

Side effects of radiotherapy in breast cancer patients

The Internet as an information source

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Abstract

Aim Breast cancer is the most common cancer type among women necessitating adjuvant radiotherapy. As the Internet has become a major source of information for cancer patients, this study aimed to evaluate the quality of websites giving information on side effects of radiotherapy for breast cancer patients.

Methods A patients' search for the English terms "breast cancer – radiotherapy – side effects" and the corresponding German terms "Brustkrebs – Strahlentherapie – Nebenwirkungen" was carried out twice (5 months apart) using the search engine Google. The first 30 search results each were evaluated using the validated 16-question DISCERN Plus instrument, the Health on the Net Code of Conduct (HONcode) certification and the Journal of the American Medical Association (JAMA) benchmark criteria. The overall quality (DISCERN score) of the retrieved websites was further compared to queries via Bing and Yahoo search engines.

Results The DISCERN score showed a great range, with the majority of websites ranking fair to poor. Significantly superior results were found for English websites, particularly for webpages run by hospitals/universities and non-governmental organizations (NGO), when compared to the respective German categories. In general, only a minority of websites met all JAMA benchmarks and was HONcode certified (both languages). We did not determine a relevant temporal change in website ranking among the top ten search hits, while significant variation occurred thereafter. Mean overall DISCERN score was similar between the various search engines.

Conclusion The Internet can give breast cancer patients seeking information on side effects of radiotherapy an overview. However, based on the currently low overall quality of websites and the lack of transparency for the average layperson, we emphasize the value of personal contact with the treating radio-oncologist in order to integrate and interpret the information found online.

Keywords Side effects · Radiotherapy · Breast cancer · Internet · Search engines

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Nebenwirkungen der Strahlentherapie bei Brustkrebspatienten

Das Internet als Informationsquelle

Zusammenfassung

Hintergrund Brustkrebs ist der häufigste Tumor bei Frauen, der eine adjuvante Strahlentherapie notwendig macht. Da das Internet eine wesentliche Informationsquelle für Krebspatienten geworden ist, hat diese Untersuchung das Ziel, die Qualität der Webseiten mit Informationen zu Nebenwirkungen einer Strahlentherapie bei Brustkrebs zu evaluieren.

Methoden Mit Hilfe der Suchmaschine Google wurde eine patientenorientierte Suche englisch- und deutschsprachiger Webseiten mit den Suchbegriffen „Brustkrebs-Strahlentherapie – Nebenwirkungen“ und „Breast cancer – radiotherapy – side effects“ an zwei verschiedenen Zeitpunkten durchgeführt. Die ersten 30 Treffer wurden anhand des validierten 16-Fragen DISCERN-Plus-Scores, der HON-Code-Zertifizierung („Health on the Net Code of Conduct“) und den JAMA-Kriterien („Journal of the American Medical Association“) untersucht. Die Gesamtqualität der untersuchten Seiten (DISCERN-Score) wurde im Weiteren mit einer separaten Analyse der Suchmaschinen Bing und Yahoo verglichen.

Ergebnisse Während die allgemeine Qualität der Internetseiten (DISCERN-Score) eine große Bandbreite zeigte, waren die Ergebnisse mehrheitlich von mäßiger bis schlechter Qualität. Englischsprachige Webseiten zeigten signifikant bessere Ergebnisse, insbesondere Seiten von Krankenhäusern, Universitäten sowie Nicht-Regierungs-Organisationen. Nur eine Minderheit erfüllte alle 4 JAMA-Kriterien und war HON-Code-zertifiziert (beide Sprachen). Die Google-Suche zu unterschiedlichen Zeitpunkten zeigte unter den ersten zehn Treffern keine wesentlichen Unterschiede. Signifikante Variationen traten erst bei hinteren Treffern auf. Der Vergleich unterschiedlicher Suchmaschinen ergab ähnliche DISCERN-Score-Ergebnisse.

