



Patient–physician communication about cancer-related fatigue: a survey of patient-perceived barriers

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Abstract

Purpose Cancer-related fatigue is a subjective, distressing, and common sequela of cancer which is often disregarded and underdiagnosed. Fatigue is assessed by self-report requiring communication between patient and physician. In this study, we investigated the patients' perspective on the patient–physician communication about fatigue.

Methods On average five months after diagnosis 1179 cancer patients, recruited in Germany, completed a survey as part of the LIFT project. The survey included questions on sociodemographic data, fatigue, depression, fatigue management, patient–physician communication, and communication barriers. Data were analyzed descriptively and using logistic regression analyses.

Results Half of the participants reported that their physician had never asked them whether they felt exhausted. Patients undergoing chemo-, radio-, or immunotherapy were more likely to be asked about fatigue, while older age and major depression decreased the likelihood. Sixty-four percent of the patients felt impeded by communication barriers. Common barriers were not knowing who to turn to for fatigue (39%), time constraints (31%), and the fear of being perceived as weak (22%). Almost half of the participants indicated that their physicians were not appreciative and did not deal adequately with fatigue-related questions.

Conclusion This study revealed gaps in the patient–physician communication regarding cancer-related fatigue. Contrary to guideline recommendations a minority of physicians addressed fatigue. On the other hand, cancer patients felt reluctant to bring up this topic due to structural barriers and fears. Physicians should routinely address fatigue and adopt a communication style which encourages patients to likewise state their symptoms and raise their questions.

Trial registration Clinicaltrials.gov, identifier: NCT04921644. Registered in June 2021.

Keywords Cancer-related fatigue · Patient participation · Patient–physician communication · Structural barriers · Supportive care

Composition of the Cancer Registry of Baden-Württemberg individual contributors is listed in Acknowledgements.

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Introduction

Cancer-related fatigue (CRF) refers to a ‘distressing, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning’ (National Comprehensive Cancer Network 2023). As shown by a large-scale multicenter study, almost half of the cancer patients undergoing treatment show moderate to severe CRF levels (Wang et al. 2014). CRF may persist years after diagnosis, with prevalences differing between cancer types (Schmidt et al. 2020). Sociodemographic characteristics as well as disease-related factors (e.g., cancer type, cancer treatment, stage, performance status) seem to affect CRF (Andrykowski et al. 2005; Bower 2019; Wang et al. 2014). Furthermore, CRF is more likely to occur in individuals with a history of depression or anxiety and in individuals who are physically inactive (Kuhnt et al. 2019; Roila et al. 2019; Wang et al. 2014). However, the underlying biological mechanisms have not yet been elucidated in detail (Bower 2019).

CRF has a negative impact on quality of life and hampers the ability to carry out daily activities and return to work (Arndt et al. 2006; Behringer et al. 2016; Jung et al. 2018; Schmidt et al. 2019). Generally, non-pharmacological interventions are superior to pharmacological interventions in the treatment of CRF (Mustian et al. 2017). High-level scientific evidence, both for patients under treatment and post-treatment, is available for physical activity including yoga and for psychosocial interventions (psychoeducation, cognitive behavioral therapy) (National Comprehensive Cancer Network 2023).

The above-introduced definition of CRF as a *subjective* experience implies that CRF is most accurately captured by self-reports (National Comprehensive Cancer Network 2023). Indeed, in the absence of specific biological markers, communication between patients and healthcare professionals (HCPs) about CRF is necessary. Clinical practice guidelines for CRF recommend HCPs to initiate communication about CRF by conducting a systematic screening and offering education about CRF (Fabi et al. 2020; National Comprehensive Cancer Network 2023). More precisely, cancer patients should be routinely and regularly screened for CRF using valid and reliable instruments with established cut-offs, such as a numeric rating scale ranging from 0 (*‘no fatigue’*) to 10 (*‘worst fatigue imaginable’*) (Fabi et al. 2020; National Comprehensive Cancer Network 2023). Furthermore, it is suggested to inform all cancer patients and their caregivers about characteristics of CRF and about general strategies for coping with CRF (e.g., physical activity and energy conservation) (National Comprehensive Cancer Network 2023).

However, previous studies indicated that the recommendations are not yet implemented in clinical practice, presumably due to HCP-related, patient-related, and structural barriers (Berger et al. 2015; Berger and Mooney 2016; Schmidt et al. 2021; Smith et al. 2019). These shortcomings in CRF management lead to knowledge gaps and helplessness in patients, and may prevent efficient self-management of CRF (Schmidt et al. 2022).

