

# Cancer-related fatigue: Quality, credibility, usability, and readability of information on websites of health care institutions in Germany

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## ABSTRACT

**Objectives:** This study aimed to portray available information on cancer-related fatigue on German health care institution websites considering the idea of patient empowerment.

**Methods:** Based on website quality criteria, we developed a website-rating tool comprising 18 items. Descriptive analyses, a Kruskal–Wallis test, and corresponding post hoc tests comparing rating sum scores between institution groups were performed.

**Results:** Websites of 283 systematically compiled health care institutions were included in the rating. Cancer-related fatigue was introduced on 21.9% and detailed information was provided on 27.9% of the websites. Information material was offered on 9.2% of the websites, while fatigue treatment offers were presented on 21.6% of the websites. The rating sum scores differed between institution groups ( $p < 0.001$ ), with Comprehensive Cancer Centers scoring significantly higher than the others.

**Conclusion:** The rating revealed an overall sparse provision of information, with fatigue being addressed on less than half of the websites.

### Practice Implications:

For patients who have access to at least one introduction about fatigue, institutions need to extend their websites. Patients could further be referred to external institutions or information booklets. The naming of contact persons may help linking patients to providers.

## 1. Introduction

A frequent side effect of cancer and/or cancer treatment, for which patients may seek information and advice online, is cancer-related fatigue (CRF). As a “distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and/or cancer treatment that is not proportional to recent activity, and significantly interferes with usual functioning”, CRF can have a major impact on patients’ quality of life and daily functioning [1–3]. Almost all patients receiving active cancer treatment suffer from CRF at some time during the treatment phase [4,5], while one-third of patients are still impaired by associated symptoms three years postdiagnosis [6,7]. However, recent studies among cancer patients regarding CRF indicate that less than half of patients feel well informed about the issue [8,9].

Despite the availability of effective evidence-based treatment options, such as physical exercise, psychosocial interventions, and mind-body interventions [3,10,11], the demand for information might be high due to the known structural and personal barriers that CRF patients face in regard to cancer care [12].

Almost half of the patients who had at least heard about CRF had received information on CRF from the internet [8,9]. Overall, the search for health information is one of the most common informational concerns people pursue on the internet [13,14]. This finding aligns with the idea of the internet as a promising medium for transferring knowledge from experts to the public [15]. Thus, enhancing patient empowerment through providing comprehensive health information on the internet has become a major issue in health care and research [3,16,17]. Feelings of autonomy and relatedness tend to drive patients’ seeking of online

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health information [18,19]. Gathering online information regarding their illness might further empower patients to actively take part in treatment decision-making [20]. Moreover, being informed about their health concerns and available treatment options might encourage patients to improve communication and patient-provider relationships [15,21]. Due to the lack of orientation on the internet and the lack of credibility of available online information, institutional websites, including governmental and hospital websites, are likely to be initial sources of information for patients [22,23]. Hence, there are clear benefits and risks associated with the influence of internet use on treatment decisions [15,23–26]. Taking this into account, as well as the fact that health care institutions and thus their websites function as direct references for patients [17,27], the content offered on institutions' websites is crucial [25,28,29].

To improve patients' knowledge about CRF early in the cancer continuum, major cancer treatment providers need to offer good evidence-based and easily comprehensible information about this potential side effect and how to prevent or ameliorate it both in person and online. Thus, the aim of the current study was to portray publicly available online information on CRF provided by health care institutions in Germany.

## 2. Methods

To portray the available online information concerning CRF on websites of health care institutions, we obtained a website rating. Therefore, we developed a rating tool comprising 18 items. All the items are presented in Table 1. Except the last one, items were rated *yes* or *no*. Items were not only affirmed if applicable to the institution's website itself, but also if applicable to a linked external webpage that was reachable in one click. Ratings were conducted independently assigned by two raters between July and September 2022.

