



Internet Information for Cancer Patients on Nutritional Behaviour

An Analysis of German-Speaking Websites

Sandra Mohring, Julia von Grundherr, Viktoria Mathies, Jutta Hübner

Abstract

The internet is becoming more important as source of health information like the “best” nutritional behaviour for cancer patients. Our aim was to assess the quality of the web-based information.

A laypersons first search for “nutrition in cancer” on German websites was simulated by using the search engines GOOGLE and ECOSIA. The first 20 hits of both search engines were assessed by 4 raters using a standardized instrument for content and formal aspects. The nutritional recommendations were assessed regarding their conformity according to the latest guidelines. They highlight the importance of a balanced nutrition for cancer patients and refer to the *10 Guidelines of the German Nutrition Society (DGE) for a Wholesome Diet*.

The assessment of 40 websites revealed that websites of professional associations and websites from non-profit organisations in contrast to profit organisations offered good content and formal quality. They provide nutritional recommendations that are consistent with the latest guidelines. There were substantial differences between the nutritional recommendations published on the websites of self-help groups and the recommendations of the DGE. A statement about the quality of the nutritional recommendations based on form and content quality is not possible.

The quality of online information on nutritional behaviour for cancer patients is heterogeneous. As patients have difficulty in assessing the quality of information, this can cause major problems when the Internet becomes an essential source of information. The patients' recognition of evidence-based recommendations needs to be improved. A critical examination is necessary.

Keywords: cancer patient, nutrition recommendations; internet, nutrition information; nutrition education

Citation

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Corresponding Author

Sandra Mohring
Klinik für Innere Medizin II, Hämatologie und Onkologie
Universitätsklinikum Jena
Am Klinikum 1, 07747 Jena/Germany
ORCID: 0000-0002-8412-3870
sandra.mohring@uni-jena.de

Introduction

According to a survey in Germany, information available online was often rated as helpful by patients and made them feel more empowered to participate in disease-related decisions [1]. It also gave patients the feeling of not being alone with their disease. Patients also stated that the information they found increased their pre-existing uncertainty [1]. When searching for information on the internet, it is important to bear in mind that there are always inaccurate information as well as security and data privacy issues [2]. The quality of online resources is not guaranteed even though quality certificates like HONcode [3] exist. It is up to the patient to differentiate between reputable and unserious sources. According to a German performance test analysis about searching for cancer-related infor-



mation on the internet, this is one of the most frequent problems resulting from an online research (95% of the participants) [4]. This problem is of particular importance considering that only few patients (21.3% of the participants) consult their oncologists about the online information they have found [1].

The patients' need to be able to do something themselves is significant regardless of age. 68% of younger patients and 61% of those over 40 years of age are concerned with the question: "What can I do myself?" [5]. More than half of the patients (72% of the adolescents and young adults vs. 55% of the over 40s) dealt with the topic of lifestyle in their internet search [5]. Part of lifestyle is, among other things, nutritional behaviour. It can be seen as part of the cancer treatment that the patient can influence independently. According to a German survey among cancer patients, print media (68.5%) and self-help groups (58.6%) are important sources of information about nutrition. Young people more often get their information from the internet or by asking their doctors about this topic. In contrast older patients cite nutritionists and self-help groups as their source of information [6].

For a long time, there were not many specific and popular recommendations on how a cancer patient's nutritional behaviour should be like. The ESPEN guidelines on nutrition in cancer patients and ESPEN practical guideline on clinical nutrition in cancer provide directives for the prevention of malnutrition, but do not contain information on the nutrition of patients in their everyday life during treatment or survivorship [7, 8]. The Cancer Prevention Recommendations [9] of the World Cancer Research Fund (WCRF) and the American Institute for Cancer Research (AICR) provide nutritional recommendations to prevent cancer development that can also be implemented after a cancer diagnosis, but they are not popular in Germany. There are many different recommendations such as the supply of vitamins and micronutrients or the use of herbal remedies, which are used and propagated in different ways. Statements on the clinical efficacy of micronutrients cannot finally be made because of the missing randomized clinical trials. Since September 2021, there has been a new guideline in Germany that addresses the nutrition issue in complementary medicine of cancer patients [10]. The guideline confirms the validity of the recommendations of the German Society for Nutritional Medicine (DGEM). The new guideline is currently being implemented.

If a patient currently deals with this subject in an online search, he or she will find a lot of quite different information. The aim of this study is to assess the quality of information on nutritional recommendations for cancer patients regardless of the stage of the cancer, taking account of the overall quality of the website. The focus is on nutritional recommendations for patients without food intake restrictions such as parenteral nutrition or patients suffering some form of therapy-associated malnutrition.

