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Evaluation of the Quality of Online Information for Patients with Rare Cancers: Thyroid Cancer

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Abstract The Internet offers an easy and quick access to a vast amount of patient information. However, several studies point to the poor quality of many websites and the resulting hazards of false information. The aim of this study was to assess quality of information on thyroid cancer. A patients' search for information about thyroid cancer on German websites was simulated using the search engine Google and the patient portal "Patienten-Information.de". The websites were assessed using a standardized instrument with formal and content aspects from the German Cancer Society. Supporting the results of prior studies that analysed patient information on the Internet, the data showed that the quality of patient information on thyroid cancer is highly heterogeneous depending on the website providers. The majority of website providers are represented by media and health providers other than health insurances, practices and professionals offering patient information of relatively poor quality. Moreover, most websites offer patient information of low-quality content. Only a few trustworthy, high-quality websites exist. Especially Google, a common search engine, focuses more on the dissemination of information than on quality aspects. In order to improve the patient information from the Internet, the visibility of high-quality websites must be improved. For that, education programs to improve patients' eHealth literacy are needed. A quick and easy evaluation tool for online information suited for patients should be implemented, and patients should be taught to integrate such a tool into their research process.

Keywords Thyroid cancer · Patient information · Internet · Evaluation tools · Quality

Abbreviations

afgis	Action Forum on Health Information Systems
ÄZQ	Agency for Quality in Medicine
DNEbM	German Network for Evidence-Based Medicine
GCS	German Cancer Society
HONcode	Health on the Net Code of Conduct

Introduction

Cancer patients have a high need for information [1]. In recent years, it has been shown that patients have a steadily growing demand to take up an active part in the decision-making process [2, 3]. Patient information is an important basis to participate in the communication and decision-making process [4–6]. Patient information is provided by diverse sources besides the physician. This information should not replace medical advice, but instead inform, strengthen knowledge and help patients to make personally-substantiated decisions [6–8].

The Internet is increasingly involved as an advisor to patient's medical issues. It provides the patient with access to versatile, even though partly difficult to understand, information and answers questions independently of doctors [1,

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9–11]. One problem is that patients often do not have the necessary expertise to identify the relevant and reliable information from the less relevant and trustworthy. In fact, many of the websites that offer patient information have qualitative deficiencies [12].

There is a broad spectrum of assessment tools to evaluate patient information. These range from quality labels such as afgis (Action Forum on Health Information Systems) [13] and HONcode (health on the Net Code of Conduct) [14], simple behaviour of code like eHealth code of Ethics, filter systems such as the patient information portal "Patienten-Information.de" to user instructions like DISCERN [15] and the evaluation system of the German Cancer Society (GCS) [16]. The assessment tools include different criteria that define high-quality information for patients as have been published before. These include formal aspects such as transparency and language style and aspects of content like intelligibility, completeness, presentation and the timeliness of the presented information.

For patients with cancer with a high incidence, there is a vast amount of information available from many sources. Yet, less is known on information provided for patients with rare cancers. The aim of the present study is to analyse the information that patients find on the Internet about thyroid cancer. As especially information on complementary and alternative medicine is often searched for in the Internet as in most cancer centres, no structured high-quality information is provided on this topic [17]. We decided to set a second focus on information concerning alternative medicine addressing patients with thyroid cancer.

Methods

In this study, a patient's search was simulated, and websites with patient information related to the theme thyroid cancer were evaluated. For the Internet search, the Google search engine and the patient portal "Patienten-Information.de" were used. "Thyroid cancer" and "Thyroid cancer alternative treatment" were used as search terms. The research was carried out in June 2015. Website links listed in the results that met the following criteria were not included in the evaluation: non-intact links, links to forums, videos or further help/addresses/literatures, as well as references to dictionaries, information on cancer in general or other thyroid diseases. Website links to identical websites were combined.

The GCS instrument served as a basis of evaluation and took formal and content-related aspects into account (Table 1). This instrument was compiled from the criteria for patient information from different instruments and recommendations as the DNEbM (German Network for Evidence-Based Medicine eV) [3], the ÄZQ (Medical Center for Quality in Medicine) [18], afgis [13], the HONcode [14] and DISCERN [15]. We extracted the decisive elements that are relevant for online information from each publication and developed merged criteria. From these, we built up an instrument considering content and formal aspects. The instrument consists of 18 content criteria and six formal criteria. For each criterion, a maximum of 3 points could be awarded, with 1 representing full, 2 representing partial and 3 representing insufficient compliance with the given criteria. Accordingly, the best score would be 24 points and the worst 72. The lower the total score is, the higher is the quality of the website [16]. Finally, we decided to classify the websites according to their total score within five classes from very good to very bad, equally distributed on the range of total points (Table 2).