Our rating tool was based on general website criteria available in the literature [30–32] and, if available, oriented toward established tools [33,34]. Accordingly, one criterion covered by the items was *content*, which addressed assessing the extent of factual knowledge about CRF provided on an institution's website (e.g., Item 6: Is the term fatigue introduced and paraphrased, e.g., as an extreme exhaustion or tiredness?). Content items were generated by gathering important CRF-related facts within the research team and additionally discussing them with clinical colleagues. Another criterion covered was *quality*, which describes the quality and reliability of health information (e.g., Item 8: Are expert references made regarding, e.g., further information, individual counseling, choice of adequate treatment, or risk assessment, before physical exercise?). The DISCERN Handbook [33], which is used for assessing the quality of written information about treatment options for health problems, served as an orientation tool in item development. A third criterion covered was *credibility*. Credibility items (e.g., Item 15: Is the source of the information mentioned? Item 16: Is the author of the information named?) were based on the JAMA benchmark tool [34]. Moreover, items aimed to cover the criterion of *usability* while assessing a website's ease of use (e.g., Item 2: Does the website have a search function? Item 5: Does the website have a particular CRF webpage containing bundled information regarding CRF?). Finally, readability is a necessary condition for the understandability of written material and was therefore used as an approach to understanding the latter [35]. We covered readability with one single item assessing the Flesch index score of the text containing CRF-related information. The Flesch index measures readability using the average sentence length and average number of syllables per word. The index ranges from 0 to 100, with low scores (<60) indicating that reading a text is "demanding" to "difficult". Additionally, the required reading age can be derived from the index, indicating the minimum age at which a person is normally able to read the written material. Accordingly, the American Medical Association (AMA) recommends not exceeding the sixth grade when writing patient information [36], i.e., formulating information in such a way that

**Table 1**

A rating instrument was used to determine the available CRF-related information provided on health care institution websites.

Item	Description	Main covered criterion:
1	Does the institution have a website?	usability
2	Does the website have a search function?	usability
3	Does the search reveal any results when entering "fatigue", "exhaustion", "tiredness", "lack of energy", or "weakness"?	usability, content
4	Among the first 10 search results, are there results that could be assumed as useful (webpages with obvious information regarding CRF and/or treatment recommendations, talk announcements, research projects, etc.)?	usability, content
5	Does the website have a particular CRF webpage containing bundled information regarding CRF?	usability
6	Is the term "cancer-related fatigue" introduced and paraphrased, e.g., as an extreme exhaustion or tiredness?	content
7	Is further information given concerning e.g., causes, duration, forms of appearance or treatment options of CRF?	content
8	Are expert references made regarding e.g., further information, individual counseling, choice of adequate treatment, or risk assessment before physical exercise?	quality
9	Does the institution's website refer to detailed information material on CRF (e.g., The Blue Guide Fatigue or The Patient Guide Fatigue?)	content
10	Does the institution's website refer to support offers or treatment offers for CRF?	content
11	Are support offers, further pages, literature, etc., linked?	usability
12	Do the links to support offers, further pages, and literature work?	usability
13	Are concrete contact persons named?	quality
14	Is the information on CRF available in different languages?	usability
15	Is the source of the information mentioned?	credibility
16	Is the author of the information named?	credibility
17	Is the creation date of the information given?	credibility
18	Understandability of the information on CRF: calculate Flesch-Index score for text containing information on CRF → enter Flesch Index score Global subjective judgment: How clear, informative, useful, appealing is the website for us as "users"?	readability -

11-year-olds are able to read it. Overall, to verify the rating decisions, corresponding information on the websites was recorded in free text fields.

After the completion of the ratings, a sum score was calculated for the binary items. Because some of the items were conditional on others, e.g., an available website (Item 1) and search function (Item 2) for any search results, as well as the presence of links (Item 11) for the functionality of the links, they were not included in the sum score. Hence, the highest possible sum score was 14 points.