Material and Methods

Material

For this study, we simulated a patient search on the internet for nutritional behaviour in cancer. For this, we used two different search engines: Google and Ecosia. Google has the largest mar-

ket share among search engines by far [11]. In fact, Ecosia's market share is quite smaller, but Ecosia is still one of the top 10 most used search engines [12]. We defined „nutrition in cancer" (in German *„Ernährung bei Krebs"*) as search term as this is the most comprehensive terminology laypeople will use in this case according to a search engine optimization (SEO) analysis.

The search took place in September 2021. Cookies and search histories were deleted beforehand to simulate a laypersons first search. SEO analyses showed that the click probability of a website is only remarkably high in positions 1 to 10. There was a clear decrease in click probability with descending position. As people only consider the first 20 or fewer hits of a search engine when researching online [13], only the first 20 hits of both search engines were saved and analysed. Only websites that matched the search term were considered. Duplicates were excluded and replaced with subsequent hits. Pages with the following criteria were not considered: incorrect links, advertisements, and videos.

The websites were assigned to groups according to their background (♦ Table 1): professional associations, self-help groups, non-profit and profit websites, health insurance service, online news, and medical practice. These groups were evaluated separately from each other. We differentiated between profit and non-profit websites. Owners of profit websites are typically companies selling products which are directly or indirectly related to the topic. In contrast, non-profit websites provide balanced information on characteristics and different perspectives on the topic to their readers. We assigned sponsoring activities to the category of profit websites as we cannot exclude any direct or indirect dependencies between the adverts and the own products of the sponsors.

Assessment of the websites

For the assessment we use the instrument of Liebl et al. [18]. This tool is based on various guidelines and recommendations for the assessment of patient information like the evidence-based recommendations on patient information from the German Network for Evidence-Based Medicine (DNEbM) published by Steckelberg et al. [19] and instruments for patients to evaluate health information websites like afgis (non-profit association with the aim of quality assurance of health information) [20], the HONcode (certificate of the HON foundation; certification according to



Category (number)	Institution	International name (including short description)
Professional medical associations (4)	<i>Deutsche Krebsgesellschaft</i>	German Cancer Society; association of all experts in oncology in Germany
	<i>Onko-Internetportal (Deutsche Krebsgesellschaft)</i>	Online portal for professionals and lay-persons on cancer
	<i>Deutsches Krebsforschungszentrum in der Helmholtz-Gemeinschaft</i>	National German Cancer Research Center
	<i>Deutsches Krebsforschungszentrum in der Helmholtz-Gemeinschaft (krebsinformationsdienst.de)</i>	Online portal on cancer for lay-persons of the German Cancer Center
Self-help groups (2)	<i>Stärker gegen Krebs</i>	private search and information platform for cancer patients and relatives
Non-profit organisations (8)	<i>Österreichische Krebshilfe</i>	non-profit organisation with the mission of fighting against cancer in Austria
	<i>Öffentliches Gesundheitsportal Österreichs</i>	online information portal on medical topics in Austria
	<i>Eat What You Need e. V. – Allianz für bedarfsgerechte Ernährung bei Krebs (Was essen bei Krebs)</i>	nutrition platform for cancer patients
	<i>Vereine für Unabhängige Gesundheitsberatung (ugb.de)</i>	private website with various advice concerning nutrition
	<i>Deutsche Krebshilfe</i>	non-profit organisation with the mission of fighting against cancer in Germany
	<i>Funke-Mediengruppe (gesundheit.de)</i>	independent health portal of a German media group
	<i>minimed.at</i>	online portal for medical information in Austria
Statutory health insurance services (1)	AOK	
	<i>Funke-Mediengruppe (lifeline.de)</i>	independent health portal of a German media group
Newspaper (online) – News (5)	Berlin.de	information portal of the city of Berlin
	<i>Focus-Online</i>	German news magazine and illustrated journal
	<i>Apotheken-Umschau</i>	health and customer magazine of the pharmacies
	RTL	private German-speaking broadcaster
	NDR	regional broadcasting corporation of the northern German states
Profit websites (13)	Winvitalis	producer of meals for special nutrition requirements
	Bodymed	nutrition concept for overweight with a focus on weight loss
	Nutricia	producer of medical enteral nutrition
	Roche Pharma AG (daskwort.de)	online platform by Roche Pharma AG
	NestléHealthScience	online platform by Nestlé S.A.
	vitasy	producer of medical enteral nutrition
	Baxter International Inc. (ernähren-bei-krebs.de)	online platform about nutrition in cancer offered by the pharmaceutical company Baxter International Inc.
	<i>ABF-Apotheke (krebs-und-ich.de)</i>	pharmacy portal about cancer treatment offered by the pharmaceutical company ABF-Apotheke
	Bristol Myers Squibb Co. (krebs.de)	online platform on cancer offered by the pharmaceutical company Bristol Myers Squibb Co.
	gesundheitskompass.de	online health care portal
	<i>3E Gesundheitszentrum</i>	center for alternative cancer therapies
	<i>smartESSEN</i>	German online nutrition magazine
	ACCURAY (die-wertvollen-momente.de)	producer of linear accelerators for radiotherapy
Websites of medical practices (8)	<i>Tumorzentrum München</i>	tumour center
	<i>Universitätsklinikum Freiburg</i>	university medical center
	<i>Zentralklinik Bad Berka</i>	hospital
	<i>Tumorzentrum am Universitätsklinikum Tübingen</i>	tumour center
	HELIOS	company owning many hospitals in Germany
	<i>Universitätsklinikum Erlangen</i>	university medical center
	<i>Onkologische Schwerpunktpraxis Dr. Anhut</i>	outpatient oncology practice
	<i>Praxis Dr. Dornschnieder</i>	outpatient nutritionist and surgeon