Schlussfolgerung Durch das Internet können sich Patienten auf der Suche nach Informationen zur Strahlentherapie einen Überblick verschaffen. Basierend auf der aktuell geringen Qualität der Internetseiten und der fehlenden Transparenz, tritt der persönliche Kontakt mit dem behandelnden Strahlentherapeuten in den Vordergrund, der zur Einordnung und Interpretation beitragen kann.

Schlüsselwörter Nebenwirkungen · Strahlentherapie · Brustkrebs · Internet · Suchmaschinen

Today the use of the Internet to search for health information is common among cancer patients. While the widespread use was still low in 2000 [1], Castleton et al. [2] reported approximately two thirds of patients with cancer using the Internet to obtain information about their disease in 2011. In the study of Nguyen et al. [3], 71% of breast cancer patients searched the Internet for breast cancer-related information. In line with that, a significant number of cancer patients seen in radiation oncology departments utilize the Internet to obtain information about their cancer type [4–6].

As breast cancer is the most frequent cancer type for women worldwide [7], there is a vast number of websites providing a plethora of information on breast cancer. For patients concerned, the greatest information need is related to the effects of their illness on their day-to-day life [8],

treatment and prognosis [3]. Relevant acute side effects can pose an imminent threat for patients undergoing planned radiotherapy. Subsequently, therapeutic side effects are also among the common search topics [9]. Thus, we set out to analyze the quality of websites in German and English language providing information on side effects of radiotherapy in breast cancer patients.

Methods

Website identification and selection

Identification, selection, and evaluation of websites took place on February 5 and 7, 2017 (9–10 p. m. CET). The following corresponding English and German keywords were entered to the search engine Google.com and Google.de, respectively: “radiotherapy, breast cancer, side effects” and “Strahlentherapie, Brustkrebs, Nebenwirkungen” to emulate real user experience. We focused on the search engine Google as it is known to be one of the most popular search engines and frequently used by cancer patients (Nguyen 2013: 100% of patients used Google as search engine [3]). A second Google search was carried out on July 9, 2017 (9–10 p. m. CET) to reveal the temporal dynamics in search results. In addition, the search was repeated with the search engines Bing and Yahoo in the same time period (Yahoo also used in [10]). The first 30 websites each (English and German) were subjected to further analysis. This selection was based on studies showing that individuals rarely browse through more sites when searching the web [11]. In the study of Nguyen et al. [3], 72% of the patients even restricted their search to 1–5 websites only. Exclusion criteria were as following: complete access restricted by password, personal experiences (e. g., blogs, videos), and limited information on radiotherapy side effects (<one paragraph) [12]. The total number of included websites (30 for each search) resulted from recruitment of lower ranks from the search result. The quality of websites was evaluated by two investigators (SJ, LK) independently using the validated tools described below. Discrepancies were discussed and a consensus was reached. We chose to evaluate German and English language websites separately because a discrepancy in quality has been described before [13].

DISCERN plus

The DISCERN instrument is a standardized validated tool originally developed in 1998 to help the general public to determine the quality of written medical information based on 15 questions [14] and has also been successfully used to analyze health information on the Internet [10, 15]. For

Table 1 DISCERN Plus instrument with 16 questions (1–5 points). Modified according to Charnock et al. [14]

DISCERN section 1 (1–5 points)	
1.	Are the aims clear?
2.	Does it achieve its aims?
3.	Is it relevant (readers' perspective)?
4.	Sources of information mentioned?
5.	Up-to-dateness of data provided?
6.	Balanced against bias?
7.	Additional sources?
8.	Refers to areas of uncertainty?
DISCERN section 2 (modified questions) (1–5 points)	
9.	Differentiation acute/chronic side effects?
10.	Point out major side effects (see below)? <i>skin, breast edema, fatigue, local pain, swallowing problems, fibrosis, teleangiectasia, hyperpigmentation, lymphedema, lung problems, heart problems, risk of radiation-induced malignancy, plexus injury, rib fracture, armpit problems/shoulder discomfort</i>
11.	Frequency distribution of side effects mentioned?
12.	Description of side effects in detail?
13.	Offer prophylactic opportunities?
14.	Offer treatment strategies?
15.	Provide contact detail?
DISCERN section 3 (1–5 points)	
16.	Overall quality (summation)