The targeted institutions consisted of all German Comprehensive Cancer Centers (CCCs) registered at that time in the CCC network of German Cancer Aid (Deutsche Krebshilfe, DKH) ( $n = 14$ ), all organ-specific certified cancer centers (CCs) registered at that time by the German Cancer Society (Deutsche Krebsgesellschaft, DKG) ( $n = 116$ ), as well as random samples of noncertified hospitals with an oncological focus ( $n = 70$ ), practices for oncology ( $n = 70$ ), and outpatient counseling units ( $n = 70$ ); the overall aim was to systematically compile list of institutions. If the data were provided on the registries' websites, the institutions' websites were directly accessed via the links. Otherwise, the websites were searched manually on the internet. The websites of the institutions were public in nature.

Descriptive analyses were conducted to portray the available information and its presentation on the websites. Subsequently, a Kruskal–Wallis test and corresponding post hoc tests were run to determine whether the rating sum scores differed according to the type of

institution. We used IBM SPSS version 29.0.0.0., with  $p < 0.05$  (two-tailed) considered to indicate statistical significance.

### 3. Results

Of the 340 initially drawn institutions, some could not be included in the rating process either because no websites were found ( $n = 51$ ) or because their websites were permanently inaccessible during our assessment period of ten weeks ( $n = 6$ ), resulting in a sample of 283 institutions ( $n = 14$  CCCs,  $n = 116$  CCs,  $n = 69$  hospitals with oncological focus,  $n = 50$  practices for oncology,  $n = 34$  outpatient counseling units).

In step one, information was searched using the search function of a website if such a function was available. Of the 283 institutions with a website, 64 (22.6%) did not provide a search function (Table 2). Overall, 80% of the websites returned results when CRF-related terms were entered. In 48.9% of the 174 websites that revealed search results for fatigue-related terms, any hit results were considered useful for patients looking for information regarding CRF.

Looking separately at the different search terms, there were no results for the search term “fatigue” on 28.8% of the 174 websites where searches revealed any results. The terms “lack of energy” and “weakness” were less likely to be linked with no results for 87.9% and 70.1% of those websites, respectively. The search terms “tiredness” and “exhaustion”, which are common terms in everyday language, almost always revealed some results (90.8%, 86.2%). The results that were classified as not useful were, e.g., pages that could not be found (any), expired events, or content associated with health concerns other than cancer, such as fatigue in patients with multiple sclerosis.

In addition, we manually screened the websites of the included institutions for CRF-related information. The results regarding the provision of detailed information on the CRF on the websites are presented in Table 3. Seventeen websites (6.0%) had a separate webpage only for CRF, which could be reached on average within three clicks from the institution’s home page. The term “cancer-related fatigue”, which is a medical term but not a common term in the German language, was introduced and paraphrased (e.g., as an extreme exhaustion or tiredness) on 21.9% of the websites. Slightly more institutions (27.9%) provided detailed information on CRF (regarding causes, forms of appearances, treatment options, etc.), indicating that detailed information was sometimes given without a preceding introduction of the term CRF. On almost all the websites offering more detailed information (92.4%), treatment options for reducing fatigue were presented, with physical exercise being listed most often. Other treatment options identified in the free text included psychosocial support, such as patient

education, time and sleep management, relaxation, nutrition-based programs, blood transfusion, pharmacological therapy with stimulants and antidepressants, mistletoe therapy, acupuncture, or physiotherapy. In addition to providing written online information, 15.5% of the institutions referred to experts regarding CRF and its treatment; i.e., they emphasized that patients need to see trained practitioners and need to be accompanied by them. Expert references were made, e.g., regarding screening and diagnostics, choice of adequate treatment, or risk assessment, before attending physical exercise.

The results regarding the provision of informational material and support are likewise included in Table 3. Less than 10% (9.2%) of the institutions provided information material on CRF, such as the fatigue booklet [37] provided by German Cancer Aid. Sixty-one (21.6%) institutions referred to treatment or support offered either inside or outside the institution. Inside the institutions, there were, e.g., individual training classes, yoga and qigong classes, art therapy classes, psycho-oncological counseling, particular consultation hours for CRF, and self-management programs provided according to the free text. Outside the institutions, patients were referred to local sports associations and outpatient counseling units. Some institutions also offered online support or training videos for home use. Treatment offers were linked on half of the 61 websites (50.8%). One such link was not working (3.2%). Contact information regarding support and treatment offers was given on 73.7% of those websites.