If HCPs do not follow guideline recommendations by addressing CRF, do patients themselves initiate communication about CRF in medical consultations or what might impede them from doing so? Previous research has shown that patients with chronic conditions commonly report barriers to participating in medical consultations (Henselmans et al. 2015). These include the fear of being bothersome, a lack of time and remembering one’s own agenda and questions only after the medical appointment (Henselmans et al. 2015). Studies explicitly targeting communication between patient and HCPs in CRF management revealed that a lack of awareness of available treatment options and the belief that CRF is an inevitable consequence of cancer (treatment) hinder patients from addressing CRF with HCPs (Passik et al. 2002; Shun et al. 2009; Stone et al. 2000). Since the just mentioned studies were conducted before CRF-specific guidelines of major cancer organizations had been published and were mainly based on relatively small sample sizes, our study aimed to assess the patients’ perspective on current patient-physician communication about CRF. More specifically, we wanted to (1) clarify to what extent physicians initiate communication about CRF by providing information and screening, (2) investigate how patients perceive the quality of CRF-related communication with physicians, (3) identify communication barriers, and (4) explore factors associated with the perception of barriers. From this, we will derive suggestions for reducing communication barriers with the aim of enhancing participatory communication of patients as a core skill of self-management as well as HCP-driven CRF management (Howell et al. 2022).

Methods

Design and participants

This observational study among cancer patients was conducted as part of the LIFT project (Clinicaltrials.gov, identifier: NCT04921644). The LIFT project pursues the goal of assessing current CRF management in Germany from the patients’, HCPs’, and institutional perspectives to identify targets for improvements. Recruitment for the patient survey was carried out between August 2021 and September 2022. Inclusion criteria were as follows: (1) ≥ 18 years of age, (2) (newly) diagnosed primary tumor, (3) recent or current

chemotherapy, radiotherapy, hormone therapy, targeted or immune therapy, (4) ability to understand and follow the study protocol. Patients were randomly sampled from the Epidemiological Cancer Registry of Baden-Wuerttemberg, Germany, stratified by cancer entity. The Trust Center of the Cancer Registry invited patients via postal mail to participate in the study. Patients who decided to participate had two options: they could either directly access the online survey with the individual access key contained in the letter or provide consent to the Trust Center to transfer their contact data to the LIFT study team in order to receive the paper–pencil version of the questionnaire.

Procedures and measures

After having provided informed consent, patients filled out either the online or the paper–pencil survey. Completing the questionnaire took patients approximately 45 min.

Severity of CRF, including interference with daily life, was assessed with the Brief Fatigue Inventory (BFI) (Mendoza et al. 1999). By calculating the arithmetic mean over the 9 items, the global BFI score was obtained, with values < 1 being classified as no fatigue, values ranging from 1 to 3 as mild, from 4 to 6 as moderate, and from 7 to 10 as severe fatigue. Furthermore, to multidimensionally measure CRF, the European Organisation for Research and Treatment of Cancer (EORTC) fatigue module (EORTC QLQ-FA12) was used (Weis et al. 2017). The EORTC-QLQ-FA12 consists of 12 items that are allocated to the physical, emotional and cognitive domains of fatigue (Weis et al. 2017, 2019). The questionnaire reveals excellent psychometric properties (Campbell et al. 2022). Depression symptoms were measured with the Patient Health Questionnaire (depression module, PHQ-9) showing good reliability and validity (Arroll et al. 2010; Kroenke et al. 2001; Löwe et al. 2004). Sum scores below 5 indicate the absence of a depressive disorder (PHQ score = 0), while sum scores between 5 and 10 correspond to a minor depression (PHQ score = 1) and scores above 10 to a major depression (PHQ score = 2). The German version of the short form of the Illness-specific Social Support Scale ('Skalen zur sozialen Unterstützung bei Krankheit'—SSUK-8) was used to assess social support (Ullrich and Mehnert 2010). The questionnaire is composed of eight items which have to be rated on a 5-point Likert scale ranging from 0 ('never') to 4 ('always'). Four items refer to the subscale 'positive support', the other four items make up the subscale 'detrimental interaction' (Revenson et al. 1991; Ullrich and Mehnert 2010).

Screening for CRF was assessed with two questions. First, participants had to indicate if and when they were asked by their treating physicians whether they felt exhausted. In a next step, they should state if and when they were asked to rate CRF by means of a scale or a questionnaire. Further,

patients should rate on a 4-point Likert scale ranging from 0 ('not informed at all') to 3 ('well informed') how well they were informed about characteristics, causes and treatment options of CRF. Moreover, agreement to the statement 'My caregivers were well informed about fatigue.' should be rated on a 4-point Likert scale with the scale endpoints 0 ('strongly disagree') to 3 ('strongly agree') to investigate if, following guideline recommendations, caregivers were involved in education about CRF. Likewise, patients' perceived quality of communication with physicians about CRF was assessed with five statements (e.g., 'My physicians are appreciative and understanding of my questions about CRF', 'My physicians take time to address my questions about CRF'). To investigate barriers hindering patients from addressing CRF in medical consultations, agreement to ten statements (e.g., 'I am afraid of being perceived as weak and sniveling', 'I do not know who to turn to for CRF') should be judged on a 4-point Likert scale. Items for assessing communication barriers were derived from the Fatigue Management Barriers Questionnaire (Passik et al. 2002) and adjusted to more recent findings in literature and guidelines. Clinical data of the study population (including cancer type, stage, cancer treatment, etc.) were provided by the Epidemiological Cancer Registry and transmitted in encrypted form to the LIFT study team.