Tab. 1: Categories of the Websites



formal criteria regarding reliability and credibility) [3] and DISCERN (user questionnaire; quality criteria for patient information materials) [21]. Moreover, the guidelines of the Agency for Quality in Medicine (ÄZQ) [22] were included in the development of this tool. The assessment is conducted according to a list of criteria (♦ Table 2). The presence of possible quality labels is not considered separately.

The instrument consists of 18 content criteria and 6 formal criteria (♦ Table 2). Three criteria on nutrition were added which are based on the consistent recommendations [23] of the 10 Guidelines of the DGE for a Wholesome Diet [24] and the WCRF-AICR-Cancer Prevention Recommendations [9]. These three criteria represent different aspects of nutrition: varied and balanced diet, low meat consumption and sufficient fluid intake. A decision on these three recommendations was made because they summarise most of the recommendations of the DGE with concrete information on the nutrient composition: The first recommendation is about a balanced and diverse nutrition with mainly plant-based products. The second one recommends a low meat consumption with 300 to 600 grams of meat weekly. The third is to consume sufficient fluids based on energy-free drinks. As the assessment is of German websites and the recommendations of the DGE [24] are better known and more accessible in Germany, in the following text only the reference to these recommendations is made.

For each website and criterion, a maximum of 3 points could be scored, with one representing complete fulfilment, 2 representing partial fulfilment, and 3 representing insufficient fulfilment of the respective criterion. For each category, the average was calculated. Thus, there was a range from 1 to 3 points for each website. The lower the total score, the higher the quality of the website.

Four persons evaluated each website: two experts with medical expertise and two medical laypersons provided with a detailed overview of the different assessment criteria including the used instruments and guidelines. For better comparability, the mean values for content, formality and DGE-conformity were calculated. The mean values were also calculated across the individual criteria. Blinding was not possible with this design. All four raters were asked to assess the 40 websites and had to deal with the respective background of the website in this context especially in terms of formal criteria. A possibly better evaluation due to a more serious appearing website cannot be excluded.

Content criteria
<ul style="list-style-type: none"> • expertise • explication of objectives and target audience • fair balance/neutrality • rigour • relevance • intelligibility for laypersons • suitability to support shared decision making • scientific evidence and timeliness • no statements on topics without evidence • detailed information on treatments, their benefits and risks, impact on quality of life, mode of action, consequences of non-treatment • information on additional resources and references • focus on the patient • layout aspects • risk communication • quality management • clear arrangement of information • completeness • labelling of missing evidence
Formal criteria
<ul style="list-style-type: none"> • transparency considering provider, supporter, funding, advertisement, etc. • privacy protection • completeness of information on source of evidence • observance of scientific knowledge on the presentation of numbers and outcome • language adapted to the needs of the target group • possibilities of feedback and participation for users
DGE-conformity
<ul style="list-style-type: none"> • varied and balanced diet (plant-based foods, 5 portions of fruit and vegetables, whole grain products) • low meat consumption (maximum 300–600 g per week) • sufficient fluid intake (water, energy-free drinks, unsweetened tea; approx. 1.5 l per day)

Tab. 2: Assessment criteria based on Liebl et al. [18] with additions to the nutritional guidelines of the German Nutrition Society (DGE)

To assess the precision of the assessment tool and improve the comparison of the results across the four raters, the measure of concordance was calculated according to Kendall's *W*. A value of one thereby implies a complete agreement of the different assessments and would confirm the complete objectivity of the assessment instrument.

Results

Description of the websites

The 40 first hits we analysed included four websites of professional medical associations, one website of a self-help group, eight



non-profit organisations, one statutory health insurance service, five websites of online newspapers, thirteen profit websites and eight websites of medical practice (♦ Table 1). There were five websites that provided information on different aspects of cancer treatment, including information on nutritional behaviour. Two websites were articles from hospitals' patient magazines which offered information on various health topics. Another website provided general information on nutrition with additional advice for cancer patients.

