Exploring the most visible websites on cutaneous T-cell lymphoma—revealing limited quality of patient health information on the internet

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Abstract

Background Patients diagnosed with cancer frequently search the Internet for health information. Yet, the quality of CTCL online information has not been investigated so far.

Objectives The aim of this study was to identify and assess the most visible websites on CTCL.

Methods An Internet search on the top three search engines Google, Yahoo and Bing was performed for the terms ‘cutaneous T-cell-lymphoma’, ‘mycosis fungoides’ and ‘Sézary syndrome’. After selecting the most frequented websites suitable for patients’ information, we investigated content quality, readability and popularity. Eighty-nine websites were evaluated for HONcode quality certification, social media popularity, Alexa popularity rank, topicality and readability levels. Furthermore, the websites’ content on 13 major topics according to guidelines on CTCL was assessed.

Results Twenty-three (25.8%) websites were HONcode certified. Evaluated websites were difficult to read requiring at least 9 years of US school education to properly understand the information. More than half of all websites (57.3%) have not been updated for three or more years (or did not contain any update information). We found greatly varying quality and popularity of online patient information. Out of 1157 topics (equivalent to 13 different topics on 89 websites), 59.44% were mentioned on the websites. Of these, 40% contained incorrect or incomplete information. Publicly provided websites presented the different topics more thoroughly. We could further show that HONcode certified websites received better quality and readability scores.

Conclusions We found major shortcomings regarding readability, completeness and reliability of websites on CTCL. Nevertheless, highly selected websites on CTCL can serve as a valuable and reliable source of patient information. As a consequence, oncologists have an obligation to be aware of and guide their patients to available websites that contain reliable and appropriate information.

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Introduction

Cutaneous T-cell lymphomas (CTCLs) comprise a heterogenous group of rare malignancies characterized by proliferation of malignant lymphocytes that primarily manifest in the skin.1 Mycosis fungoides (MF) is the most common CTCL subtype with an incidence of six cases per million. Sézary syndrome (SS) represents a very rare leukaemic subtype of CTCL with an approximate incidence of one case per million.

Clinical presentations of MF are versatile ranging from pruritic plaques and patches in early stages to painful tumours, ulcerations, erythroderma, lymphadenopathy, blood and organ involvement in advanced stages and SS.2–4 The Internet gained an increasing importance as an easy accessible source for health information for a large population and its importance is growing. In a study conducted in the USA, approximately 70% of American adult internet users have checked health related information on the Internet within 1 year.5 Most patients tend to use search engines rather than directly assessing a specific site. Especially patients diagnosed with cancer frequently search the Internet to obtain information and ‘cancer’ is one of the most
searched health conditions on Google. Although there are no regulations or standardizations to ensure accuracy and reliability of health related online information, patients tend to believe in its trustworthiness and correctness without further critical consideration. Due to widespread insufficient health literacy patients may falsely trust online information which bears the risk to cause serious harm in terms of cancer outcomes and psychological wellbeing.

To the best of our knowledge the quality and accuracy of online information concerning CTCL is uninvestigated. Therefore, we assessed the quality, readability, topicality and popularity of consumer-focused online CTCL information.

**Materials and methods**

**Google search strategy**

On 19 Mar 2021 we performed an internet search on 'cutaneous T-cell-lymphoma', 'mycosis fungoides' and 'Sézary syndrome' using the top three search engines Google, Yahoo and Bing.

We selected these search tools since they represent the top three online search engines with a global market share of 95%. We further selected these engines as patients prefer to use general search tools rather than medical search tools, such as PubMed. Thus, our search strategy covered the majority of the worldwide patient search queries for CTCL key words.

The search was done on a new installed Firefox browser version 86.0.1 in English language and US set as geolocation. We included the first 50 search queries of each search engine for 'cutaneous T-cell-lymphoma', 'mycosis fungoides', 'Sézary syndrome' in our study. We did not consider websites beyond the first 50 results as users rarely enter these websites.

Searches were done using private mode to prevent bias arising from previous searches. After excluding duplicate websites, we further excepted scientific articles, websites without information for patients, websites with paid content, PDF files, social media websites, solely visually based websites, forums/blogs, videos, online dictionaries and advertisement. Websites were categorized as physician provided and publicly provided.