Statistical methods

Patient characteristics and data concerning CRF management, patient–physician communication, and perceived communication barriers are presented descriptively. To determine the factors associated with physicians addressing CRF (yes vs. no) or informing about CRF (yes vs. no), respectively, separate multiple logistic regression analyses were calculated. Based on univariate analyses and theoretical considerations, the categorical factors sex, educational level, German native language, metastasis, chemotherapy, radiotherapy, hormone therapy, immunotherapy, fatigue severity and depression, and the continuous variable age were included. The number of perceived barriers was determined as follows: First, each of the eight items assessing communication barriers were dichotomized. The value of 0 was assigned if participants had selected the answer options 'strongly disagree' or 'disagree', while the value of 1 was given if patients had (strongly) agreed to the statement. A sum score of the dichotomized variables was then calculated, resulting in a minimum of 0 and a maximum of 8. To explore which patient-related factors are associated with perceiving communication barriers, further multiple logistic regression analyses were performed separately for each dichotomized barrier. The following factors were included simultaneously: sex, age, educational level, chemotherapy, fatigue severity, depression, and social support (subscale 'positive support'

of the SSUK-8). Likewise, a logistic regression analysis was performed for the outcome variable ‘number of communication barriers’ (no communication barrier vs. ≥ 1 communication barrier).

Results

Study population

The recruitment flow is presented in Fig. 1. Between August 2021 and September 2022, a total of 7,531 cancer patients were contacted by the Cancer Registry of Baden-Württemberg, Germany, of which 230 were deceased and 182 were unreachable due to incorrect address data. Of the remaining

7,119 patients, 240 actively refused transfer of data to the study center. Of the 802 patients who consented to be sent a paper–pencil questionnaire, a total of 579 patients completed the questionnaire, leading to a return rate of 72.2%. Additionally, 664 patients accessed the online survey and provided informed consent, 604 of these (91.0%) completed the online questionnaire. Thus, the overall sample consisted of 1,183 cancer patients. Due to missing data, four patients had to be excluded for the present analyses, resulting in the final sample of 1,179 participants. Descriptive statistics of the study population are displayed in Table 1. The mean age of the study population was 63 years ($SD = 12.5$) and 56% were female. Mean time since diagnosis was 5.2 months ($SD = 1.5$). The most common cancer types in this sample were breast cancer (26%), colorectal cancer (16%) and