Quality of the assessment tool – inter-rater concordance

In terms of content, there was good agreement among both the experts and the laypersons (Kendall's $W = 0.795$ vs. 0.781). Even when all four raters were considered together, there was a reasonable agreement (Kendall's $W = 0.622$). The inter-rater concordance of the formal assessment and the DGE-conform nutrition guidelines was also acceptable: The experts' consensus on the formal assessment was higher than that of the laypersons (Kendall's $W = 0.703$ vs. 0.620). In the case of DGE-conformity, similar agreement was achieved among experts and laypersons (Kendall's $W = 0.653$ vs. 0.659). When the four raters were considered together, the level of agreement in both the formal (Kendall's $W = 0.525$) and the DGE-conform assessment (Kendall's $W = 0.578$) was still acceptable.

Assessment of individual websites

Content rating

In the individual assessment of the websites, *Deutsche Krebshilfe* (German Cancer Aid) received the best content rating directly followed by *daskwort.de* by Roche Pharma AG and *krebsinformationsdienst.de* by *Deutsches Krebsforschungszentrum* (DKFZ, German Cancer Research Center). The website *berlin.de* – the information portal of the city of Berlin – received the worst content rating (♦ Table 3).

Formal rating

The website of *Deutsche Krebshilfe* also received the best formal rating. Second place in the formal rating is shared by four websites: *Deutsches Krebsforschungszentrum* (DKFZ), *krebsinformationsdienst.de* (DKFZ), *Was essen bei Krebs* by Eat What You Need e. V. (nutrition platform for cancer patients) and *daskwort.de* (Online Platform – Initiative of Roche Pharma AG) (♦ Table 3). The website *berlin.de* also received the worst formal rating followed by *smart-ESSEN* – a profit website about nutrition.

Association between content and formal assessment

There was a strong positive correlation between the average of formal and content assessment (Pearson's $r = 0.748$; $p < 0.05$). The largest deviation in the comparison of the formal and content average scores of the individual websites was 0.5 points and was achieved by *3E Gesundheitszentrum*. This website received one of the worst content ratings. When the four different assessments by the raters are considered separately, isolated major deviations between the content and formal assessment could be found. The largest deviation was 1.1 points and was achieved by the website of *Zentralklinik Bad Berka*, a non-academic larger hospital in a small town (content criteria: 1.4 points; formal criteria: 2.5 points). This

observation was not made in the assessment of the other three raters, here a maximum deviation of 0.5 points resulted for this web page.

DGE-conform nutritional recommendations

The best DGE-conform nutritional recommendations were found on the following websites, which achieved the minimum score of 1 point: *Deutsche Krebshilfe*, *Onko-Internetportal* and *Deutsche Krebsgesellschaft* (German Cancer Society) (♦ Table 3). HELIOS (hospital owner) and NDR (regional broadcasting corporation of the northern German states) received a comparable high rating. The website *berlin.de* also scored the worst in terms of DGE-conform nutritional recommendations.

Association between the assessment of content and form and DGE-conformity

There was a clear positive correlation between the assessment of content and DGE-conformity (Pearson's $r = 0.590$; $p < 0.05$). The correlation between the assessment of form and DGE-conformity was weak (Pearson's $r = 0.364$; $p < 0.05$). Some websites had a consistent rating in all three categories. For example, *Deutsche Krebshilfe* received a consistently good rating, while *berlin.de* scored poorly in all categories. Consequently, these websites are at the top or the bottom of the total rating. Other websites scored well in terms of form and content, while DGE-conformity was rated as very poor for example *stärkergegenkrebs.de* or *krebsinformationsdienst.de*. The reverse constellation is rather rarer. The nutritional recommendations of NDR were rated very well according to their DGE-conformity. In comparison, the evaluation of content and form was worse.

Total rating

The websites with the best total rating are *Deutsche Krebshilfe* followed by *Onko-Internetportal* and *Deutsche Krebsgesellschaft*. The worst rating in all three categories was given to *berlin.de* (♦ Table 3).

Assessment based on the provider classification

When looking at the websites based on their categorization (♦ Table 1), websites in some categories have a constant score across all three assessment criteria, either good or bad. These scores consequently correlate to the overall rating (♦ Figure 1).

