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Websites on Bladder Cancer: an Appropriate Source of Patient Information?

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Abstract

A growing number of patients search for health information online. An early investigation of websites about bladder cancer (BCa) revealed mostly incomplete and particularly inaccurate information. We analyzed the quality, readability, and popularity of the most frequented websites on BCa. An Internet search on www.google.com was performed for the term "bladder cancer." After selecting the most frequented websites for patient information, HONcode quality certification, Alexa popularity rank, and readability scores (according to US grade levels) were investigated. A 36-point checklist was used to assess the content according to the EAU guidelines on BCa, which was categorized into seven topics. The popularity of the 49 websites analyzed was average, with a median Alexa popularity rank of 41,698 (interquartile range [IQR] 7–4,671,246). The readability was rated difficult with 11 years of school education needed to understand the information. Thirteen (27%) websites were HONcode certified. Out of 343 topics (seven EAU guideline topics each on 49 websites), 79% were mentioned on the websites. Of these, 10% contained incorrect information, mostly outdated or biased, and 34% contained incomplete information. Publically provided websites mentioned more topics per website (median [IQR] 7 [5.5–7] vs. 5.5 [3.3–7]; $p = 0.022$) and showed less incorrect information (median [IQR] 0 [0–1] vs. 1 [0–1]; $p = 0.039$) than physician-provided websites. Our study revealed mostly correct but partially incomplete information on BCa websites for patients. Physicians and public organizations should strive to keep their website information up-to-date and unbiased to optimize patients' health literacy.

Keywords Internet information · Guidelines · Patient information · Bladder cancer · New media · Websites · Patient education · Health literacy

J.S. and P.P. contributed equally to this study.

Keypoints
1. Online health information on bladder cancer is mostly mentioned correctly, and selected websites can serve as an appropriate source of patient information.
2. Improvement of readability and completeness of the given information is needed.
3. Physicians and public organizations should strive to keep their website information up-to-date and unbiased.

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Abbreviations

BCa   Bladder cancer
EAU   European Association of Urology
IQR   Interquartile rage

Introduction

The Internet is gaining increasing importance in medicine as 70% of US Internet users search for health information online [1]. Thus, the Internet can potentially serve as a source for suitable medical information for a large population [2]. Since insufficient health literacy is widespread and associated with poor patient outcomes, improved access and understanding of medical information on the web is required [2, 3].

Thematically, "cancer" is the most searched health condition on Google [4]. Recently, websites providing information on prostate cancer and testicular cancer have been analyzed and showed a promising quality of online health information

[5, 6]. On the contrary, a study presented at the European Association of Urology (EAU) Congress 2016 stated that the majority of websites providing information on prostate cancer are not adhering to the EAU Guidelines [7]. In this context, accuracy and reliability of online health information is particularly important, since patients may falsely trust online information [8].

Little is known about the quality or accuracy of online information concerning bladder cancer (BCa), the fourth most common cancer in men [9]. An early evaluation of websites about BCa was published in 2003 and revealed mostly incomplete websites; in 32%, inaccurate information on BCa was published [10]. Considering the fast-paced development of the web in the recent years, this study might be outdated. Thus, updated information on the completeness and accuracy of websites for the potentially large group of patients seeking information about BCa is required.

In our study, we performed a qualitative analysis of websites and their concordance to EAU guidelines on BCa [11, 12]. We hypothesized that the quality of online information on BCa has improved over the past 13 years.

Methods

Search Strategy

On 18 May 2016, we performed an Internet search on "bladder cancer" in the USA using the search engine Google Search (www.google.com) by Google Inc., which in January 2016 had a global market share of 88% [13]. In a previous study, we had shown that Google has 90% coverage in different regions, suggesting the transferability of search results between countries [5]. Consequently, our search strategy covered the majority of the worldwide search queries for BCa. The search was done on a new installed Firefox browser version 46.0.1 with the English language setting in private mode. We encompassed the first 100 search queries for "bladder cancer" in our study. Duplicated websites, PDF files, videos, company websites, personal experience, news, inaccessible websites, websites solely addressed to physicians, and other websites not intended for patient information were excluded. Websites were categorized as physician-provided and publically provided.