Fig. 1 Recruitment flow

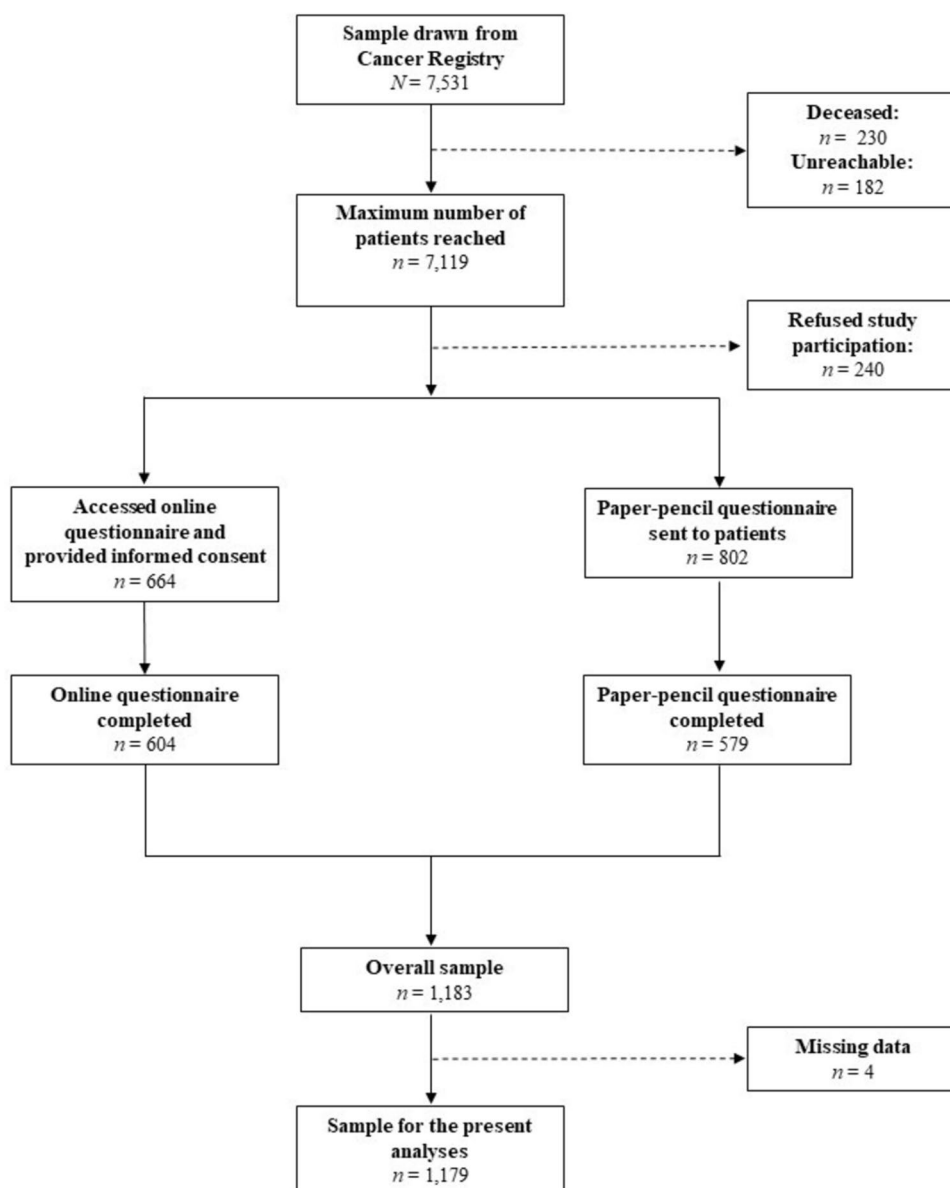


Table 1 Sociodemographic and medical characteristics of the study population (*N* = 1179)

Characteristic	Mean	Standard deviation
Age [years]	63.3	12.5
Time since diagnosis [months]	5.2	1.5
Characteristic	Number of cases ^a	%
Sex		
Female	659	55.9
Male	520	44.1
Educational level ^b		
Lower	734	62.8
Higher	434	37.2
German native language		
Yes	1062	90.9
No ^c	106	9.1
Current work status ^d		
Currently not working	915	79.2
Currently working	240	20.8
Cancer type		
Breast	308	26.1
Colorectal	193	16.4
Prostate	166	14.1
Lung	92	7.8
Malignant melanoma	81	6.9
Lymphoma	54	4.6
Pancreas	43	3.6
Stomach	40	3.4
Leukemia	38	3.2
Thyroid gland	36	3.1
Bladder or kidney	34	2.9
Gynecological tumors except breast	32	2.7
Liver	26	2.2
Multiple ^e	36	3.1
Metastasis		
No	897	76.1
Yes	226	19.2
Unknown	56	4.7
UICC stage		
0	2	0.2
I	352	29.9
II	223	18.9
III	145	12.3
IV	156	13.2
Unknown	301	25.5
Comorbidities		
None	257	22.0
≥ 1	909	78.0
Surgery		
No	304	25.8
Yes	875	74.2

Table 1 (continued)

Characteristic	Number of cases ^a	%
Chemotherapy ^f		
No	672	57.0
Yes	507	43.0
Radiotherapy ^f		
No	801	67.9
Yes	378	32.1
Hormone therapy ^f		
No	918	77.9
Yes	261	22.1
Immunotherapy ^f		
No	951	80.7
Yes	228	19.3
Targeted therapy ^f		
No	1,128	95.7
Yes	51	4.3
Fatigue severity ^g		
No fatigue	233	21.0
Mild fatigue	463	41.6
Moderate fatigue	334	30.0
Severe fatigue	82	7.4
Depression ^h		
No depression	946	84.5
Minor depression	67	6.0
Major Depression	106	9.5
Characteristic	Median	First quartile, third quartile
EORTC QLQ-FA12		
Physical fatigue	53	27, 73
Emotional fatigue	22	0, 56
Cognitive fatigue	0	0, 33

^aNumbers in cells may not add up to total $N=1,179$ due to missing data

^bLower: no degree or (lower-) secondary education degree; *Higher*: diploma qualifying for university or university degree

^cNo: 'No, but I speak German fluently' ($n=70$), 'No, but I understand almost everything when German is spoken' ($n=18$), 'No, I have difficulty understanding and speaking German' ($n=18$).

^dCurrently not working: on sick leave ($n=297$), retired ($n=545$), unemployed ($n=13$), homemaker ($n=60$); Currently working: employed ($n=235$), student/in training ($n=5$)

^eMultiple primary tumors at different locations

^fNo: Not (yet) having received or receiving the treatment; Yes: Treatment completed or currently ongoing treatment