In addition, the websites are categorized in subsequent groups depending on the provider—professional societies, actors in healthcare, insurance, media, medical practices and other providers (e.g. Wikipedia, Netdoctor and other websites focusing on medical information from providers besides the aforementioned).

The sites were evaluated by four independent evaluators (one patient, two other lay persons (UK, TM) and one physician (SS)). For a better comparison, the mean value of the content, formal and total results of the individual websites as well as the respective categories and search terms were calculated. As the evaluators had to assess the original website, no blinding was possible. The achieved scores were allocated to quality categories, shown in Table 2, were assessed proportionally to the maximum score (very good, good, medium, poor, very poor).

Results

The search on the platform "Patienten-Information.de" resulted in 25 results for the query "Thyroid cancer", no website link for the term "Thyroid cancer alternative treatment" was found. Due to the high number of results in the Google search engine for both search terms, only the first 30 links were included in the evaluations (Figures 1 and 2).

After filtering the relevant sites, total 41 sites were evaluated. Twenty-three results for the search term "Thyroid cancer" were included in the analysis, of which three website links were from the patient portal "Patienten-information.de" and 20 were from the Google search engine. Since the term "Thyroid cancer" was automatically classified as "head and neck cancer" in the filter system of the patient portal "Patienten-information.de", a large proportion of website links was not related to thyroid cancer and was therefore not included in the assessment. Eighteen website results for the word "Thyroid cancer alternative treatment" were included in the review, of which all originated from the search with the Google search engine.

Table 1 Criteria for the evaluation on websites [16]

Criteria to evaluate quality of information	Formal criteria
Completeness	Transparency concerning provider, supporter, funding, advertisement, etc.
Expertise	Privacy protection
Explication of objectives and target audience	Completeness of information on sources of evidence
Achievement of these objectives	Observance of scientific knowledge on the presentation of numbers and outcomes
Fair balance/neutrality	Language adapted to the needs of the target group
Rigour	Possibility of feedback and participation for users
Relevance	
Intelligibility for lay persons (suitable graphics)	
Suitability to support shared decision-making	
No statements on topics without evidence	
Scientific evidence and timeliness	
Information on additional resources and references (benefits and risks, impact on quality of life, consequences on non-treatment)	
Focus on the patient	
Lay out aspects	
Quality management	
Clear arrangement of information	
Labelling of missing evidence and risks	

The categories of the website providers included in the evaluation are listed in Table 3. We found only one website in the category of professional associations. In contrast, 20 links fell within the category of "other providers".

As shown in Table 3, all in all patient information from both of the two search terms obtained a high rating in all criteria (formal, content and total quality), whereby the search for "Thyroid cancer alternative treatments" was rated slightly worse. The patient information from the cancer society was rated as very high quality and received the best rating. Also, the patient information of the health insurance companies and medical practices all in all was of high quality. However, especially the contents from the categories media and other providers were only of average quality. Patient information from the "other providers" category overall showed the worst result.

In Tables 4 and 5, the websites for the respective search terms are listed according to their achieved score as well as their rank in the result list of the corresponding Internet search. The best results, according to the scores in both search groups, were achieved by the patient information of the Foundation of the German Cancer Aid, the GCS and the patient information

Table 2 Quality categories divided by scores

Categories	Total score	Content criteria	Formal criteria
Very good	24 to ≤33.6	18 to ≤25.2	6 to <8.4
Good	>33.6 to ≤43.2	>25.2 to ≤32.4	> 8.4 to ≤10.8
Medium	>43.2 to ≤52.8	>32.4 to ≤39.6	>10.8 to ≤13.2
Poor	>52.8 to ≤62.4	>39.6 to ≤46.8	>13.2 to ≤15.6
Very poor	>62.4 to ≤72	>46.8 to ≤54	>15.6 to ≤18