Quality, Popularity, and Readability

To assess a website's quality standards, we installed the Health On the Net Foundation Firefox plug-in before the search [14]. The Health On the Net Foundation is a Swiss-based non-profit organization providing a website quality certification (HONcode). Websites can apply for certification and must adhere to eight ethical principles:

authorship, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, and advertising policy. To estimate the website's popularity, we used the Alexa web analytics tool (www.alexa.com), based on 3 months of aggregated traffic data from 30 million Alexa Toolbar users. A low Alexa popularity rank, calculated as a combination of visitors and page views, expresses high popularity compared to other websites [15]. The Flesch-Kincaid Grade Level and the Automated Readability Index on www.readability-score.com were used to calculate the level of education needed to read text easily based on the US education system. The Flesch-Kincaid Reading Ease score grades the readability of a text ranging from very confusing (0–29), difficult (30–49), fairly difficult (50–59), standard (60–69), fairly easy (70–79), and easy (80–89) to very easy (90–100).

Guideline Concordance

To assess the content, accuracy, and completeness of each website, our working group consented on a 36-point checklist rating scale for patient information on BCa according to the EAU guidelines on muscle-invasive and non-muscle-invasive BCa [11, 12]. Two urologists (PP and AC) each rated all websites on the topics epidemiology, etiology and pathology, staging, diagnosis, disease management, recurrence, and prognosis and follow-up, including subcategories. Content was determined as "mentioned" if any aspect of the checklist item was addressed. Guideline concordance was compared to the EAU guidelines after studying the guideline content and the webpage very carefully. The content was stated as "incorrect" if the information was divergent to the EAU guidelines and/or the information was obviously biased. We defined the content as "incomplete" if the content addressed less than 70% of the EAU guideline content. In the case of rating mismatches, JS, AC, and PP found consent in a group decision. For the mentioned, incorrect, and incomplete content for each website, a maximum of seven points could be achieved, respectively.

Statistics

Statistical assessment was performed using Statistical Package for the Social Sciences 23.0 software (SPSS Inc., Chicago, IL, USA). Values were expressed as median plus interquartile range (IQR) as appropriate. The inter-rater reliability was calculated using the intraclass correlation coefficient. The analysis of data distribution was assessed by the Kolmogorov-Smirnov test. Continuous variables were compared using the Mann-Whitney U test. Pearson's chi-square test was used to compare categorical variables. A P value < 0.05 was considered statistically significant.

Results

Search Results

Our analysis of 100 websites in Google Search revealed 49 unique and patient-addressed websites on BCa. Supplementary Table 1 lists all included websites with provider name, website address, HONcode certification, content topic, Alexa popularity rank, and readability scores. Figure 1 shows the flowchart of selection criteria and content analysis. Excluded websites frequently contained news articles on new developments in BCa treatment or were exclusively addressed to physicians.

Quality, Popularity, and Readability

Of all 49 websites, 13 (27%) were HONcode certified. According to the Flesch-Kincaid Reading Ease, the websites were difficult to read (median 40.2, IQR 34.8–49.4) and about 11 years of US school education were needed according to the Flesch-Kincaid Grade Level (median 11.3, IQR 9.2–12.9) and the Automated Readability Index (median 11.0, IQR 8.7–12.5). The median Alexa popularity rank 41,698 ranking from 7 to 4,671,246 showed an average popularity.

Guideline Concordance

Before the group consensus, the intraclass correlation coefficient ranged within the seven EAU guidelines topics from 0.93 to 1 for the rating of mentioned, from 0.72 to 0.89 for the rating of incorrect, and from 0.62 to 0.84 for the rating of incomplete. A group consensus was found for all divergent
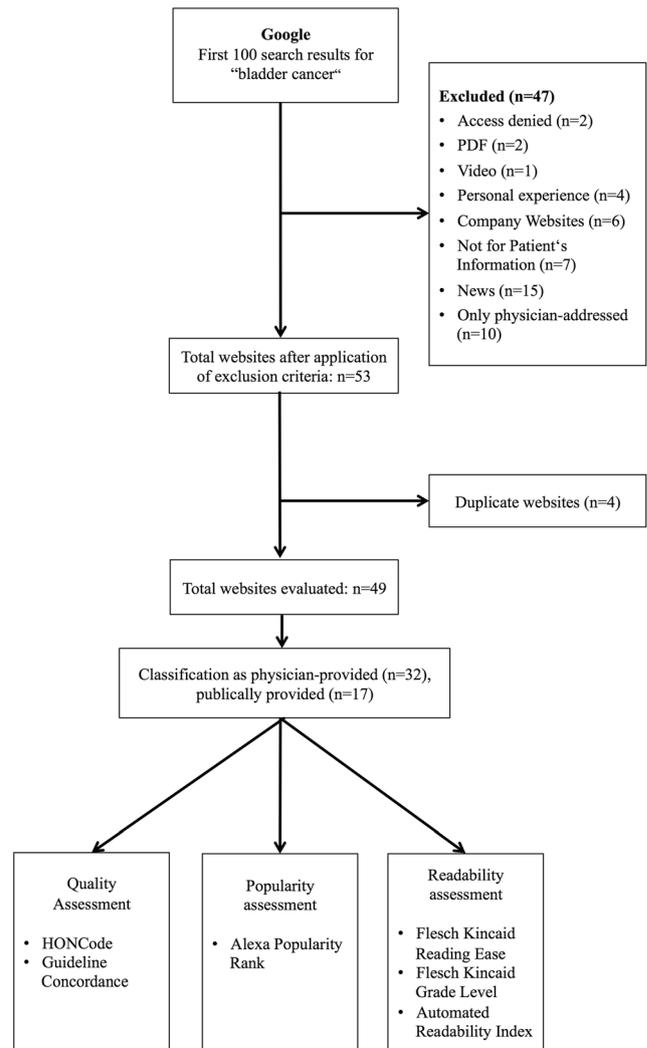