On 4 of 109 websites addressing CRF (3.7%) (i.e., which at least offered an introduction of the term fatigue, having provided any useful fatigue-related information, information material, or treatment options), information was available in at least one language other than German. The language options were English, Polish, or Arabic. On 23 of the 109 websites addressing CRF (21.1%), sources of CRF-related information were clearly apparent. Twenty-four institutions providing information (22.0%) disclosed their website’s authors, and 22 institutions (20.2%) mentioned the information’s date of creation on their website.

We finally assessed the readability of the CRF-related information provided on the websites using the Flesch index score. The mean Flesch index score was 34. The mean required reading age was  $> 15$  years. Overall, the contents were difficult to read.

Rating sum scores had a median of 1.0 points ( $Q1 = 0$ ;  $Q3 = 4$ ). One-third (32.9%) of the institutions scored a minimum of 0 points, indicating that the institutions had provided no information about CRF. Twenty-seven percent of the institutions scored 1 point, mostly indicating that the automatic search had revealed at least some kind of result. The rating sum scores for each type of institution are presented in Fig. 1.

**Table 2**  
Information on CRF retrieved using search functions on health care institution websites.

All		Comprehensive Cancer Centers		Organ-specific Cancer Centers		Noncertified hospitals with oncological focus		Practices for Oncology		Outpatient counseling units		
N	%	n	%	n	%	n	%	n	%	n	%	
Website of institution available												
Yes	283	83.2	14	100.0	116	100.0	69	98.6	50	71.4	34	48.6
No	57	16.8	0	-	0	-	1	1.4	20	28.6	36	51.4
Search function on the website available <sup>a</sup>												
Yes	219	77.4	14	100.0	105	90.5	67	97.1	11	22.0	22	64.7
No	64	22.6	0	-	11	9.5	2	2.9	39	78.0	12	35.3
Any results received when searching for CRF-related terms <sup>b</sup>												
Yes	174	79.5	13	92.9	92	87.6	56	83.6	4	36.4	9	40.9
No	45	20.5	1	7.1	13	12.4	11	16.4	7	63.6	13	59.1
Useful results received when searching for CRF-related terms <sup>c</sup>												
Yes	85	48.9	11	84.6	34	37.0	28	50.0	4	100.0	8	88.9
No	89	51.1	2	15.4	58	63.0	28	50.0	0	-	1	11.1

Abbreviations. n, number of institutions/websites; N, number of all institutions; CRF, Cancer-related Fatigue

<sup>a</sup> reported proportions refer to institutions (per group) with available website

<sup>b</sup> reported proportions refer to websites (per group) with available search function

<sup>c</sup> reported proportions refer to websites (per group) with available search function returning any results when entering CRF-related terms (fatigue, tiredness, exhaustion, lack of energy, lack of power)

**Table 3**

Information on CRF available on health care institution websites: Detailed results from the website rating.