**Coverage and accuracy**

To analyse content, accuracy and completeness of each website, our working group developed a rating scale based on a checklist including 13 parameters for health information on CTCL that were in agreement with current NCCN and ESMO guidelines and expert opinion. The final items evaluated were 'definition', 'epidemiology', 'aetiology', 'symptoms', 'diagnostic evaluation', 'therapy', 'course of disease', 'prognosis', 'differential diagnosis', 'complications', 'pictures', 'authorship and references' and 'reference to guidelines'.

Accuracy of each topic was assessed and scored by classifying each section as 'completely accurate and containing all required information' (2 points), 'mostly accurate and/or missing some required information' (1 point) or 'completely inaccurate and/or missing all required information' (0 points). A maximum of 26 points could be achieved by each website. All websites that fulfilled inclusion criteria were rated/assessed independently by two dermatologists with expertise in the field of CTCL. Consensus was reached in a group decision with the larger author team in cases of rating mismatch. We further evaluated topicality and reference to study registers of each website.

**Readability**

The readability of websites was rated by automated tools on https://readable.com/. The Flesch Reading Ease score and Flesch–Kincaid Grade Level incorporate the number of syllables, words and sentences, while the Automated Readability Index considers characters instead of syllables. The Flesch Reading Ease score results in a total score expressing 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), easy (80–89), to very easy (90–100). The Automated Readability Index and the Flesch–Kincaid Grade Level are based on US grade levels and express the years of school education necessary to understand the information.

**Website certification**

To assess a website’s quality standards, we used the Health On the Net Foundation code of conduct Firefox plug-in. The HON-code is a certification online site from the Health On the Net Foundation to standardize reliability and credibility of information over the Internet. Websites that are certified by the HON-code adhere to eight ethical principles: authorship, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, and advertising policy. HONcode was selected, as it is the most widely accepted certification online site.

**Popularity**

To measure the website’s popularity, we used the Alexa web analytics tool (www.alexa.com). This tool allows to estimate a websites’ popularity and importance based on 3 months of aggregated traffic data from 30 million internet users who have the Alexa Toolbar installed. The website with the highest combination of visitors and page views is ranked as 1, the lowest rank is somewhere around 30 million. All other websites are rated in between. To assess the popularity on social media, we used the sharedcount tool (https://www.sharedcount.com/app/) to assess the links of websites that were shared on Facebook.

**Statistics**

Statistical analyses were performed using GraphPad Prism 8 software for Mac. Values are expressed as median plus interquartile range (IQR) or mean ± standard deviation, as appropriate. Normal distribution of data was assessed by the Kolmogorov–
Smirnov test. Statistical differences between the groups were analysed with the Mann–Whitney U test or the Student’s t-test. A P value of <0.05 was considered statistically significant.

**Results**

The search using the three different keywords resulted in 1000 of websites. Of them, the first 450 websites (first 50 websites from each search engine and key word) were considered.

A flow chart for selection criteria and content analysis is shown in Fig. 1.

There were considerable overlaps for each keyword and 206 were excluded for duplication of websites. We then analysed 244 websites (83 for ‘mycosis fungoides’, 86 for ‘Sézary syndrome’, 75 for ‘cutaneous t-cell lymphoma’). From those we further excluded scientific articles (n = 74), websites without information for patients (n = 20), websites with paid content (n = 12), PDF files (n = 5), social media websites (n = 1), solely visually based websites (n = 4), forums/blogs (n = 5), videos (n = 1), online dictionary (n = 1), advertisement (n = 2), inaccessible websites (n = 4). Finally, websites that were mentioned more than once for the different keywords (n = 26) were excepted resulting in an analysis of the 89 most searched patient-addressed websites. Table 1 shows a summary of quality, readability and popularity of all websites.

The majority of all websites (n = 67; 75.3%) were publicly provided. Of all 89 websites 23 (25.8%) were HONcode certified (Table 1). According to the Flesch Reading Ease score, the websites were difficult to read (mean 42.57 ± 16.49). In average 9 years of US school education was needed to comprehend the presented content properly according to the Flesch–Kincaid Grade Level (mean 9.89; SD ± 2.31) and the Automated Readability Index (mean 8.82 ± 2.31). Only 13 (14.6%) websites were rated as understandable with a grade-level of 8 or lower. There was no significant difference regarding readability between publicly provided and physician provided websites.