Fig. 1 Flowchart of selection criteria and content analysis

Table 1 Comparison between physician-provided and publically provided websites

Criterion	All Websites ($n = 49$)	Physician-provided Websites ($n = 32$)	Publically provided Websites ($n = 17$)	p value
Guideline concordance rating (max. 7) (median; IQR)				
Content topic mentioned	79%	73%	90%	0.022*
Content topic incorrect	10%	14%	5%	0.039*
Content topic incomplete	34%	37%	30%	0.239
Popularity (median; IQR)				
Alexa popularity rank	41,698; 6154–198,553	69,956; 161,94–297,213	6818; 1711–52,974	0.005*
Readability (median; IQR)				
Flesch-Kincaid Reading Ease	40.2 (34.8–49.4)	37.8 (33.8–41.7)	48.3 (39.9–56.9)	0.011*
Flesch-Kincaid Grade Level	11.3 (9.2–12.9)	12.2 (10.4–13.0)	10.6 (8.9–11.9)	0.012*
Automated Readability Index	11.0 (8.7–12.5)	12.2 (9.0–12.9)	9.8 (8.3–11.1)	0.018*
Quality (no. of websites, %)				
HONcode	13 (27%)	4 (13%)	9 (53%)	0.002*

Comparison of qualitative characteristics between 32 physician-provided and 17 publically provided websites on bladder cancer

*$p < 0.05$

items. A median (IQR) of 6 (5–7) guideline topics on BCa were mentioned by the websites (Table 1). Disease management was mentioned on all websites. Epidemiology (78%), etiology and pathology (86%), staging (78%), and diagnosis (90%) were mentioned on most websites (Table 2). Recurrence and prognosis (69%) as well as follow-up (53%) were mentioned less often (Table 2).

Disease-specific statements were correct on most websites (88–100%), except for the staging (63%). In contrast to the recommendations of the EAU guidelines, 37% of the websites used the Union Internationale Contre le Cancer (UICC) classification system instead of the TNM classification system. The content itself was not wrong but was not adhering to the EAU guidelines. Biased information was

Table 2 Overview on 36 points website rating

36 points website checklist	Percentage of websites on which the content was...		
	Mentioned	Incorrect	Incomplete
Epidemiology	78%	0%	11%
Etiology and pathology	86%	5%	15%
Staging	78%	37%	14%
TNM	45%		
Grading	37%		
UICC	47%		
Diagnosis	90%	9%	15%
Symptoms	86%		
Imaging	86%		
Cytology	84%		
Cystoscopy	90%		
Narrow band imaging	6%		
Photodynamic diagnostics	18%		
Disease management	100%	12%	29%
TURBT	94%		
Instillation	90%		
Radical cystectomy	96%		
Palliative cystectomy	33%		
Complications	40%		
Urinary diversion	88%		
Incontinent Stoma	80%		
Continent Stoma	51%		
Neobladder	63%		
Chemotherapy	94%		
Neoadjuvant	65%		
Adjuvant	67%		
Palliative	53%		
Radiotherapy	94%		
Radiochemotherapy	69%		
Palliative radiotherapy	47%		
Recurrence and prognosis	69%	6%	54%
Recurrence	65%		
Prognosis	57%		
Follow-up	53%	4%	52%
Follow-up cytology	33%		
Clinical trials	67%		