^gReferring to the Brief Fatigue Inventory (BFI) score

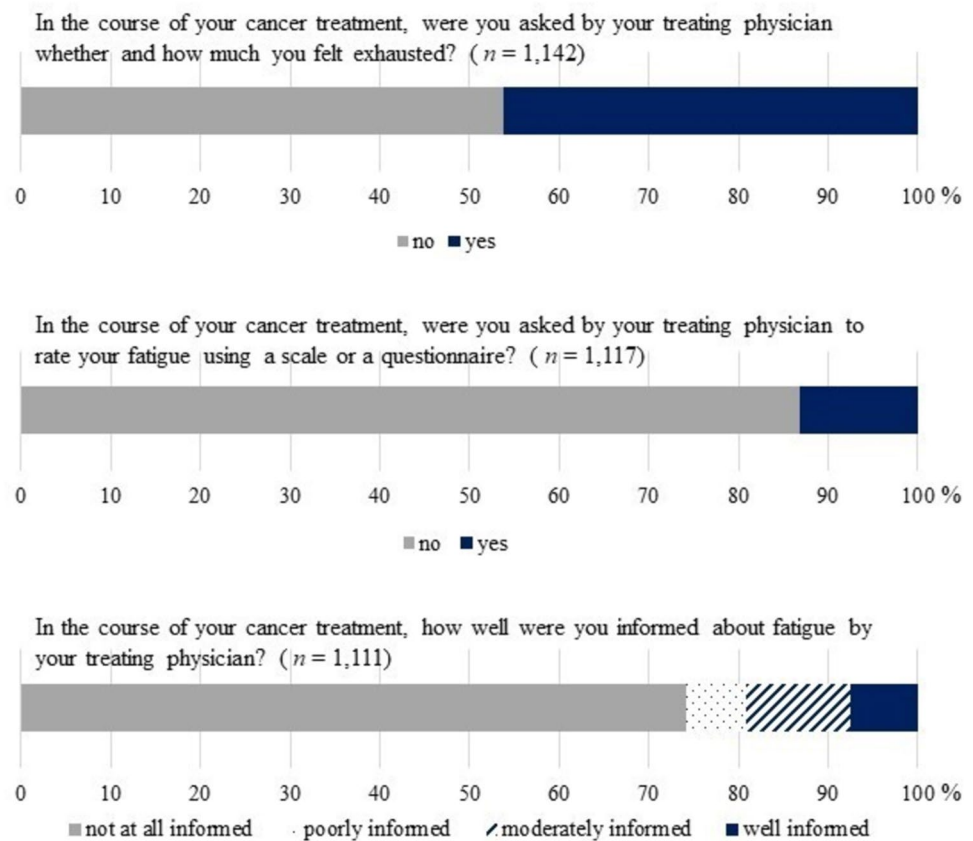
^hReferring to the Patient Health Questionnaire, depression module (PHQ-9) score

prostate cancer (14%). Metastases were reported by 19% of the study population. Seventy-four percent had received tumor surgery, 43% had either completed or were currently receiving chemotherapy. The majority of the participants reported CRF symptoms with 42% being classified as mild, 30% as moderate and 7% as severe. According to the PHQ-9, the diagnostic criteria for a major depression were met in approximately 10% of the participants.

Physician-initiated communication about CRF

As shown in Fig. 2, more than half of our participants (54%) reported that they have never been asked by their treating physician whether and how much they felt exhausted. Only 36 participants (3%) indicated that their physicians brought up the topic of CRF either before and repeatedly during cancer therapy. Results of the logistic regression analysis

Fig. 2 The patients' perspective on physician-provided screening and education about cancer-related fatigue



are displayed in Table 2. The logistic regression revealed chemotherapy, radiotherapy and immunotherapy as significant predictors, meaning that patients who had received or who were currently receiving the respective treatment were more likely to be asked by their treating physician about CRF (chemotherapy: OR = 2.56, 95% CI [1.90; 3.45], $p < 0.001$; radiotherapy: OR = 1.67, 95% CI [1.22; 2.31], $p = 0.002$; immunotherapy: OR = 1.54, 95% CI [1.07; 2.21], $p = 0.020$). Furthermore, higher age decreased the likelihood of being asked by physicians about CRF (OR = 0.98, 95% CI [0.97; 0.99], $p < 0.001$). Patients without depression were two times more likely to be asked about CRF by their treating physician than patients with major depression (OR = 0.50, 95% CI [0.29; 0.85], $p = 0.011$).

Contrary to the guideline recommendation, a minority of 13% of the sample was asked by their treating physicians to rate fatigue using a scale or a questionnaire (see Fig. 2). Additionally, 74% of the participants were not at all informed about CRF by their treating physician in the course of cancer treatment. About 8% stated to be well informed about the topic. A small percentage of participants (6%) rather or fully agreed that their caregivers were well informed about CRF. The logistic regression analysis showed that recent or current chemotherapy and radiotherapy were associated with an increased likelihood of

being informed by physicians about CRF (chemotherapy: OR = 2.03, 95% CI [1.45; 2.85], $p < 0.001$; radiotherapy: OR = 1.48, 95% CI [1.03; 2.12], $p = 0.033$). Higher age and German native language, on the other hand, decreased the likelihood of being informed about CRF (age: OR = 0.98, 95% CI [0.97; 0.99], $p = 0.001$; German native language: OR = 0.45, 95% CI [0.28; 0.73], $p = 0.001$). The corresponding results are presented in Table 2.