The websites of professional associations received the best rating for all assessment crite-



Category	Provider	Content criteria	Formal criteria	DGE-conformity	Overall rating
Professional medical associations	<i>Deutsche Krebsgesellschaft</i>	1.7	1.9	1.0	1.5
	<i>Onko-Internetportal (Deutsche Krebsgesellschaft)</i>	1.7	1.7	1.0	1.5
	<i>Deutsches Krebsforschungszentrum in der Helmholtz-Gemeinschaft</i>	1.9	1.6	2.3	1.9
	<i>Deutsches Krebsforschungszentrum in der Helmholtz-Gemeinschaft (krebsinformationsdienst.de)</i>	1.6	1.6	2.5	1.9
Self-help groups	<i>Stärker gegen Krebs</i>	2.0	1.7	2.8	2.2
Non-profit organisation	<i>Österreichische Krebshilfe</i>	1.7	1.9	1.7	1.7
	<i>Öffentliches Gesundheitsportal Österreichs</i>	1.7	1.7	2.4	2.0
	<i>Eat What You Need e.V. – Allianz für bedarfsgerechte Ernährung bei Krebs (Was essen bei Krebs)</i>	1.9	1.6	1.8	1.7
	<i>Vereine für Unabhängige Gesundheitsberatung (ugb.de)</i>	2.1	2.1	2.8	2.3
	<i>Deutsche Krebshilfe</i>	1.5	1.5	1.0	1.3
	<i>Funke-Mediengruppe (gesundheit.de)</i>	2.0	1.8	1.8	1.9
	<i>minimed.at</i>	1.8	1.9	2.0	1.9
	<i>Funke-Mediengruppe (lifeline.de)</i>	2.3	1.9	2.6	2.2
Statutory health insurance services	AOK	2.1	1.8	1.9	1.9
Newspaper (online) – News	<i>Berlin.de</i>	2.8	2.6	2.9	2.8
	<i>Focus-Online</i>	2.4	2.2	1.8	2.1
	<i>Apotheken-Umschau</i>	2.0	2.0	2.1	2.0
	<i>RTL</i>	2.6	2.4	2.6	2.5
	<i>NDR</i>	2.2	2.2	1.3	1.9
Profit websites	<i>Winvitalis</i>	2.3	2.2	2.6	2.3
	<i>Bodymed</i>	2.1	2.1	2.8	2.3
	<i>Nutricia</i>	2.0	2.1	1.9	2.0
	<i>Roche Pharma AG (daskwort.de)</i>	1.6	1.6	1.8	1.7
	<i>NestléHealthScience</i>	2.2	1.9	2.7	2.2
	<i>vitasy</i>	2.0	2.0	1.7	1.9
	<i>Baxter (ernähren-bei-krebs.de)</i>	2.3	2.1	2.1	2.2
	<i>ABF-Apotheke (krebs-und-ich.de)</i>	2.0	2.0	2.2	2.0
	<i>Bristol Myers Squibb (krebs.de)</i>	1.7	1.8	1.6	1.7
	<i>gesundheitskompass.de</i>	2.2	2.2	2.4	2.3
	<i>3E Gesundheitszentrum</i>	2.6	2.1	2.7	2.4
	<i>smartESSEN</i>	2.5	2.5	2.3	2.4
	<i>ACCURAY (die-wertvollen-momente.de)</i>	2.1	2.0	2.4	2.2
Websites of medical practices	<i>Tumorzentrum München</i>	1.7	1.7	1.8	1.7
	<i>Universitätsklinikum Freiburg</i>	2.1	2.1	2.1	2.1
	<i>Zentralklinik Bad Berka</i>	1.7	2.2	1.4	1.8
	<i>Tumorzentrum am Universitätsklinikum München</i>	1.9	1.7	1.6	1.7
	<i>HELIOS</i>	1.7	2.0	1.3	1.7
	<i>Universitätsklinikum Erlangen</i>	2.0	2.3	2.5	2.3
	<i>Onkologische Schwerpunktpraxis Dr. Anhut</i>	2.3	2.0	2.3	2.2
	<i>Praxis Dr. Dornschneider</i>	2.0	2.1	2.7	2.3

Average score (1: complete fulfilment; 2: partial fulfilment; 3: insufficient fulfilment)

Tab. 3: Average score of individual websites sorted according to provider category



ria and are therefore also on top of the overall ranking. Websites with a profit background are in one of the last places in all three assessment categories and consequently also in one of the lowest positions in the overall ranking. Including two websites of pharmaceutical companies (daskwort.de and krebs.de by Bristol-Myers Squibb) with a good rating over all three categories, which are not of great importance in the overall ranking among a total of thirteen websites with a profit background. Health insurance companies, non-profit organisations and websites of hospitals and doctors' practices are consistently in the midfield of the rating. Health insurance companies are above the medical practices in the formal ranking and in DGE-conformity. They consequently have a minimally better overall rating than the websites of medical practice. Only one website of a statutory health insurance company was included in the evaluation. In terms of DGE conformity and content criteria, non-profit organisations and medical practices have a comparable rating. Due to a better formal assessment, the non-profit organisations are ranked prior to the medical practices in the overall ranking.