The content was scored as mentioned, if any information on the item point was given. The topic was incorrect if there was a statement not supported by the EAU guidelines. The topic was incomplete if less than 70% of the guideline content was addressed

given in favor of the benefits of new technology. Robotic-assisted cystectomy was claimed to be the state-of-the-art technique regarding radical cystectomy, resulting in 12% of disease management recommendations not adhering to the guidelines. Similarly, blue light cystoscopy and narrow band imaging were reported to be exceedingly positive, resulting in 9% of diagnosis recommendations not adhering to guidelines. The incorrect information given on recurrence and prognosis (6%), etiology and pathology (5%), as well as follow-up (4%), was due to wrong numbers or old data. HONcode-certified websites showed more correct information when compared to non-HONcode-certified websites ($p = 0.028$).

Information on epidemiology (89%), etiology and pathology (85%), staging (86%), and diagnosis (85%) addressed on most websites more than 70% of the EAU guideline content. Overall, 71% of the analyzed websites gave complete information on disease management. Information given on recurrence and prognosis as well as follow-up were complete on less than half of the websites (46–48%). There was no difference concerning the completeness of information between HONcode- and none-HONcode-certified websites ($p = 0.12$).

Overall, out of 343 topics (seven EAU guideline topics each on 49 websites), 270 (79%) were mentioned on the websites. Of these, 28 (10%) contained incorrect information, mostly outdated or biased, and (93) 34% contained incomplete information.

Comparison of Website Providers

Table 1 summarizes a comparison between physician-provided and publically provided websites. Publically provided websites mentioned more topics of the EAU guideline (median (IQR) = 5.5 (3.3–7) vs. 7 (5.5–7); $p = 0.022$) with less incorrect content (median (IQR) = 1 (0–1) vs. 0 (0–1); $p = 0.039$) compared to physician-provided websites. There was no difference concerning the completeness of information between publically provided and physician-provided websites (median (IQR) = 1 (1–2) vs. 1 (0–2); $p = 0.239$). Publically provided websites were more often HONcode certified (53% vs. 13%, $p = 0.002$) and easier to read. The median popularity according to Alexa popularity rank was higher (median (IQR) = 69,956 (16,194–297,213) vs. 6818 (1711–52,974); $p = 0.005$) on publically provided websites. Table 3 shows the 10 websites with the highest quality measured by the content scores and Google Search rank.

Discussion

Internet usage has continuously increased, with 78% of US adults going online in 2012. Overall, 70% of these Internet users employ it as their first diagnostic tool when facing a health issue [16]. Thus, physicians need to provide reliable

websites. In 2003, an analysis on websites regarding BCa showed incomplete and partially inaccurate information (32%) [10]. Our current analysis on 49 patient-addressed websites on BCa revealed mostly correct websites according to EAU guidelines besides the topic staging. The completeness of information varied from nearly complete to 54% incomplete between the different guideline topics. Overall, the websites' readability for patients was difficult.

Our recent assessment of BCa websites follows an assessment from 2003, which suggests a comparison of these two studies' methodologies and findings [10]. The advance of our study is the standardized comparisons on the basis of the EAU guidelines and a quantitative assessment. Due to an altered checklist between the two studies, the parameters could only be partially compared. In detail, 12 checklist points were completely comparable; nine of these 12 items had a higher score in 2016, and 3 items had slightly lower scores compared to the study of 2003. In our study, the important topic "staging" was more often mentioned (78 vs. 53%) as well as "cytology" (84 vs. 68%) and "recurrence" (65 vs. 47%). Incorrect information was mainly due to old data and classification system in 2003 as well as in 2016. The challenge seems to be keeping websites up-to-date. A new trend was promoting a new technology as too expedient. Robotic-assisted radical cystectomy has not yet shown to be superior to classical open radical cystectomy [17]. Similarly, blue light cystoscopy only shows a reduction in the recurrence rate; advances in progression or survival rates remain to be demonstrated [12]. Also, the reduction in recurrence rate for narrow band imaging is not yet fully confirmed [12]. Consequently, physicians should avoid using new technology as marketing instruments. Using the most innovative technologies, a challenging uncertainty remains concerning improved patient care, leading to a need for the preservation of both treatment economy and ethics [18]. Summarized, there is a clear improvement in correctness (32 vs. 10% incorrect information) in the last 13 years.