Patient-perceived communication barriers

The majority of the patients (64%) reported ≥ 1 barrier impeding them from addressing exhaustion in medical consultations. While 18% perceived just one communication barrier, 17% felt impeded by ≥ 5 barriers. Of those perceiving exactly one communication barrier, the most frequently affirmed barriers were 'There is/was no opportunity to address fatigue', 'I do not know who to turn to for fatigue' and 'I am afraid of being perceived as weak and sniveling'. Overall, 39% of the participants agreed to the statement 'I do not know who to turn to for fatigue' and 27% to 'I think that my physicians consider fatigue not to be important'. Moreover, 26% of the study population agreed that their physicians did not have enough knowledge about fatigue. The least frequently named barrier was 'I am afraid that this

Table 2 Logistic regression results on factors associated with patients reporting that their physicians addressed fatigue and informed about fatigue

	Physicians addressed fatigue ^a			Physicians informed about fatigue ^b		
	(N = 1005)			(N = 984)		
	OR	CI	p	OR	CI	p
Sex						
Male	Reference			Reference		
Female	0.96	(0.72; 1.28)	0.760	0.88	(0.63; 1.22)	0.439
Age						
Per one year	0.98	(0.97; 0.99)	< 0.001	0.98	(0.97; 0.99)	0.001
Educational level ^c						
Lower	Reference			Reference		
Higher	1.04	(0.78; 1.37)	0.802	1.03	(0.75; 1.41)	0.875
German native language						
No	Reference			Reference		
Yes	0.69	(0.43; 1.11)	0.125	0.45	(0.28; 0.73)	0.001
Metastasis						
No	Reference			Reference		
Yes	1.30	(0.92; 1.85)	0.142	1.13	(0.76; 1.67)	0.551
Unknown	1.60	(0.77; 3.34)	0.207	1.38	(0.65; 2.95)	0.402
Chemotherapy ^d						
No	Reference			Reference		
Yes	2.56	(1.90; 3.45)	< 0.001	2.03	(1.45; 2.85)	< 0.001
Radiotherapy ^d						
No	Reference			Reference		
Yes	1.67	(1.22; 2.31)	0.002	1.48	(1.03; 2.12)	0.033
Hormone therapy ^d						
No	Reference			Reference		
Yes	1.41	(0.98; 2.03)	0.064	1.29	(0.86; 1.94)	0.223
Immunotherapy ^d						
No	Reference			Reference		
Yes	1.54	(1.07; 2.21)	0.020	1.40	(0.95; 2.06)	0.088
Fatigue severity ^e						
No fatigue	Reference			Reference		
Mild fatigue	0.93	(0.65; 1.32)	0.671	0.71	(0.47; 1.06)	0.092
Moderate fatigue	1.12	(0.75; 1.66)	0.592	0.92	(0.59; 1.43)	0.701
Severe fatigue	1.36	(0.70; 2.65)	0.371	0.82	(0.38; 1.74)	0.597
Depression ^f						
No depression	Reference			Reference		
Minor depression	1.28	(0.72; 2.27)	0.400	1.38	(0.75; 2.55)	0.299
Major depression	0.50	(0.29; 0.85)	0.011	0.54	(0.28; 1.02)	0.058

Bold values indicate statistical significance at the $p < 0.05$ level

^aPatient reported to be asked by a physician whether and how much he/she felt exhausted

^bPatient reported to be informed by a physician about fatigue

^cLower: no degree or (lower-) secondary education degree; Higher: diploma qualifying for university or university degree

^dNo: Not (yet) having received or receiving the treatment; Yes: Treatment completed or currently ongoing treatment

^eReferring to the Brief Fatigue Inventory (BFI) score

^fReferring to the Patient Health Questionnaire, depression module (PHQ-9) score

[addressing my exhaustion] could lead to a dose reduction or to a discontinuation of cancer therapy' (see Table 3).

The results of the logistic regression analyses are depicted in Table 4. Significant associations between educational level, fatigue severity, depression and perceiving ≥ 1 communication barrier were revealed, with higher education ($OR = 1.34$, 95% CI [1.00; 1.80], $p = 0.049$), a more pronounced CRF severity (mild fatigue—BFI score 1 vs. no fatigue: $OR = 2.21$, 95% CI [1.57; 3.11], $p < 0.001$) and major depression ($OR = 3.54$, 95% CI [1.50; 8.37], $p = 0.004$) increasing the likelihood of perceiving ≥ 1 communication barrier. When separately considering the communication barriers, CRF severity was significantly associated with each individual communication barrier (e.g., 'fear of being perceived as weak', mild fatigue: $OR = 2.05$, 95% CI [1.17; 3.58], $p = 0.012$). Furthermore, female sex ($OR = 1.94$, 95% CI [1.36; 2.75], $p < 0.001$) and depression (major depression: $OR = 2.50$, 95% CI [1.46; 4.29], $p < 0.001$) increased the likelihood of perceiving the barrier 'fear of being perceived as weak' whereas chemotherapy ($OR = 0.48$, 95% CI [0.34; 0.68], $p < 0.001$) and higher age decreased the likelihood ($OR = 0.97$, 95% CI [0.95; 0.98], $p < 0.001$). The likelihood of feeling impeded by the communication barrier 'physicians consider fatigue not important' was increased by higher CRF severity (mild CRF: $OR = 1.90$, 95% CI [1.16; 3.11], $p = 0.010$) and depression (major depression: $OR = 1.90$, 95% CI [1.11; 3.25], $p = 0.019$) and decreased by

chemotherapy ($OR = 0.57$, 95% CI [0.41; 0.80], $p < 0.001$) as well as positive social support ($OR = 0.93$, 95% CI [0.89; 0.98], $p = 0.003$). Individuals with more severe CRF (mild CRF: $OR = 2.06$, 95% CI [1.36; 3.14], $p < 0.001$) or higher depression scores (major depression: $OR = 4.87$, 95% CI [2.65; 8.98], $p < 0.001$) were more likely to perceive the barrier 'not knowing who to turn to for fatigue'. Moreover, higher education ($OR = 0.73$, 95% CI [0.54; 0.99], $p = 0.040$) as well as more positive social support ($OR = 0.95$, 95% CI [0.91; 0.99], $p = 0.022$) decreased the likelihood.