	All		Comprehensive Cancer Centers		Organ-specific Cancer Centers		Noncertified hospitals with oncological focus		Practices for Oncology		Outpatient counseling units	
	n	%	n	%	n	%	n	%	n	%	n	%
<b>Webpage on CRF available<sup>a</sup></b>												
Yes	17	6.0	5	35.7	7	6.0	2	2.9	1	2.0	2	5.9
No	266	94.0	9	64.3	109	94.0	67	97.1	49	98.0	32	94.1
<b>Term cancer-related fatigue introduced or paraphrased<sup>a</sup></b>												
Yes	62	21.9	12	85.7	29	25.0	15	21.7	3	6.0	3	8.8
No	221	78.1	2	25.0	87	75.0	54	78.3	47	94.0	31	91.2
<b>Detailed information (but an introduction of the term cancer-related fatigue) provided<sup>a</sup></b>												
Yes	79	27.9	12	85.7	31	26.7	17	24.6	6	12.0	13	38.2
No	204	72.1	2	14.3	85	73.3	52	75.4	44	88.0	21	61.8
<b>Number of websites providing more detailed information regarding...<sup>b</sup></b>												
CRF as a common consequence (of cancer therapy)	47	59.9	7	58.3	17	54.8	11	64.7	5	83.3	7	53.8
Duration of CRF	25	31.6	4	33.3	9	29.0	3	17.6	3	50.0	6	46.2
Forms of appearance of CRF	20	25.3	6	50.0	5	16.1	2	11.8	3	50.0	4	30.8
Causes and risk factors for CRF	31	39.2	7	58.3	12	38.7	4	23.5	2	33.3	6	46.2
Treatment options of CRF	76	92.4	12	100.0	31	100.0	14	82.4	6	100.0	13	100.0
Yoga/Tai Chi/ Qigong	16	20.5 <sup>c</sup>	5	41.7 <sup>c</sup>	4	12.9 <sup>c</sup>	1	7.1 <sup>c</sup>	2	33.3 <sup>c</sup>	4	30.8 <sup>c</sup>
Physical exercise	57	75.0 <sup>c</sup>	11	91.7 <sup>c</sup>	25	80.6 <sup>c</sup>	9	64.3 <sup>c</sup>	4	66.7 <sup>c</sup>	8	61.5 <sup>c</sup>
Psychotherapy/ Psycho-oncology	32	42.5 <sup>c</sup>	7	58.3 <sup>c</sup>	17	54.8 <sup>c</sup>	2	14.3 <sup>c</sup>	1	16.7 <sup>c</sup>	5	38.5 <sup>c</sup>
Other	43	54.8 <sup>c</sup>	7	58.3 <sup>c</sup>	16	51.6 <sup>c</sup>	9	64.3 <sup>c</sup>	2	33.3 <sup>c</sup>	9	69.2 <sup>c</sup>
<b>Expert references made regarding CRF</b>												
Yes	44	15.5	13	92.9	16	13.8	8	11.6	2	4.0	5	14.7
No	239	84.5	1	7.1	100	86.2	61	88.4	48	96.0	29	85.3
<b>Information material regarding CRF provided</b>												
Yes	26	9.2	4	28.6	8	6.9	4	5.8	4	8.0	6	17.6
No	257	90.8	10	71.4	108	93.1	65	94.2	46	92.0	28	82.4
<b>Support/Treatment offers provided</b>												
Yes	61	21.6	13	92.9	15	12.9	20	29.0	1	2.0	12	35.3
No	222	78.4	1	7.1	101	87.1	49	71.0	49	98.0	22	64.7
<b>Support/Treatment offers linked<sup>d</sup></b>												
Yes	31	50.8	10	76.92	8	53.33	7	35.0	1	100.0	5	41.67
No	30	49.2	3	23.08	7	46.67	13	65.0	0	-	7	58.33
<b>Links of support offers working<sup>e</sup></b>												
Yes	30	96.77	9	90.0	8	100.0	7	100.0	1	100.0	4	80.0
No	1	3.23	1	10.0	0	-	0	-	0	-	1	20.0
<b>Contact persons regarding support/treatment offers named<sup>d</sup></b>												
Yes	45	73.7	12	92.3	8	53.3	14	70.0	1	100.0	10	83.3
No	16	26.3	1	7.7	7	46.7	6	30.0	0	-	2	16.7

Abbreviations. n, number of institutions/websites; CRF, Cancer-related Fatigue

<sup>a</sup> reported proportions refer to institutions (per group) with available website<sup>b</sup> reported proportions refer to institutions (per group) providing more detailed information on CRF<sup>c</sup> reported proportions refer to institutions (per group) providing more detailed information regarding treatment options<sup>d</sup> reported proportions refer to institutions (per group) providing support offers<sup>e</sup> reported proportions refer to institutions (per group) linking support offers

No institution reached the maximum of 14 points. The highest sum score, which was reached by three institutions, was 12 points. Three further institutions reached 11 points. All of these institutions provided informational material based on which the rating was at least partially carried out, but they did not necessarily have a particular webpage dedicated to CRF. According to the Kruskal–Wallis test, the scores differed significantly between the different types of institutions ( $H(4) = 75.298, p < .001$ ), with the CCC score being significantly greater ( $Q1 = 8, Q3 = 10$ ) than the others. The Dunn–Bonferroni post hoc correction results indicated significant differences (Table 4).

