpages achieving all 4 JAMA benchmarks being more difficult to read and understand. However, similarly to the HON seal, the median Flesch scores for both groups fell into the 'difficult' category [13] again indicating that to be able to fully understand the text, a reader needs to have at least high school or some college/university education [19].

Treatment sections scoring 3 to 5 on the last DISCERN item (moderate to high quality) versus from those that scored 1 to 3 on the last DISCERN item (low quality).

We assigned treatment materials to two groups – 'moderate to high quality' (score 3 to 5 on the last DISCERN item; n = 18) and 'low quality' (score less than 3 on the last DISCERN item; n = 9) group and tested the difference between the median Flesch Reading Ease Scores. The cut-off point was chosen based on the scoring system of the last DISCERN item [12]. The median Flesch Reading Ease Scores were 50.56 for the' moderate to high quality' group and 33.5 for the 'low quality' group. The Mann-Whitney *U* test showed that

there was a significant difference (Z = -3.55; $p < 0.001$) between the two groups with the 'moderate to high' quality' webpages being easier to read and understand than 'low quality' webpages. Still, the median score for the higher quality webpages fell into the 'fairly difficult' category (with the lower cut-off point for this category being 50), while the median for the lower quality webpages fell into the 'difficult' category according to Flesch [13]. This indicates that for the 'moderate to good quality' webpages at least high school level of education is needed to understand the text whereas for 'poor quality' webpages, it is high school or some college/university education level [19].

Discussion

General quality and readability assessment

In our sample, less than 30% of webpages displayed the HON seal or achieved all JAMA benchmarks, indicating that the information most frequently accessed by consumers was generally of poor quality. Treatment-related sections presented several shortcomings (including the lack of clarity of the aims, the lack of sources of information used to compile the publication, the lack of information about what would happen if no treatment was used, and the lack of information related to the quality of life after treatment); however 66.7% of webpages in our sample scored above 3 on the last DISCERN item indicating that the overall quality of treatment-related contact was 'moderate to high'.

These results suggest that there is a substantial variability in the quality of online information related to gynaecological cancer. They also indicate that the three scoring systems we used refer to different aspects of quality assessment and this likely contributed to the discrepancy of the quality scores provided by the different instruments. Both the HON seal and the JAMA benchmarks focus more on the editorial side of the material presented while the DISCERN examines the content more in depth.

The readability scores we obtained for symptoms and signs, and treatment sections were on average in the difficult range, indicating that to understand the text at least a high school or some college/university education is required [19].

Using instruments to assess the quality of health-related online information should be recommended to both healthcare professionals and patients. Checking a webpage for the presence of the HON seal is the easiest way to ascertain reliability, followed by JAMA benchmarks [11], the use of which is slightly more time-consuming and entails identifying four indicators of reliable information: the authorship, attribution, disclosure, and currency. Finally, the DISCERN instrument [12] only applies to the treatment-related information and its

use is the most time-consuming (16 items) of all. However, it is important to make sure that patients know which information to trust and for clinicians to know which information to recommend. The high readability scores also call for a change in the way online information is written.

Differences in readability in relation to quality

We did not find a significant association between the presence of the HON seal as a quality indicator and the readability score of the webpages. However, the readability was related to the quality score as assessed by JAMA benchmarks and the DISCERN instrument. Webpages achieving all four JAMA benchmarks were significantly more difficult to read than those that missed any of the JAMA benchmarks. 'Moderate to high quality' treatment-related information (as assessed by the last DISCERN item) was significantly easier to read compared to 'low quality' information. These results diverge depending on the instrument used to assess the quality of a webpage which might again reflect different aspects of the webpages these instruments target to evaluate. However, regardless of whether the webpage was in the high or low quality group (according to both JAMA and DISCERN), the textual content was, on average, classified as 'difficult' or 'fairly difficult' to read. According to the latest OECD data, 38.2% and 41.7% of the 25 to 64 year olds in the UK and the US respectively, attained tertiary education [20]. Therefore, for the majority of consumers, the online information related to gynaecological cancer, even if it is rated highly on reliability, may be too difficult to understand.

Limitations

Although the present study looked at the most frequently visited webpages providing information on gynaecological cancer, the number of webpages we obtained using the Alexa Rank was limited and thus, does not represent all the information available to the Internet users. The instruments we used to assess the quality, especially the DISCERN, imply some degree of subjectivity in assessment which we tried to address by evaluating the content of the webpages by two raters. This diminishes the risk of bias, yet, it does not eliminate it completely. Our agreement on the DISCERN items was generally acceptable, however, we failed to achieve significant agreement on one item. This may indicate that DISCERN can be interpreted differently by professionals from different disciplines as well as lay people and this should be borne in mind while using it for research or clinical purposes. Moreover, the Flesch Reading Ease Score used in this study, although one of the most frequently used formulas to assess readability of print and web-based cancer information [21] presents shortcomings common to all the

formulas based on the sentence and word length. As discussed by Klare [22] and Redish [23], mathematical readability formulas focus on a single aspect of the text – its style, not taking into account the vocabulary or the content. Furthermore, readability formulas are often criticised for only concentrating on the difficulty of the text (without acknowledging other aspects of style that might be important to the reader) and not being able to measure what could be called good style [22]. Therefore, Redish [23] argues that instead of using mathematical equations to calculate readability scores, we should prefer the usability tests that directly involve consumers working with documents and give answers to whether problems with the documents exist, where and how to best remedy them.

Finally, because we failed to retrieve the information on symptoms and signs, and treatment from one of the webpages at the time of conducting this study, this webpage was not included in the final analysis.

Conclusions

Overall, the online information about gynaecological cancers in our sample of webpages proved to be of variable quality and generally difficult to read and understand. Achieving a high quality score according to the DISCERN instrument meant that the textual content of the webpage was easier to read but still fell within the fairly difficult range according to Flesch [13]. Therefore, although quality assessment tools can indicate if a webpage contains reliable information, they do not predict its readability.

Given the limitations of the readability formula used in this study, the poor readability scores should only be considered as a red flag [23] and the existing room for improvement, ideally with the involvement of consumers who will then benefit from the information provided online.

Provision of information enables patients to make more informed choices [1] and also gain control over their illness, adhere better to their treatments, and feel less anxious [3]. Yet, the available information has to be both reliable and understandable to the patient. If not, there exists some evidence that information could be more harmful than beneficial [24]. According to the HON survey from 2010, 29% of participants indicated that they felt anxious after consulting the Internet for health-related information, even though, at the same time, 65% declared that they usually understand complex medical information provided online [25].

In light of these results and the evidence from the literature, healthcare professionals in the domain of gynaecologic oncology should direct patients to the reliable sources of information online and advise them on how to assess the reliability of online content recommending the use of the HON seal or JAMA benchmarks. However, we note that reliable information does not translate to readable information. Therefore, healthcare

professionals should also discuss the online information accessed by patients to clarify misconceptions that can result from patients consulting the Internet for health-related content on their own. Finally, since gynaecological cancers are one of the most frequently diagnosed in the group of younger women [26] it is important for gynaecological oncologists to discuss with their patients the possible impact of cancer diagnosis and treatment on fertility, given that only a minority of webpages seem to address this topic.

Conflict of interest

Aleksandra Sobota and Gozde Ozakinci declare that they have no conflict of interest.

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Human and Animal Rights and Informed Consent

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