Perceived quality of the patient–physician communication about CRF

Results concerning the patients' perspective on the quality of patient–physician communication with regard to CRF are presented in Table 5. Of the participants who reported to be affected by CRF 27% (strongly) agreed that their exhaustion was not taken seriously by their physicians. Furthermore, 45% (strongly) disagreed with the statement 'My physicians are appreciative and understanding of my questions about fatigue'. More than half of the participants who judged the respective statement (strongly) disagreed that their physicians took time to address questions about CRF. Furthermore, 28% of the respondents felt that their physicians did not feel responsible for CRF. About 40% (strongly) agreed that their physicians could give competent advice on CRF.

Table 3 Perceived barriers impeding patients to address their exhaustion with their physicians

Communication barrier	Strongly disagree		Disagree		Agree		Strongly agree	
	n	%	n	%	n	%	n	%
I am afraid of being perceived as weak and sniveling. (N= 1122)	657	58.6	215	19.2	179	16.0	71	6.3
I am afraid that this could lead to a dose reduction or to a discontinuation of cancer therapy. (N= 1107)	809	73.1	207	18.7	71	6.4	20	1.8
There is/was no opportunity. (N= 1085)	510	47.0	187	17.2	246	22.7	142	13.1
I think that my physicians do not have time to talk about this issue. (N= 1093)	483	44.2	272	24.9	250	22.9	88	8.1
I think that my physicians consider fatigue not to be important. (N= 1061)	457	43.1	320	30.2	224	21.1	60	5.7
I think that there are no treatments for fatigue. (N= 1044)	460	44.1	347	33.2	182	17.4	55	5.3
I do not know who to turn to for fatigue. (N= 1064)	435	40.9	216	20.3	263	24.7	150	14.1
My physicians do not have enough knowledge about fatigue. (N= 1001)	401	40.1	344	34.4	204	20.4	52	5.2
Number of communication barriers ^a (N= 1096)	n	%						
0	394	35.9						
1 ^b	192	17.5						
2	122	11.1						
3	103	9.4						
4	100	9.1						
≥ 5	185	16.9						

^aBased on dichotomized variable with 0: fully disagree, rather disagree; 1: rather agree, fully agree

^bOf those, the most frequently perceived barriers were: 'There is/was no opportunity' (31.3%); 'I do not know who to turn to for fatigue' (20.8%); 'I am afraid of being perceived as weak and sniveling' (14.6%)

Table 4 Results of the separate multiple logistic regression analyses on factors associated with the perception of communication barriers