## 4. Discussion and conclusion

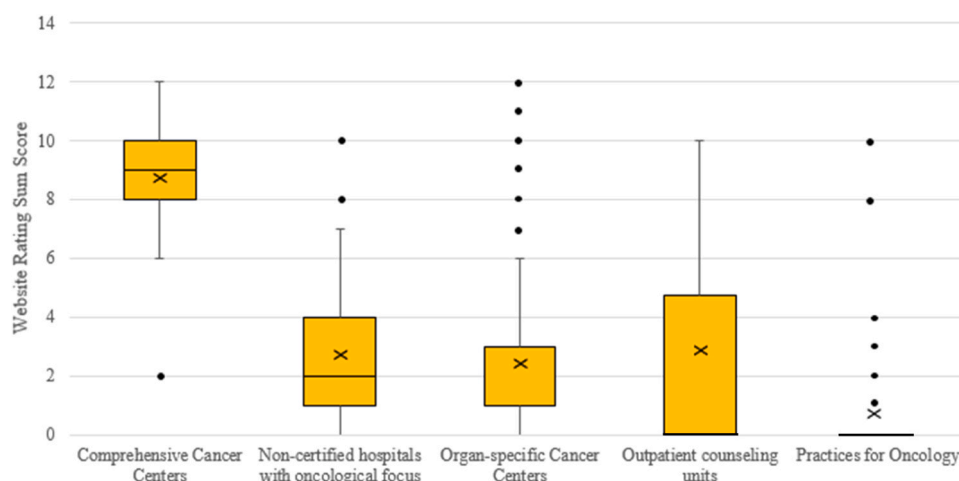
### 4.1. Discussion

To determine the current state of available online information on CRF provided on the websites of health care institutions in Germany, we conducted a website-rating process. The rating process included the assessment of a website's CRF-related content and its quality, credibility, usability, and readability. Overall, the results showed that the

information on CRF provided on German health care institution websites is scarce.

According to previous research, however, patients refer to health care institutions when searching for health-related information on the internet [22,23] as sources for acknowledgment, reduction of uncertainty, and perspective [19]. According to our results, Comprehensive Cancer Centers (CCCs), which are certified as centers of excellence in cancer care, scored significantly higher than did all other institution groups regarding the provision of information on CRF. Practices for oncology, on the other hand, scored significantly lower. Although websites of well-known health care institutes, such as the CCCs, might be accessed by patients because of their perceived outstanding professionalism, websites of smaller, local institutions, such as general hospitals, practices, and outpatient counseling units, might also be accessed due to familiarity and patient personal identification [23].

Turning to the detailed rating results, on only half of the websites whose search algorithm revealed any hit at all for the term “fatigue” or associated terms, the search results were appropriate, while one-fifth of the included websites did not provide a search function. The search terms “tiredness” and “exhaustion” almost always revealed results.



**Fig. 1.** Overall website rating sum scores per health care institution group. *Note.* Boxplot of website rating sum scores per institution group showing mean scores, median scores, upper quartiles, lower quartiles, and outliers as extreme values (all scores being 1,5 times the interquartile range above the upper or below the lower quartiles) with higher scores indicating more information about cancer-related fatigue on the website.

**Table 4**

Comparison of the overall website rating sum scores between health care institution groups.

Group 1	Group 2	Comparison of rating sum scores (Group 1 – Group 2)				
		<i>H</i>	<i>SE</i>	<i>z</i>	<i>p</i>	<i>d</i>
Practices for Oncology	Outpatient counseling units	-59.03	17.67	-3.34	.008	-.0736
	CCs	76.65	13.45	5.70	< .001	-.0665
	Noncertified hospitals with oncological focus	89.91	14.76	6.09	< .001	-.0854
Outpatient counseling units	CCCs	187.79	24.04	7.81	< .001	-.3829
	CCs	17.62	15.50	1.14	1.00	
	Noncertified hospitals with oncological focus	30.89	16.66	1.86	0.637	
CCs	CCCs	128.76	25.24	5.10	< .001	-.1833
	Noncertified hospitals with oncological focus	-13.26	12.09	-1.10	1.00	
	CCCs	111.15	22.49	4.94	< .001	-.2337
Noncertified hospitals with oncological focus	CCCs	97.88	23.30	4.20	< .001	-.2342

Abbreviations. CCCs, Comprehensive Cancer Centers; CCs, Organ-specific Cancer Centers.