Table 2 DISCERN score results (questions 1–15, 1–5 points/question, mean \pm standard deviation) in detail for German and English sites (1st Google search)

DISCERN Plus score question number	Mean value English sites	Mean value German sites	<i>p</i> -value
1	3.4 \pm 0.89	2.7 \pm 0.7	0.001
2	2.8 \pm 1.06	2.1 \pm 0.64	0.002
3	3.6 \pm 0.96	2.9 \pm 0.88	0.008
4	2.0 \pm 1.23	2.3 \pm 1.47	0.4473
5	3.0 \pm 1.39	2 \pm 1.26	0.005
6	1.5 \pm 0.97	1.6 \pm 0.96	0.8989
7	2.4 \pm 1.14	1.9 \pm 1.16	0.04
8	3.6 \pm 1.04	2.7 \pm 0.95	0.003
9	3.2 \pm 1.57	2.2 \pm 1.41	0.011
10	2.7 \pm 1.16	2.0 \pm 1.02	0.011
11	3.1 \pm 1.07	1.8 \pm 0.66	<0.0001
12	2.6 \pm 1.25	1.4 \pm 0.5	<0.0001
13	2.3 \pm 1.01	1.5 \pm 0.57	0.002
14	2.2 \pm 1.17	1.3 \pm 0.52	<0.0001
15	3.0 \pm 1.66	3.0 \pm 1.31	0.8002

each question, a score from 1–5 (1 for definitely no, 2–4 partially true, and 5 for definitely yes) is given. The first section consists of eight questions and addresses reliability, while the second section with seven questions refers to the details of treatment. We modified the last seven questions as shown in Table 1 in order to adapt the tool to our search situation. The DISCERN Plus version added a 16th question (overall quality), giving a final score of 80. Websites were rated as “excellent” (63–80), “good” (51–62), “fair” (39–50), “poor” (27–38) and “very poor” as described by Nghiem et al. [16].

HONcode

The Health On the Net Foundation (HON) was founded in 1995 as a nongovernmental organization (NGO) in Switzerland (www.healthonnet.org). It has initiated the Code of Conduct (HONcode) which aims to enable patients and medical professionals to obtain quality, objective, and transparent medical information. The HONcode mainly includes the following aspects: the author's credentials, the date of the last modification with respect to clinical documents, confidentiality of data, source of data reference, funding, and the advertising policy [17]. Certified websites display the HONcode logo. We recorded whether each website was HONcode accredited.

JAMA benchmarks

The Journal of the American Medical Association (JAMA) benchmarks were developed in 1997. They contain recommendations regarding the provision of information on authorship, attribution, disclosure, and accuracy [18] on websites and, hence, the compliance with these benchmarks indirectly reflects the webpage quality.

Statistical analyses

Statistical analysis was performed using GraphPad Prism 7 (GraphPad Software Inc., La Jolla, CA, USA). The following tests were employed: Spearman correlation, linear regression analysis and two-tailed nonparametric Wilcoxon–Mann–Whitney test for group comparisons. A *p*-value of <0.05 was considered as significant. Results are given as mean \pm standard deviation (SD), unless otherwise stated. Graphical layout was created with Excel 2010 (Microsoft Corporation, Redmond, WA, USA) and Photoshop CS6 (Adobe Systems Inc., San Jose, CA, USA).