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**Figure 1** Flow chart showing selection and assessment of 89 websites on CTCL and related terms.
The mean Alexa popularity rank of all websites was 525,107 ranking from 13 to 5,366,352, representing an average popularity of all websites. Comparison of website providers showed that physician provided websites were more popular compared to publicly provided websites ($P = 0.015$). There was no significant difference in readability and HONcode certification between the providers.

HONcode certified websites were easier to read according to Flesch–Kincaid Grade Level (mean 8.79 ± 1.82) compared to non HONcode certified websites (mean 10.28 ± 2.36; $P = 0.0071$). Further HONcode websites were significantly more popular according to Alexa popularity rank ($P = 0.0006$).

Accuracy of 13 topics was assessed for each website by two dermatologists with expertise in the field of CTCL. In average 8 of 13 CTCL topics (SD: 3.02) were mentioned per website of those 3.43 (SD: 2.22) subtopics contained incomplete or incorrect information.

26.5% of all mentioned topics contained incomplete or incorrect information (Table 1). 38% of potential topics were not represented by the websites at all. Presented information was mostly correct and lower accuracy scores were in most cases due to missing required information. Subgroup analysis revealed that ‘definition’ (95.5%), ‘symptoms’ (92.1%), and ‘therapy’ (80.9%) were the most mentioned topics. ‘Reference to guidelines’ (22.4%), ‘pictures’ (31.5%), and ‘complications’ (37.1%) were the most frequently underrepresented topics (Fig. 2a). The most accurately presented topic was ‘definition’ with 62 of 89 websites completely and correctly covering this topic.

Although information on ‘symptoms’ were mentioned by most websites, this was the least accurately reported subtopic with 37 out 89 websites classified as giving inaccurate or incomplete information. The overall content score was significantly higher for publicly provided compared to physician provided websites ($P = 0.0001$, Table 1). Subgroup analysis revealed that the subtopics ‘epidemiology’ ($P < 0.0001$), ‘aetiology’ ($P < 0.0001$), ‘differential diagnosis’ ($P = 0.02$), ‘pictures’ ($P = 0.0003$) and ‘authorship and references’ ($P = 0.0056$) were more accurately reported by publicly provided websites (Table S2). HONcode certified websites showed a significant higher overall content score ($P = 0.023$). In detail the subtopics ‘aetiology’ ($P = 0.0088$), ‘complications’ ($P = 0.0194$) and ‘authorship and references’ were more accurately and completely mentioned by HONcode certified websites (Table S2). We further evaluated the topicality of the websites. 70 (78.6%) websites gave clear information on the last date of update. For 11 (12.36%) websites this information could be extracted from the websites’ source code. 38 (42.7%) of all websites were updated in the last 2 years. All other websites (57.3%) have not been updated for 3 or more years or did not contain any update information.

Besides, we analysed if the content score differentiated between websites with high Flesch–Kincaid Grade Level (Grade Level > 8, mean content score: 10.46 + 3.711) and websites...
that were understandable by the general public (Grade Level ≤ 8, mean content score: 14.05 ± 6.408). Grade Level > 8 was associated with significant higher content scores (*P* = 0.0086, Fig. 2b).

Table 2 shows the top 10 websites according to the quality of information given. All of the top 10 websites were publicly provided. Only three websites were HONcode certified. The readability was mostly difficult or very confusing according to the Flesch Reading Ease score. Only one website was rated with a ‘standard’ readability and by this could be comprehended by the general public. Most websites were updated in the last 2 years.

We further analysed the top five ranked Google search results for each keyword (Table S1). Of the 15 websites, 13 were publicly provided. Seven websites were HONcode certified. All websites required reading capabilities beyond those of general public. Accuracy-scores did not significantly differ from the other websites. Two top-ranked websites (both from the same provider) were among the top content rated websites. We also present the top 5 shared websites on Facebook (Table 3). These websites were mostly physician provided and not HONcode certified showing variable readability and quality. None of the top 5 shared websites on social media were among the top websites according to content quality.