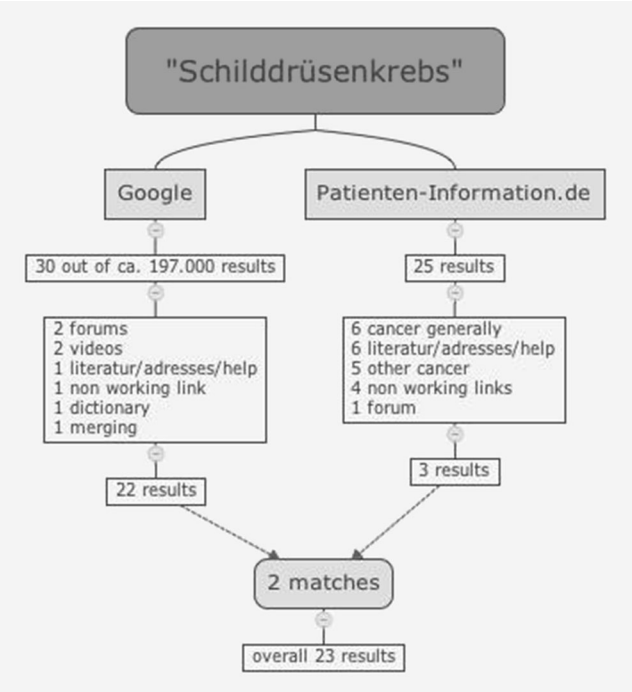

Fig. 1 Selection of the results on "Thyroid cancer"

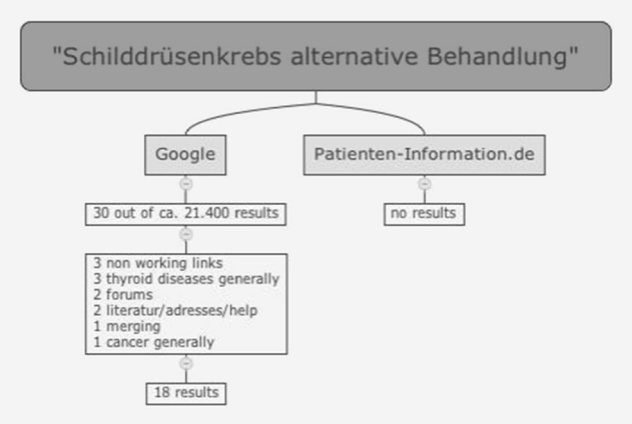

Fig. 2 Selection of the results for the word "Thyroid cancer alternative treatment"

of gofeminin.de GmbH (Onmeda). The worst result was achieved by a provider belonging to the category "other providers". In the search for "Thyroid cancer", three sites were included in the analysis from the platform "Patienten-Information.de" and all were rated as being of very good quality. The results through Google search on the other hand showed a wide range of different websites with patient information, both of good and bad quality. The first ten websites of the result pages of Google do not reflect the ten best sites concerning quality of information.

Discussion

The quality of websites with patient information on thyroid cancer varies from high to poor quality. Especially the most often used search engine Google does not support the patient to identify the high-quality patient information because the ranking in the results list does not correspond to the independent quality ranking [16]. In contrast to the search engine Google, the filter system "Patient-Information.de" contains quality-approved patient information, which was assessed as being of very good quality in this study. Nevertheless, the filter system's information service is very limited. Only 7% (3/41) of the included site links are from the patient portal. The search for more specific questions, for example, the search term "Thyroid cancer alternative treatments", delivered no results.

There are several limitations for our study. First of all, it was restricted to the first 30 hits in one search engine and one landing page. Yet, the visibility of other sites is much lower so that all relevant sites should have been included. Second, our search was simulated by a simple combination of search terms which may be misleading in case patients use other terms or combinations or navigate form of one site to another. We asked four raters (two professionals and one lay person and one patient) to rate the websites. Accordingly, the validity of the ratings may be limited particularly through this small number of reviewers. On the other hand, the four different ratings

Table 3 Quality evaluation of the websites on "Thyroid cancer" and "Thyroid cancer alternative medicine"