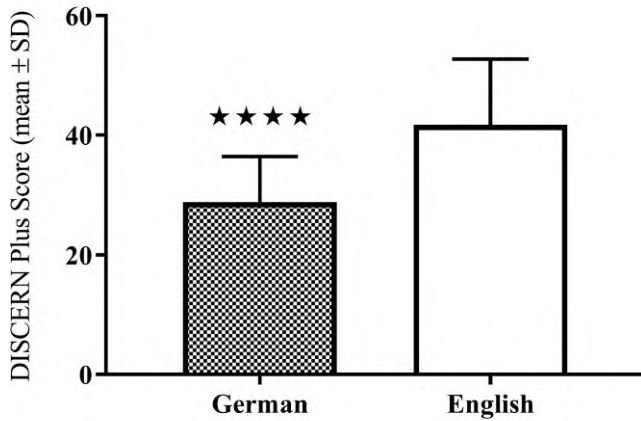


Fig. 1 Overall DISCERN Plus Score for German (*shaded*) and English (*white*) websites, $p < 0.0001$ (1st Google search)

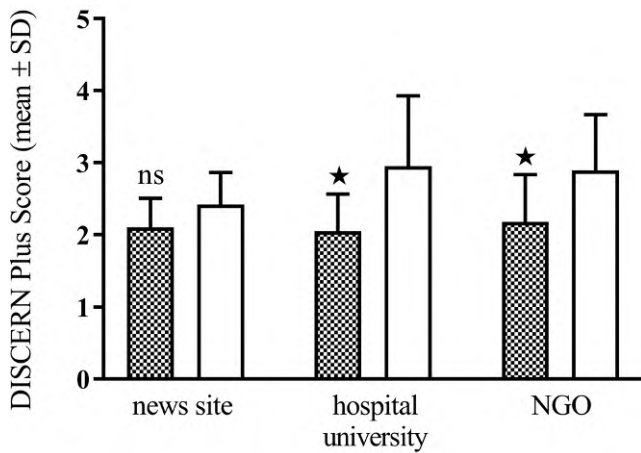


Fig. 2 DISCERN Plus results for different institutions (news site, hospital/university [$p = 0.03$] and nongovernmental organizations [NGO, $p = 0.04$]) for German (*shaded*) and English (*white*) sites (1st Google search). *SD* standard deviation

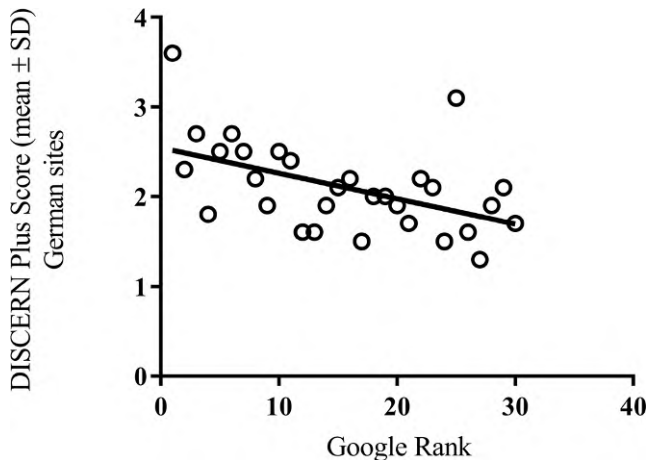


Fig. 3 Mean German DISCERN Plus score per item according to Google ranking (1–30; 1st Google search). *SD* standard deviation

Results

A total of 60 websites providing information on side effects of radiotherapy for patients with breast cancer were evaluated in German ($n = 30$) and English language ($n = 30$), respectively.

The German websites were mainly sponsored medical news sites ($n = 12$), hospital/university sites ($n = 10$), and charity/NGO originated ($n = 8$). The English sites were mainly charity/NGO originated ($n = 15$), followed by hospital/university sites ($n = 6$), medical news sites ($n = 6$), and governmental sites ($n = 3$). No governmental sites were found within the first 30 German Google ranks. Within the German search, 13 sites did not meet the inclusion criteria and had to be excluded from further analysis: <1 paragraph on side effects ($n = 3$), interview with expert ($n = 2$), forum/blog ($n = 6$), and personal field report ($n = 2$). For the English search, only three search results had to be excluded: scientific article on cardiac side effects only ($n = 2$) and newspaper article about specific radiation technique ($n = 1$).