Nevertheless, improvements in the quality of information on BCa are encouraging. The best websites summarized in Table 3 mentioned all guideline topics and stated no incorrect information. In comparison, online information on prostate cancer showed a lower quality, as classification system, staging, grading, prognosis, and follow-up were not mentioned in over 50% of the websites [19]. Only 35% of the websites on prostate cancer were concordant with the EAU guidelines regarding the diagnostic assessment [19].

In particular, the readability is too difficult for laypersons. Our readability analysis showed that 11 years of US school education is needed to understand the given information. The US Department of Health and Human Services states that information is "easy to read" if written below a 6th-grade level and "average difficulty" if written between the 7th and 9th grade levels [20, 21]. Also, the Flesch-Kincaid Reading Ease

Table 3 Top 10 websites on bladder cancer according to content, concordance, and completeness in conformity with EAU guidelines

Website	Content mentioned (max. 7)	Content incorrect (max. 7)	Content incomplete (max. 7)	Google search rank	Readability level*
American Cancer Society http://www.cancer.org/cancer/bladdercancer/	7	0	0	1	Standard
eMedicineHealth http://www.emedicinehealth.com/bladder_cancer/article_em.htm	7	0	0	6	Difficult
MedicineNet http://www.medicinenet.com/bladder_cancer/article.htm	7	0	0	8	Difficult
OnkoLink http://www.oncolink.org/types/article.cfm?c=588&id=9464	7	0	0	25	Difficult
Urology Care Foundation http://www.urologyhealth.org/urologic-conditions/bladder-cancer	7	0	1	5	Standard
American Society of Clinical Oncology http://www.cancer.net/cancer-types/bladder-cancer	7	0	1	10	Difficult
Cancer Research UK http://www.cancer.net/cancer-types/bladder-cancer	7	0	1	16	Standard
Remedy Health Media http://www.healthcommunities.com/bladder-cancer/overview-of-bladder-cancer.shtml	7	0	1	43	Difficult
NHS Choices http://www.nhs.uk/conditions/Cancer-of-the-bladder/Pages/Introduction.aspx	7	0	1	49	Difficult
Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Bladder/Bladdercancer.aspx	7	0	1	50	Fairly difficult

[a] Readability level according to the Flesch-Kincaid Reading Ease score

classified the website information as difficult. Our results are in line with other studies in the field of urology, which classified written information on websites as being too difficult [5, 6, 20]. This might impede well-informed patients resulting in suboptimal patient outcome [3]. However, online patient information can be significantly amended by simple assessment and language editing, as shown for patient information material provided by the Canadian Urological Association [22].

The responsibility and the website quality itself belong to the website providers, which were classified into physician and public providers. Publically provided websites mentioned more guideline topics ($p = 0.022$) and showed less incorrect ($p = 0.039$) information according to EAU guidelines. Also, publically provided websites were more popular according to the Alexa popularity rank ($p = 0.005$) and were more often HONcode certified ($p = 0.002$). One explanation might be the primary intention of the website provider and the available resources. Online health information providers like WebMD (http://webmd.com), which contain two of the best-rated websites, as shown in Table 3 (eMedicineHealth and MedicineNet), primarily provide commercial online health information, but their reputation seems to be disputable [23, 24]. In contrast, hospitals casually provide online patient information as their manpower as well as financial resources may be restricted. Moreover, economic pressure may inveigle to present new acquired technology in a biased way [25]. There are

also highly rated websites from non-profit organizations like the American Cancer Society (publically provided); the American Society of Clinical Oncology; and the Urological Care Foundation, a foundation from the American Urological Association, which are naturally trustworthy.

Our study does have some limitations. Although there are some standardized instruments like HONcode, Alexa popularity rank, and readability tools to evaluate a websites quality, the main challenge of assessing the website content remains. There is always the need for an intellectual assessment, to evaluate the value of the medical content, and so a website's rating will be slightly different from rater to rater. We evaluated the content according to the EAU guideline topics, but the question remains how comprehensive a website for patients has to be. A future website assessment could involve patients to encompass their needs. Website certificates like HONcode help with orientation but have to be actively requested by the website managers and do not assess the content itself. Additionally, our findings may be limited due to other websites found in other countries and at other points in time.

Conclusion

Our study revealed mostly correct but partially incomplete information on BCa websites for patients. Physicians and

public organizations should strive to keep their website information up-to-date and unbiased to optimize patients' health literacy.

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