**Discussion**

The Internet is an important source of information for cancer patients.6,7 However, patients are mostly incapable to evaluate the quality of information presented online, thus physicians need to be aware of and provide patients with reliable websites.17,18 To date, no work has been published comprehensively assessing the most visible websites providing CTCL patient online information.

In our review of CTCL websites, we found greatly varying quality of online patient information. Most of the information presented on CTCL was technically correct, yet key information was missing in more than 26% of mentioned topics. Besides mentioned but incompletely reported health topics, completely absent topics were a problem as well with 38% of websites neglecting one or more topic completely. Among the least covered topics were ‘reference to guidelines’ and ‘complications’. In addition, only half of the websites stated authorship and references completely accurate. There were further important shortcomings related to topicality. Less than half (42.7%) of the websites were updated in the last 2 years. Mentioning guidelines, authorship, references and the date of last update increases the credibility and reliability of a website. Missing information might complicate patients’ validation of the reliability of cancer information found online. The unsatisfying presentation of important complications such as infections, fatigue or potential side effects of common therapies was another major deficiency. Adequate information of potential complications might raise awareness and might empower patients to consult their oncologist on time when needed.

Another hurdle patients are facing when searching online for CTCL information is comprehension of presented material. Most of the websites analysed (85.4%) were written at an
Flesch–Kincaid grade level of nine or above which is deemed as difficult to read. The United States Department of Health and Human Services, and the American Medical Association guidelines recommend that patient information resources should be written at or below the grade six level to improve comprehension of laypersons.\textsuperscript{19,20} In our analysis only four websites fulfilled this recommendation. Analysis of the ten most accurate websites according to guideline concordance revealed that nine of ten websites were difficult or very difficult to read with five websites requiring college graduate reading skills. The difficult readability may be based on a common use of complex medical terms without explaining them in layperson’s terms. In general, we could show that CTCL websites that were of better quality regarding accuracy of presented material were classified as significantly

| Website URL | Content scoring | Search engine rank | Provider | HONcode | Alexa Rank | Readability Level | Topicality |
|-------------|-----------------|--------------------|---------|---------|------------|------------------|------------|
| StatPearls https://www.statpearls.com/articlelibrary/viewarticle/25428/ | 25 | 40 (B) | Publical | No | 116 341 | Very confusing | 2020 |
| CancerTherapyAdvisor https://www.cancertherapyadvisor.com/home/decision-support-in-medicine/hospital-medicine/mycosis-fungoides-2/ | 24 | 11 (G) | Publical | No | 149 310 | Very confusing | 2017 |
| Pathology outlines https://www.pathologyoutlines.com/topic/lymphomanonBsezary.html | 24 | 16 (G) | Publical | Yes | 132 101 | Difficult | 2021 |
| Dermnetz https://dermnetnz.org/topics/cutaneous-t-cell-lymphoma/ | 23 | 3 (G) | Publical | Yes | 50 073 | Difficult | 2021 |
| Dermnetz https://dermnetnz.org/topics/sezary-syndrome/ | 23 | 6 (G) | Publical | Yes | 50 073 | Very confusing | 2021 |
| Dermatology Advisor https://www.dermatologyadvisor.com/home/decision-support-in-medicine/dermatology/mycosis-fungoides-and-sezary-syndrome/ | 23 | 33 (G) | Publical | No | 384 170 | Difficult | 2017 |
| Wikidoc https://www.wikidoc.org/index.php/Sezary_syndrome | 22 | 41 (Y) | Publical | No | 87 511 | Difficult | 2019 |
| HealthJade https://healthjade.net/sezary-syndrome/ | 21 | 30 (B) | Publical | No | 250 263 | Standard | 2019 |
| Lymphoma Action https://lymphoma-action.org.uk/types-lymphoma-skin-lymphoma/skin-cutaneous-t-cell-lymphoma | 20 | 8 (G) | Publical | No | 741 586 | Very confusing | 2019 |
| CancerTherapyAdvisor https://www.cancertherapyadvisor.com/home/decision-support-in-medicine/haematology/sezary-syndrome/ | 20 | 11 (G) | Publical | No | 149 310 | Very confusing | 2017 |