Categories	Number of providers	Content criteria		Formal criteria		Total	
Search terms		Median (range)	Quality	Median (range)	Quality	Median (range)	Quality
"Schilddrüsenkrebs"							
Professional associations	1	22 (21–28)	Very good	8 (7–9)	Very good	30.5 (29–35)	Very good
Actors in health care	4	28.25 (18–44)	Good	11.75 (7–14)	Medium	40.75 (25–55)	Good
Statutory health insurances	1	24.5 (19–30)	Very good	9 (6–10)	Good	34 (25–39)	Good
Media	3	36 (22–49)	Medium	11 (7–15)	Medium	46 (30–64)	Medium
Practices	2	28 (21–33)	Good	10.5 (9–14)	Good	39 (30–46)	Good
Other	12	33.5 (19–45)	Medium	10.5 (6–25)	Good	44.25 (22–59)	Medium
Total of "Schilddrüsenkrebs"	23	30.5 (18–49)	Good	10.5 (6–25)	Good	41.5 (22–64)	Good
"Schilddrüsenkrebs alternative Behandlung"							
Professional associations	1	22 (21–28)	Very good	8 (7–9)	Very good	30.5 (29–35)	Very good
Actors in health care	1	27 (18–31)	Good	12 (7–14)	Medium	40.5 (25–42)	Good
Statutory health insurances	0	–	–	–	–	–	–
Media	5	32.5 (21–52)	Medium	10.5 (6–15)	Good	42 (30–67)	Good
Practices	3	29 (19–43)	Good	10.5 (7–16)	Good	38.5 (26–59)	Good
Other	8	32 (19–53)	Good	11.25 (7–17)	Medium	43.5 (26–70)	Medium
Total of "Schilddrüsenkrebs alt. Behandlung"	18	31 (18–53)	Good	10.5 (6–17)	Good	41.75 (25–70)	Good
Total of both search terms	41	31 (18–53)	Good	10.5 (6–25)	Good	41.5 (22–70)	Good

Table 4 Ranking of the evaluation results "Thyroid cancer"

Search term "Schilddrüsenkrebs"

Quality	Ranking	Total	Search engine (ranking)	Category	Provider
Very good	1	28.5	Google (8), PI	Actors in health care	Stiftung Deutsche Krebshilfe
	2	30.5	Google (5), PI	Professional associations	Deutsche Krebsgesellschaft e.V.
	3	32.5	Google (3)	Other	gofeminin.de GmbH (Onmeda)
	4	33	PI	Other	Stiftung für Qualität und Wirtschaftlichkeit im Gesundheitswesen (gesundheitsinformation.de)
Good	5	34	Google (11)	Statutory Health Insurances	Techniker Krankenkasse
	6	35.5	Google (7)	Practices	Charité – Universitätsmedizin Berlin
	7	36	Google (19)	Other	Netdoktor.at GmbH
	8	40.5	Google (6)	Actors in health care	Bundesverband deutscher Internisten e.V. (Internisten im Netz)
	8	40.5	Google (28)	Other	Mediscope AG (sprechzimmer.ch)
	9	41	Google (1)	Other	Wikimedia Deutschland e.V. (Wikipedia)
	9	41	Google (13)	Actors in health care	Robert Koch-Institut
	10	41.5	Google (2)	Media	Wort & Bild Verlag Konradshöhe GmbH & Co. KG (Apotheken Umschau)
	11	42.5	Google (22)	Practices	SchilddrüsenZentrum Köln e.V.
Medium	12	43.5	Google (17,18)	Actors in health care	Bundesärztekammer (Deutsches Ärzteblatt)
	13	44	Google (10)	Other	Genzyme GmbH (schilddruesenkrebs.de)
	14	44.5	Google (27)	Other	DocCheck Medical Services GmbH (DocCheck Flexikon)
	15	45.5	Google (4)	Other	NetDoktor.de GmbH
	16	46	Google (16)	Media	Ärzte Zeitung Verlags-GmbH
	17	46.5	Google (9)	Other	eesom AG
	18	49.5	Google (26)	Other	Genzyme GmbH (schilddruesenkrebs.net)
	19	50	Google (29)	Media	Govi-Verlag Pharmazeutischer Verlag GmbH (Pharmazeutische Zeitung)
	20	51	Google (21)	Other	Eric Bernstein (Symptomat.de)
Poor	21	53.5	Google (15)	Other	Deutscher Verlag für Gesundheitsinformationen GmbH (leadingmedicineguide)

PI Patienten-Information.de

were quite similar, with the lay person rating consistently better than the others.

Similar studies also showed that the quality of patient information on the Internet varies greatly [1, 12, 16]. A big number of patient information has been rated as highly-deficient. Some information is contradictory, unconfirmed and not evidence-based. Some questionable to unfaithful promises of healing are promoted. This leads patients to be misinformed, uncertain and even deceived [1].