Of the 30 English websites, 25 (83%) provided information on breast cancer exclusively, while this was the case in only 17 of 30 German websites (57%). Six out of 30 English (20%) and five out of 30 German websites (17%) were HONcode certified, respectively. There were four German and four English websites that met all four JAMA benchmark criteria. Three, two, and one JAMA criteria were met in 5 vs. 7, 11 vs. 3 and 10 vs. 16 English vs. German websites, respectively. No significant difference was seen for the frequency of HONcode certification and JAMA benchmarks criteria between German and English sites.

In the DISCERN Plus score, a maximum of 80 points can be achieved (Table 1). Table 2 shows the distribution of score points for each question for German and English websites in a side-by-side fashion. The mean overall DISCERN Plus score was significantly superior for the English websites with 41.7 ± 11.0 vs. 28.8 ± 7.6 for German sites, respectively ($p < 0.0001$, Fig. 1). English sites were rated good or fair in 15 and five cases, respectively. There was one excellent website. In contrast, no excellent or good-rated sites in German language were detected. The best-rated German sites were ranked as “fair” ($n = 5$). The majority of German sites were rated poor and very poor ($n = 17$ and 11, respectively). There were 15 poor and only one very poor-rated English site. Looking at the questions in detail, there was a significant superior DISCERN score for nearly all English sites in the two DISCERN score sections (Table 2).

Moreover, a significantly superior DISCERN score was found for English hospital/university sites and NGO sites compared to the German equivalents ($p = 0.03$ and $p = 0.04$, respectively; Fig. 2).

Fig. 4 Google search ranking for English websites at two different time points (*open circles* February 7, 2017; *black dots* July 9, 2017)

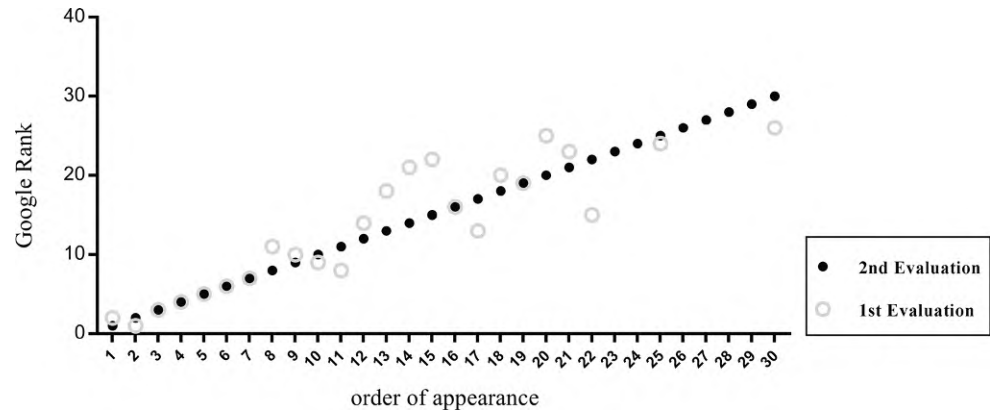
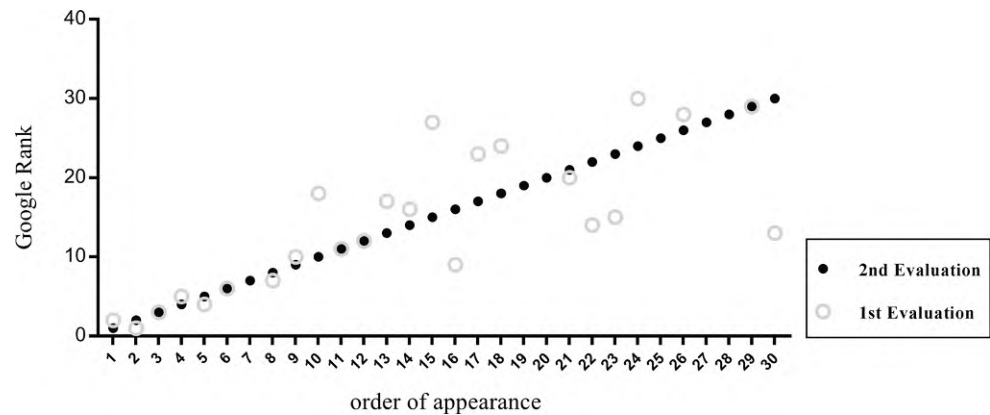