The other groups show a heterogeneous result in the evaluation of content, form, and DGE-conformity: While self-help groups are ranked in the upper range for the formal assessment and in the middle range for the content assessment, they are by far in last place in terms of DGE-conformity of the nutritional recommendations. Online news ranks last in terms of content and form by a clear margin. A place in the midfield of the ratings regarding DGE-conformity cannot compensate for this in the overall ranking. This results in both groups coming last in the overall evaluation (♦ Figure 1).

The analysis of websites concerning nutritional recommendations for cancer patients shows that the information a patient will find during a simple internet search is very heterogeneous. A mixture of professional associations, self-help groups, profit and non-profit websites, statutory health insurance service, online newspapers and websites of medical practice are the first sources of information a patient will get while searching online. The quality of these websites covers a wide range in terms of content and form, as well as in terms of nutritional recommendations. Information on the internet cannot be applied without first being questioned. A critical approach to information is essential.

Integration of the study results into the research context

Our analysis confirms the observation of similar studies: the quality of information is very heterogeneous and quite limited [26, 35]. When searching the internet, only a few trustworthy websites with high quality information are found [27]. The assessment tool used in this study also was used for the assessment of websites in other studies investigating information for cancer patients [28]. This enables a more detailed comparison.

In all three studies, non-profit websites received consistently good ratings for their content and

Discussion

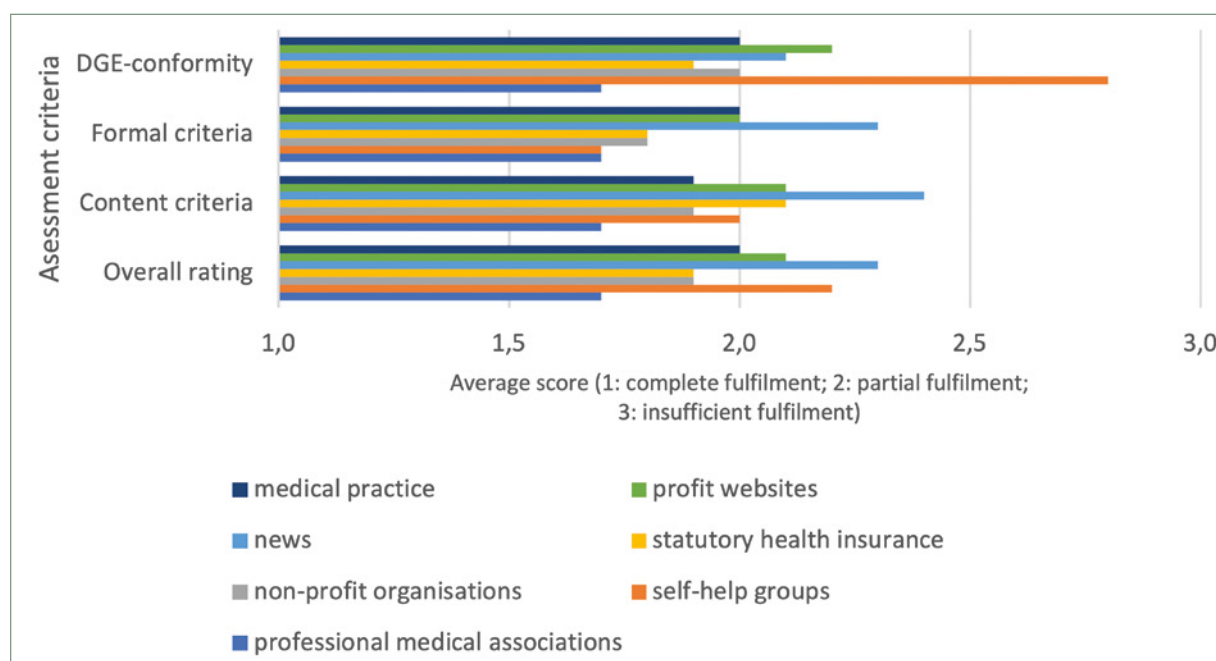


Fig. 1: Scoring of the Website categories with respect to content and formal quality and DGE-conform nutritional recommendations



form. In contrast, the websites with a profit background were rated low in all three studies for content and form. Although there is no overlap in the news providers included in the three studies, their content quality was rated comparably poor in all studies. This supports Janssen et al.'s hypothesis that sponsorship lowers the quality of information [25]. In the formal ranking Liebl et al. [18] and Herth et al. [28] ranked online newspapers in the midfield. In our study, the online newspaper was ranked on the last place. One explanation for this might be that we only included websites from less reputable news providers, while Liebl and colleagues as well as Herth and colleagues included both daily newspapers and scientific journals in their search hits. For both publications, the inclusion criterion was that the websites should primarily provide relevant information for cancer patients [18, 28]. To simulate a patient search as realistic as possible, we omitted comparable exclusion criteria and only excluded incorrect links, advertisements, and videos.