The basis of evaluation of patient information is the definition of distinct quality criteria as supported by the German Network for Evidence-Based Medicine [3] and other organizations. Yet, today there are many evaluation tools to assess the quality of patient information websites. These differ in their criteria from each other and only insufficiently meet the criteria for evidence-based patient information [3]. In order to help patients to identify relevant and high-quality patient information from the wide range of available information, it is necessary to improve as well as standardize the existing applications [19].

Landing pages which filter websites may help patients to find high-quality websites. Yet, their usefulness depends on the visibility of the landing page itself. With respect to the heterogeneity of evaluation tools, the selection of a tool is crucial for any organization recommending other websites. For example, the patient portal "Patienten-Information.de" selects good quality patient information based on the HONcode, which takes the authoritative, complementarity and financing policy into account. External aspects, such as the design of the site view or the use of graphic images, are not considered. The GCS evaluation tool used in this study also focuses on the later-mentioned layout aspects. Zschorlich et al. have already shown that the design and user-friendliness play an important role in the estimation of patient information's credibility [11].

Table 5 Ranking of the evaluation results "Thyroid cancer alternative treatment"

Search term "Schilddrüsenkrebs alt. Behandlung"

Quality	Ranking	Total	Search engine (ranking)	Category	Provider
Very good	1	30.5	Google (4)	Professional Associations	Deutsche Krebsgesellschaft e.V.
	2	32.5	Google (9)	Other	gofeminin.de GmbH (Onmeda)
Good	3	35.5	Google (2)	Practices	Charité - Universitätsmedizin Berlin
	4	38.5	Google (23)	Practices	Kliniken der Stadt Köln gGmbH
	5	39	Google (7)	Media	Verlag Der Tagesspiegel GmbH
	6	40	Google (18)	Other	Wikimedia Deutschland e.V. (Wikipedia)
	7	40.5	Google (3)	Actors in health care	Bundesverband deutscher Internisten e.V. (Internisten im Netz)
	8	41	Google (28)	Other	Gesundheitsberater Berlin GbR
	9	41.5	Google (16)	Media	Wort & Bild Verlag Konradshöhe GmbH & Co. KG (Apotheken Umschau)
	10	42	Google (20)	Media	Medical Tribune Verlagsgesellschaft mbH
	11	42.5	Google (24)	Other	Sascha Amolsch (Gesundheitlicheaufklaerung.de)
	11	42.5	Google (10)	Other	GFMK GmbH & Co. KG (schilddrüsenkrebs.org)
Medium	12	44.5	Google (27)	Other	MCP Wolff GmbH (Medizin-Aspekte.de)
	13	46	Google (14;15)	Media	Deutsche Telekom AG (T-Online.de)
	14	50.5	Google (11)	Other	International Services Company S.A. (Homepharma)
	15	52.5	Google (6)	Media	news aktuell GmbH (Presseportal)
Poor	16	53.5	Google (1)	Other	Neosmart Consulting AG (Zentrum der Gesundheit)
	17	60.5	Google (8)	Other	Krebs-Info.Blogspot.de

Another problem is that some of the used criteria are subjective and rely on the user of the patient information. As a result, people who evaluate a patient information using the same instrument can arrive at different results. Professionals rating a website may rate the understandability of an information for patients quite different from the patients themselves, and patient's ratings may differ according to their literacy and education.

In general, patients want information that is easy to understand and corresponds to their personal situation [11]. Liebl et al. therefore propose interactive websites that provide selected, adapted information to the patient [16]. However, the implementation only seems to be possible at considerable expense. The design of information, with focus on clear content, good structure and appropriate headings, could guide the patient's selection of topics. The limitation of the "information radius" alone is, however, not enough. The adaptation of information to the patient's prior knowledge seems to be of greater relevance [20, 21]. In addition to a well chosen content and a precise vocabulary adapted to the needs of lay people, concepts for the presentation of numbers, probabilities and risks as well as benefits are mandatory [22–24]. In conclusion, the development of patient information corresponding to the individual needs, wishes and ideas in detail is extremely difficult.

Conclusion

In order to improve the patient information from the Internet, the visibility of high-quality websites must be improved. For that, education programs to improve patients' eHealth literacy are needed. A quick and easy evaluation tool for online information suited for patients should be implemented, and patients should be taught to integrate such a tool into their research process. Overall, we found information on general questions being slightly better than information for more specific details; patients might start a search with more general questions and then navigate on these sites.

Professionals may help patients in finding high-quality websites. This entails that they have knowledge concerning eHealth themselves and know the relevant sites for patients. Professional organizations and institutions may help by providing lists and landing pages.

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