Fig. 5 Google search ranking for German websites at two different time points (*open circles* February 5, 2017; *black dots* July 9, 2017)



For German websites there was a significantly positive correlation for Google ranking and the mean DISCERN rating per item (Fig. 3). This was not seen for English websites.

In order to reveal temporal dynamics in search results, we carried out a second Google search 5 months later. There were only minor changes among the top ten search results, while websites ranks varied substantially thereafter for both English and German websites (Figs. 4 and 5, respectively). Compared to the first search there were six new sites for both languages within the first 30 search results. The overall quality (DISCERN Plus score) remained unaffected.

Additionally, the Internet search was performed using Bing and Yahoo search engines and results were compared to our latest Google analysis: Bing and Yahoo search results differed by up to 14 websites each (German: 14 websites each; English 12 and 14, respectively). There was no significant difference in total DISCERN Plus scores between search engines (both languages, Fig. 6).

Discussion

The need for additional information in cancer patients receiving radiotherapy is high [19–22]. In recent years, the

Internet has become an important source for cancer patients seeking information on their disease. Finding accurate information is difficult due to the vast number of websites [23]. As described by Littlechild et al. [24], 31% of breast cancer patients experiencing problems used the Internet to find information.

We employed validated tools to determine the quality of websites providing information on side effects of radiotherapy in breast cancer patients [15, 17, 18]. Our focus were side effects of radiotherapy, as these are of imminent importance for patients before or during their course of treatment and are known to be frequently searched topics [9].

The overall quality of websites using the DISCERN score was very heterogeneous. Despite the highly dynamic nature of the Internet, we were surprised to find that the overall quality of the top ten ranked websites remained stable over a relevant amount of time (5 month). Switching to other search engines than Google did not alter the overall quality of websites found, albeit an approximately 50% difference in search output. This finding underscores the relevance of our analysis, as patients are exposed to websites of limited quality independent of their search engine preferences.

Weissenberger et al. [13] previously found significant differences between the quality of German and English

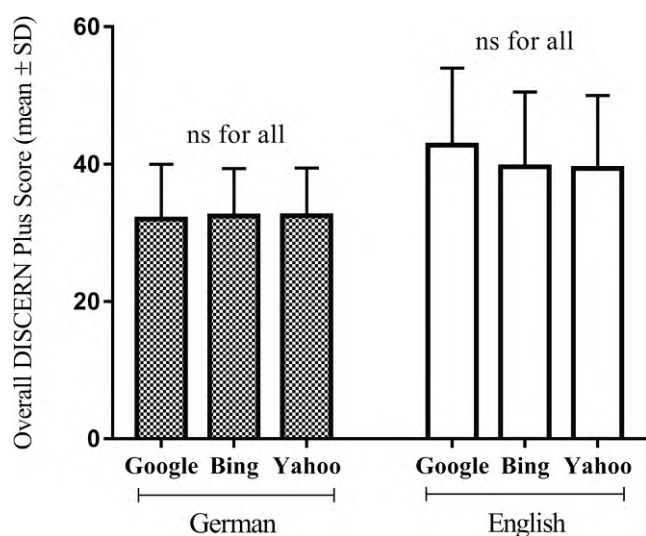


Fig. 6 DISCERN Plus score results for different search engines for German (*shaded*) and English sites (*white*). *SD* standard deviation, *ns* not significant

breast cancer-related websites, based on the emphasis of English webpages on curative treatment options and side effects. In line with the latter, we found that English websites had a significantly higher DISCERN Plus score overall, indicative of a superior quality. Irrespective of the worse overall quality regarding the DISCERN score, one can imagine that it is hard for laypersons to find sufficient information on side effects of radiotherapy when the vast majority (93%) of websites are rated poor or very poor, as seen for German websites.