Dunn-Bonferroni post hoc-tests comparing each group of institution to another. *H*, test statistic; *z*, standardized test statistic; *SE*, standardized error; *p*, *p* value (adjusted for ties); *d*, Cohen's *d*.

Considering that most patients suffering from CRF might also use such information when they are searching for information, especially if they have not yet heard of the foreign French-based term “cancer-related fatigue”, this seems opportune. Moreover, these terms lead to less specific search results due to their relatively broad meaning. Thus, to

further facilitate patients' access to provided health information, a website's usability, for example, the algorithms used in the website's search function, needs to be considered. There can be no use of information if the information is too difficult to find. Therefore, people's digital health literacy, i.e., their personal requirements to understand, evaluate, and use (online) information and services for health-related decisions, also needs to be taken into account [38].

Beyond the small number of institutions providing a particular webpage on CRF, detailed information on CRF was provided on one-fourth of the websites. Within detailed information, treatment options were almost always considered, especially physical exercise, comprise the most promising intervention for reducing CRF [3,10]. On the other hand, psychotherapy, and mind-body practices as further evidence-based treatment options [3,10,39,40] were cited on less than half of the websites. While previous research has noted a commercial focus on institutional websites, asserting that health care institutions primarily promote their own services rather than empowering patients by providing information [14,28], this is rather not applicable to our study. Treatment offers were more often provided than comprehensive information material was. However, considering the overall scarce amount of information and/or treatment offers, there was no considerable imbalance found.

While detailed information on CRF does not necessarily need to be provided on an institution's website itself, the term “cancer-related fatigue” should at least be introduced and shortly prescribed, as well as the fact that CRF is manageable. For further comprehensive information on causes, duration, forms of appearances, evidence-based treatment options, etc., references should then be made to adequate external websites of known institutions such as German Cancer Aid, the German Cancer Society, the German Fatigue Society, or patient advocate websites to utilize already existing, credible, and currently updated information on CRF. As patient advocates websites are primarily based on the patients' perspective their interests and worries might be reflected which, in turn, makes patients feel seen. Likewise, existing informational materials such as information booklets can be linked for detailed information (e.g., The Blue Guide Fatigue of German Cancer Aid [37], The Patient Guide Fatigue of the Bavarian Cancer Society [41], or the Fatigue Brochure of the National Center for Tumor Diseases Heidelberg [42]).

According to previous studies, other criteria that patients consider important when searching for information online are the interpretability and up-to-dateness of the information [22,23]. Regarding the up-to-dateness, in our study, few institutions reported the information's date of creation. However, due to ongoing research on CRF, online information needs to be regularly updated. The creation date, author, and



source should generally be indicated to increase the level of credibility and, subsequently, the level of patient confidence. Regarding understandability, the CRF-related information found during the study was difficult to read overall. To break down barriers and empower patients, online health information should be translated into short sentences. Medical terms, if any, should then be used as necessary alongside corresponding explanations. The use of well-explained medical terms is important for empowering patients to communicate with their health care professionals (HCPs). Thus, patients learn not only that their symptoms need to be spoken when talking to their HCPs but also that they need to acquire the words necessary to explain those symptoms.

In addition to providing information on websites, some institutions refer patients to experts on CRF, indicating that the provided online information, no matter how comprehensive it is, is not meant to be a replacement for in-person contact with HCPs. Hence, CRF needs to be treated professionally or at least according to professional guidance. If contact data are provided that extend beyond expert references, this might further increase a patient's confidence in the institution and willingness to contact the institution.