Moreover, in our study, self-help groups are in the middle of the field in terms of content quality. In both publications of Liebl et al. and Herth et al., self-help groups were at the top of the list [18, 28]. While the first search hits in our analysis only resulted in one smaller self-help group, the other two studies found hits from the leading self-help organisations that provide support for cancer patients. Compared to smaller self-help groups, the leading self-help organisations have better possibilities to provide good quality information due to their organisation structure and financial as well as staff resources. The formal assessment of the self-help group websites is consistent between our study and the publication of Herth et al. [28]. The only self-help group considered in Herth et al.'s publication received a particularly good rating [28].

In our study, the content and formal assessment of the health insurance companies was significantly worse compared to Liebl and colleagues [18]. Our study confirms the best overall assessment of the professional associations as already observed in similar studies [27]. An improvement in the content quality of medical websites already described by Herth and colleagues can be confirmed by our study [28]. In addition, there was a small improvement in the formal quality compared to previous studies. However, the quality of the websites of medical practice is still in the midfield of the assessment [27].

The differences to the previous publications may partly be attributed to the dynamics of

the internet. The comparative studies were conducted a few years ago. In the meantime, the information offered on the internet has changed. Due to the increasing importance and demand of online health information [14, 16, 17, 29, 30], there is a larger, more differentiated offer. This information offer varies greatly in quality as existing instances of verification are only partially applied.

In the meantime, the importance of patient information material has been recognised by the clinics. Efforts have been made to establish requirements for good information material. These clarify the requirements for understandable content, for example, by using visual displays [31, 32]. Besides, a further development of the content between studies, the formal requirements for websites have also changed. Especially in data privacy a lot has already changed. Almost every website now automatically displays a dialogue window on data privacy when it is opened, where the privacy policy must be accepted by the user.

Recommendations on nutritional behaviour

Our study revealed significant discrepancies between the 10 Guidelines of the DGE for a Wholesome Diet [24] and the published recommendations of the self-help groups. StärkergegenKrebs.de bundled essential information on cancer for patients. It explains treatment methods and supports the networking of patients and experts. The main objective of the website is not to provide information about nutritional behaviour in cancer. This might be one explanation for the worst rating in the DGE-conformity for self-help groups. The included self-help website provided non-guideline adherent information to patients. As self-help groups are an important source of information on nutritional behaviour in cancer especially for older patients between 45 and 70 [6], this problem needs to be considered. The heterogeneous assessment of the 40 websites regarding their DGE-conformity in general confirms that at the time of our assessment the new guideline [10] had not been integrated into the available online information. Only some websites like *Deutsche Krebshilfe* and *Deutsche Krebsgesellschaft* have very good recommendations on nutritional behaviour. The 10 Guidelines of the DGE for a Wholesome Diet [24] were either directly mentioned or there was a reference to the website of the DGE.

To be able to evaluate the information as a patient, the current guidelines must be known. Patients should be provided booklets with a version of the guidelines that can be understood without prior knowledge. The attention of patients should be drawn to already existing patient-friendly guidelines. Further patient variants of medical guidelines should be developed, enabling patients to be informed about current, evidence-based medical standards. This was for example realised by *krebsinformationsdienst.de*. In this context, *krebsinformationsdienst.de* is the German Cancer Center's information portal and provides comprehensible and scientifically proven information about oncological topics for everybody.

Another possibility could be the education of patients in the critical use of the provided information. A German performance test analysis about searching for cancer-related information on the internet showed that none of the participants verified the information on a website by comparing it with another one [4]. In fact, several nationwide surveys have shown that health literacy and



eHealth literacy in Germany are rather in the medium to lower level. More than three quarters of the adult persons in Germany rate their ability to judge, whether web-based information is to be trusted, as low [33]. Considering the web-based information and its quality, most users may not be able to select trustable information and apply them on their own situation.

Advertisement

The question arises whether patients recognise indirect advertising during online research like Roche Pharma AG behind the information page daskwort.de. The blog "*Wertvolle Momente*" seems to be a self-help platform, but ACCURAY, the producer of linear accelerators for radiotherapy, is in fact the founder of the website [34]. Transparency of especially commercial websites must be considered critically. The classification of the information provider could be an assistance for the evaluation of the information. However, this classification is not always unambiguous, and some websites can be assigned to several groups. Self-help groups might also be considered a subgroup of non-profit websites. Yet, we decided to assess them separately as information provided to patients by patients is a special offer.