In contrast to Quinn et al. [23], we did not observe a correlation between site operator and quality. This study group showed that interest group-run sites were significantly less accurate than other sites. There were almost twice as many sponsored medical news sites in German language compared to English sites. Sponsoring might deteriorate quality. Regarding the NGO or hospital/university operated sites, we found a significantly better DISCERN score for English compared to German sites. In addition, significantly more English sites focused on side effects of radiotherapy in breast cancer exclusively (83% vs. 57%). In our opinion, the focus on breast cancer side effects might be of more help for breast cancer patients compared with information on side effects of radiotherapy in general, as side effects of radiotherapy can differ tremendously depending on localization of irradiation. Moreover, there were 13 German websites to be excluded from further evaluation because they did not meet the inclusion criteria. We believe that interviews, blogs, and personal field reports or less than one paragraph on the search topic might not accomplish the standard for a sufficient website giving well-balanced information for breast cancer patients. In contrast there were only three websites to be excluded from the English search,

which might indicate higher availability of reliable information for English-speaking patients.

The overall rate of HONcode certified sites was low for our search topic (18% overall). In line with Quinn et al. [19], we were not able to show any association between increasing quality regarding the DISCERN score and HONcode certification. This precludes an exclusive and very simple assessment for patients searching the web.

The algorithm used by Google to rank websites may not reflect those sites useful for patient information and the popularity of websites according to Google rank may be associated with type rather than quality [3, 25]. In our analysis we found no correlation of Google rank and question-based quality for English websites, but for German websites. In theory this could be a momentary advantage for patients searching the web, as it is known that the search ends after the first few hits [11]. However, this has to be interpreted with caution, as the ranking within a search engine can change over time (see above).

As neither website categories, the HONcode certification, JAMA benchmark criteria nor the Google rank (at least for English sites) showed a correlation with quality using the DISCERN Plus score, it remains challenging to recommend a strategy for breast cancer patients seeking for continuative information on the Internet. Our results do not generally argue against the use of the Internet by patients to gain information on possible side effects of radiotherapy in breast cancer, as we did not find any false or misleading information. In fact, the occurrence of potential side effects was reported by the majority of the analyzed websites, thereby, contributing to the awareness of the relevance of the condition.

Our aim was to inform the treating physician that quality and comprehensiveness of online information is currently very heterogeneous and subject to constant change. Hence, recommendation of a single website to patients seems futile. Furthermore, use of the HONcode tool did not help to identify websites of better quality (DISCERN PLUS Score), as only 20–30% of the top 30 and top 10 websites, respectively, were accredited. Thus, it remains the responsibility of the treating radio-oncologist to discuss possible questions raised by the information gained through the Internet with the patients. It is hoped that the increasing use of the Internet in health care will offer new opportunities for patient information in the future, calling upon the radio-oncological society.

Conclusion

The Internet offers a vast quantity of information on breast cancer and, thus, provides an overview for patients seeking information on side effects of radiotherapy. However,

overall quality of related websites is low and lacks the transparency required for sufficient guidance of the average layperson. In addition, a simple classification or recommendation was not feasible for German or for English websites. This emphasizes the value of personal contact to the treating radio-oncologist in order to integrate and interpret the information obtained online.

Conflict of interest S. Janssen, L. Käsmann, F.B. Fahlbusch, D. Rades and D. Vordermark declare that they have no competing interests.

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