Several strengths and limitations should be noted. To our knowledge, this is the first study to map the currently available online information regarding CRF on health care institution websites. Thus, the information gaps indicated in the explorative results of our study can serve as starting points for improvements in the information offered by health care institutions on the internet. Moreover, the study sample was systematically compiled to represent all types of health care institutions involved in cancer care, which also enabled a comparison between the types of institutions.

We are aware that our rating might have set high expectations for the websites of institutions and that the expected conditions might not be feasible. To address this concern, we included not only information from the websites themselves but also linked information material or linked external websites. By linking credible information, an institution may already signal its awareness of CRF and be responsible for guiding patients' often demanding online health information searches. Furthermore, we did not consider the provision of information regarding other health concerns on the institutions' websites for comparison. Moreover, the actual need for online health information among CRF patients is mostly unknown. However, owing to barriers in CRF care reported in the literature and the unmet need for information among patients suffering from CRF, we expect frequent internet use when searching for adequate information. Further studies should therefore further determine the online information needs related to online health information seeking among CRF patients to further adjust the internet offerings. Likewise, websites other than those of health care institutions, which patients with CRF probably rely on in addition to or as an alternative to the latter, should be taken into consideration.

#### 4.2. Conclusion

While health care institutions serve as direct references for patients when searching for health information both in person and online, our website rating process revealed an overall sparse provision of information on CRF on corresponding German websites. Searching for CRF-related information using a website's search function resulted in a similar picture as when searching manually. Overall, only 40.0% of the institutions addressed CRF on their website. In comparison to the other health care institution groups in our study, CCCs currently provide the most comprehensive online information concerning CRF, even if half of them also lack such information.

#### 4.3. Practice implications

As there is a highly unmet need for information among cancer patients with CRF, e.g., because of time constraints in daily clinical practice, online information is an important resource. Since online

information is free and accessible at any time, it could also empower patients and increase their level of self-efficacy. However, according to our results, the contents of health care institution websites mostly do not meet the outlined needs of patients. Hence, several practical implications can be drawn from our results. While detailed information on CRF does not necessarily need to be provided on the institution's website itself, the provision of credible up-to-date information can be seen as a health care provider's task to help guide patients in their search for credible health information. This may be achieved by referring to adequate external websites of known institutions and patient advocate websites or by linking existing informational material such as information booklets on CRF. What needs to be provided on the health care institutions' websites is an introduction of the term "cancer-related fatigue" and a short description. Additionally, because CRF is manageable, treatment offered at the institution should be presented. Specifically naming concrete persons as experts inside the institution who are trained on CRF and whose corresponding contact information will further signal and raise awareness of CRF. Moreover, regarding website content creation, there is a need for collaboration and arrangements between HCPs working inside an institution, related external institutions, and informatics specialists. To further facilitate patients' access to the provided information, a search function should be available on the website containing adequate search algorithms. In addition, information should be presented in plain language, ideally with other language options available aside from German. Starting from previous recommendations, the use of health care institution websites as an available key resource for patient empowerment could be enhanced. Thus, this study may help to improve CRF management at the institutional level, which will then lead to a reduced disease burden and increase quality of life for the patients themselves.

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#### CRedit authorship contribution statement

**Milzer Marlena:** Writing – review & editing, Methodology, Investigation. **Wagner Anna S.:** Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Data curation. **Steindorf Karen:** Writing – review & editing, Project administration, Funding acquisition, Conceptualization. **Maatouk Imad:** Writing – review & editing, Project administration, Funding acquisition, Conceptualization. **Schmidt Martina E.:** Writing – review & editing, Project administration, Funding acquisition, Conceptualization. **Kiermeier Senta:** Writing – review & editing, Methodology, Investigation.

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The authors declare the following financial interests/personal relationships which may be considered as potential competing interests. Prof. Dr. Imad Maatouk reports financial support was provided by German Research Foundation. Prof. Dr. Karen Steindorf reports a relationship with German Ministry of Education and Research that includes: funding grants. Karen Steindorf received personal fees for lectures with some relation to fatigue by Adviva and Takeda.

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