| Social Media Share | Top 5 | Number of shares on Facebook | Provider | HONcode | Alexa Rank | Readability Level | Content scoring |
|--------------------|-------|------------------------------|---------|---------|------------|------------------|----------------|
| Mayoclinic https://www.mayoclinic.org/diseases-conditions/cutaneous-t-cell-lymphoma/symptoms-causes/syc-20351056 | 1399 | Physician | Yes | 716 | Fairly difficult | 8 |
| Cutaneous Lymphoma Foundation https://www.clfoundation.org/mycosis-fungoides | 1286 | Publical | No | 2 764 778 | Difficult | 18 |
| Johns Hopkins Medicine https://www.hopkinsmedicine.org/health/conditions-and-diseases/lymphoma/cutaneous-tcell-lymphoma | 393 | Physician | No | 5883 | Fairly easy | 8 |
| Wikipedia https://en.wikipedia.org/wiki/Mycosis_fungoides | 385 | Publical | No | 13 | Very confusing | 19 |
| National Cancer Institute https://www.cancer.gov/types/lymphoma/patient/mycosis-fungoides-treatment-pdq | 359 | Physician | No | 14 472 | Fairly difficult | 17 |
more complicated to read. This combination of highly accurate content but low readability has also been found for other websites providing patient cancer information including those providing information on melanoma skin cancer.\textsuperscript{21–25} As Google is the most popular search engine and most users tend to consume the first listed websites proposed, we analysed the top 5 ranked websites for three different CTCL related terms.\textsuperscript{12} Our analysis revealed difficult readability and only average accuracy of presented information. Only two of the top listed websites were among the most quality ranked websites. Similar results could also be seen for the top five most shared websites on social media. Suggesting that popular CTCL patient information websites may not necessarily be the most suitable for patient education. This is in line with findings for other cancer patient online material.\textsuperscript{24,25}

Comparison of physician and publicly provided websites revealed important differences. Publicly provided content was more accurate according to the quality of information given. In addition, all high ranked websites according to content quality were publicly provided. One reason for these observations might be that non-physician webmasters have better financial and personnel conditions to review and present information. This pattern could also be seen in previous analysis of websites providing bladder cancer online information.\textsuperscript{24} HONcode quality certification indicates that a website meets an ethical standard and contains quality health information. Only 23 (25.8\%) websites provided HONcode certification. This low use of quality certificates in CTCL websites is in accordance with certification of other cancer information providing websites including websites on melanoma.\textsuperscript{21,26–30} One reason for the low presence of certified websites might be the certification process. After registration webmasters have to apply every year for fee-based website certification.\textsuperscript{14} Yet, we could show that HONcode certified websites received better quality, readability and popularity scores. This is similar to other studies looking at HONcode certification of cancer information websites.\textsuperscript{21,30,31}

There are several limitations in this study. The content evaluation was based on intellectual assessment and thus may have given rise to some minor discrepancies. Further, we did not consider patient expectations and the question how widespread online cancer information for patients should be. Future works on CTCL online information should involve patients to define their needs. Our review of websites was predominantly based on readability and content analysis of written text. We did not assess layout, diagrams or content of pictures which significantly contribute to the quality and perceivability of medical information. Additionally, to guarantee reproducibility we used predefined search settings, yet most internet users use default settings and may have varying search results among others influenced by their individual Internet habits. Besides, our search was limited to English language and does not provide information on the quality of patient online material in other languages. Furthermore, the Internet is a rapidly changing medium, our current analysis is, therefore, a timely limited snapshot. The Internet is one of the most important sources for patient information and it is certain that in the future more and more patients will use online websites to get information. However as seen in our analysis high-quality material is often hidden, and trusting on the top of Google’s search results will in most cases not be the best option to find accurate and comprehensive material. Therefore, patients need to browse through a large number of sites to find relevant, reliable and accurate information. Besides being time-consuming, most laypersons may not be able to evaluate websites adequately due to widespread insufficient health literacy.

As a consequence, especially oncologists have an obligation to be aware of and guide their patients to available websites that contain reliable and appropriate information. We further suggest that physicians and national cancer services develop high quality, trustworthy and easily readable information related to CTCL. Till then recommending patients HONcode certified CTCL online information may be an acceptable and practicable stop-gap solution.

**Data availability statement**
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1 Top websites based on their Google search rank.

Table S2 Comparison of average quality score per topic. *P < 0.05.