Content and formal quality

The critical approach to online information by patients is made more difficult since the fulfilment of one quality feature does not necessarily indicate high-quality patient information. The correlations in our study reveal that good content quality implies good formal quality. However, conclusions about the DGE-conformity can only be derived to a small extent from good content and formal quality.

This discrepancy of quality might be due to the controversial discussion on nutrition in general and the recurring development of nutrition trends [35, 36]. In the clinical context, little attention was paid to the topic of nutrition for many years.

A clear discrepancy in the assessment of content and DGE-conformity is no contradiction. The content assessment considered the content in general and examined criteria like relevance of the information or the communication of risks (♦ Table 2). The DGE-conformity focused on the specific mention of the three selected recommendations: varied and balanced diet, moderate meat consumption and sufficient fluid intake.

The inter-rater concordance showed a heterogeneity between the raters in the formal assessment and the assessment of the DGE-conformity.

For the formal criteria a more precise definition might improve the instrument. For example, the current instrument combines the separation of advertising and editorial contributions, the disclosure of funding and sponsors as well as the naming of authors and sources into one criterion – "transparency" (♦ Table 2). Three individual criteria could help to make the tool more precise. Some websites have links to further information on nutritional behaviour in cancer. The four raters considered this information either to be part of the information on the web pages or they felt that this information was missing on the respective website, and it received a poor rating in this category. This might explain especially the heterogeneity in DGE-conformity between the raters.

Limitations

To improve the objectivity of the individual ratings, four persons independently conducted the assessment. The two experts and two laypersons all had a tertiary degree. They were skilled in working with information from the internet. This implies a bias, as health literacy – the ability to understand and evaluate health information – is partly correlated with the level of education. Consequently, the rating by less skilled/educated laypeople might have been different. In a next step it would be important to test the instrument with laypersons to find out whether they would be able to use the instrument and whether this would be helpful for them.

As the inter-rater concordance shows, the rating tool is not completely objective. This confirms observations from other studies: the assessment of the quality of a website depends on the rater regardless of the used assessment tool [27]. To verify this observation, Kendall's W could be determined as parameter in similar studies based on this assessment tool. To prevent bias due to the raters' educational background, a study using this tool could be conducted by people with different levels of education. By determining Kendall's W over the individual criteria instead of the categories of criteria like content or form, it would be possible to identify which individual criterion needs to be improved by a more precise formulation or an additional description.

Our assessment is not exactly reproducible, as some websites can no longer be found, or the content has changed. Two of the websites (*Gesundheitskompass*, berlin.de) were already unavailable at the time of the evaluation by one of the raters. With the Wayback Machine [37] we could restore only one these websites.

Conclusion

The fast-moving nature of information on the internet can be seen as both an advantage and a disadvantage. On the one hand, an outdated, potentially incorrect entry can be updated easily and quickly. On the other hand, there is also the possibility of a deterioration in quality of information. Regular control would be advisable. Nevertheless, it will not be possible to protect patients from inappropriate and possibly misleading health information.

By improving health literacy in society



through educational work already in schools, individual health awareness should be enhanced. One focus could be on protective factors like physical activity and a balanced daily nutrition. In this context, the visibility of certificates as HONcode [3] or afgis [20] as a sign of qualitative patient information can be increased. The currently used patient information media should be revised regularly and written in simple language mode so they can provide low-threshold information for the whole society, regardless of level of education. The creation of a sufficiently sized offer for nutritional counselling and the dissemination of intelligible patient booklets could be possible attempts. Cancer patients could receive nutrition counselling in a standardised way as part of diagnosis and therapy. Within the context of a study, a patient guide could be developed for handling and assessing information from the internet. This could simplify the assessment of the quality of health information by patients through some simple questions and also improve the perception of serious information.

Recommendations for using information on the Internet:

- verify that the displayed information matches to the search request
- caution with profit websites
- comparison of information from two or more websites
- orientation and targeted search for quality certificates like HONcode
- initial orientation provided by the professional associations
- consultation with doctors about information found on the internet

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Conflict of Interest

The authors declare non conflict of interest.

Sandra Mohring^{1,2}

Julia von Grundherr, Diätetik B. Sc., MPH³

Viktoria Mathies, M. Sc.⁴

Prof. Dr. Jutta Hübner¹

¹ Klinik für Innere Medizin II, Hämatologie und Onkologie

Universitätsklinikum Jena

Am Klinikum 1, 07747 Jena

² sandra.mohring@uni-jena.de

³ Hubertus Wald Tumorzentrum – Universitäres Cancer Center Hamburg (UCCH)

Universitätsklinikum Hamburg Eppendorf

Martinistr. 52, 20246 Hamburg

⁴ UniversitätsTumorZentrum Jena

Universitätsklinikum Jena

Bachstr. 18, 07743 Jena



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