	Fear of being perceived as weak			Fear of dose reduction or discontinuation of therapy			No opportunity to discuss fatigue		
	(N = 1008)			(N = 997)			(N = 978)		
	OR	CI	p	OR	CI	p	OR	CI	p
Sex									
Male	Reference			Reference			Reference		
Female	1.94	(1.36;2.75)	< 0.001	1.05	(0.63;1.74)	0.854	1.07	(0.80;1.42)	0.645
Age									
Per one year	0.97	(0.95;0.98)	< 0.001	0.98	(0.97;1.00)	0.105	1.00	(0.98;1.01)	0.347
Educational level ^a									
Lower	Reference			Reference			Reference		
Higher	1.14	(0.80;1.61)	0.469	1.00	(0.60;1.67)	0.994	1.37	(1.03;1.82)	0.033
Chemotherapy ^b									
No	Reference			Reference			Reference		
Yes	0.48	(0.34;0.68)	< 0.001	1.34	(0.82;2.19)	0.248	0.82	(0.62;1.09)	0.175
Fatigue severity ^c									
No fatigue	Reference			Reference			Reference		
Mild fatigue	2.05	(1.17;3.58)	0.012	2.40	(0.80;7.16)	0.117	2.01	(1.34;3.01)	< 0.001
Moderate fatigue	3.75	(2.10;6.67)	< 0.001	6.40	(2.19;18.70)	< 0.001	4.13	(2.67;6.39)	< 0.001
Severe fatigue	5.22	(2.38;11.47)	< 0.001	7.09	(2.01;25.04)	0.002	2.62	(1.33;5.18)	0.006
Depression ^d									
No depression	Reference			Reference			Reference		
Minor depression	2.73	(1.52;4.90)	< 0.001	1.34	(0.58;3.10)	0.498	1.54	(0.88;2.70)	0.132
Major depression	2.50	(1.46;4.29)	< 0.001	2.30	(1.18;4.47)	0.015	1.64	(0.98;2.74)	0.061
SSUK-8 positive support									
Per step	0.95	(0.91;1.00)	0.067	0.97	(0.91;1.05)	0.476	0.99	(0.95;1.03)	0.546
	Lack of time			Physicians consider fatigue not important			Belief that there are no treatments for fatigue		
	(N = 980)			(N = 952)			(N = 944)		
	OR	CI	p	OR	CI	p	OR	CI	p
Sex									
Male	Reference			Reference			Reference		
Female	1.51	(1.12;2.05)	0.008	1.18	(0.86;1.63)	0.307	1.38	(0.97;1.95)	0.072
Age									
Per one year	1.01	(0.99;1.02)	0.333	1.01	(0.99;1.02)	0.324	1.01	(1.00;1.03)	0.109
Educational level ^a									
Lower	Reference			Reference			Reference		
Higher	1.14	(0.84;1.54)	0.410	0.92	(0.66;1.28)	0.614	1.03	(0.72;1.46)	0.881
Chemotherapy ^b									
No	Reference			Reference			Reference		
Yes	0.75	(0.56;1.02)	0.065	0.57	(0.41;0.80)	< 0.001	1.11	(0.79;1.57)	0.551
Fatigue severity ^c									
No fatigue	Reference			Reference			Reference		
Mild fatigue	2.94	(1.82;4.76)	< 0.001	1.90	(1.16;3.11)	0.010	2.66	(1.45;4.88)	0.002
Moderate fatigue	5.16	(3.10;8.57)	< 0.001	4.13	(2.48;6.89)	< 0.001	5.77	(3.11;10.70)	< 0.001
Severe fatigue	5.64	(2.73;11.67)	< 0.001	4.09	(1.95;8.58)	< 0.001	6.81	(2.99;15.52)	< 0.001
Depression ^d									
No depression	Reference			Reference			Reference		
Minor depression	1.98	(1.13;3.48)	0.017	2.34	(1.32;4.16)	0.004	1.24	(0.67;2.30)	0.486

Table 4 (continued)

	Lack of time			Physicians consider fatigue not important			Belief that there are no treatments for fatigue		
	(N=980)			(N=952)			(N=944)		
	OR	CI	p	OR	CI	p	OR	CI	p
Major depression	2.03	(1.20;3.43)	0.009	1.90	(1.11;3.25)	0.019	2.68	(1.56;4.60)	<0.001
SSUK-8 positive support									
Per step	0.95	(0.91;0.99)	0.021	0.93	(0.89;0.98)	0.003	0.95	(0.90;1.00)	0.032
	Not knowing who to turn to for fatigue			Physicians' lack of knowledge of fatigue			Perceiving ≥ 1 communication barrier ^e		
	(N=963)			(N=910)			(N=986)		
	OR	CI	p	OR	CI	p	OR	CI	p
Sex									
Male	Reference			Reference			Reference		
Female	1.32	(0.98;1.77)	0.072	1.07	(0.76;1.50)	0.697	1.12	(0.84;1.50)	0.439
Age									
Per one year	1.01	(1.00;1.02)	0.078	1.01	(1.00;1.03)	0.073	0.99	(0.98;1.00)	0.084
Educational level ^a									
Lower	Reference			Reference			Reference		
Higher	0.73	(0.54;0.99)	0.040	0.98	(0.70;1.39)	0.923	1.34	(1.00;1.80)	0.049
Chemotherapy ^b									
No	Reference			Reference			Reference		
Yes	0.79	(0.59;1.07)	0.132	0.83	(0.59;1.16)	0.275	0.83	(0.62;1.11)	0.196
Fatigue severity ^c									
No fatigue	Reference			Reference			Reference		
Mild fatigue	2.06	(1.36;3.14)	<0.001	2.14	(1.26;3.64)	0.005	2.21	(1.57;3.11)	<0.001
Moderate fatigue	3.93	(2.50;6.16)	<0.001	4.65	(2.68;8.07)	<0.001	4.68	(3.09;7.11)	<0.001
Severe fatigue	4.40	(2.11;9.15)	<0.001	3.20	(1.42;7.23)	0.005	5.96	(2.47;14.39)	<0.001
Depression ^d									
No depression	Reference			Reference			Reference		
Minor depression	2.44	(1.36;4.37)	0.003	1.34	(0.72;2.51)	0.358	1.79	(0.88;3.62)	0.106
Major depression	4.87	(2.65;8.98)	<0.001	3.99	(2.23;7.14)	<0.001	3.54	(1.50;8.37)	0.004
SSUK-8 positive support									
Per step	0.95	(0.91;0.99)	0.022	0.94	(0.90;0.99)	0.021	0.97	(0.92;1.02)	0.182

Bold values indicate statistical significance at the $p < 0.05$ level

For each barrier, all factors were included simultaneously in the models

^aLower: no degree or (lower-) secondary education degree; *Higher*: diploma qualifying for university or university degree

^bNo: Not having received or receiving chemotherapy or chemotherapy planned; Yes: Chemotherapy completed or currently receiving chemotherapy

^cReferring to the Brief Fatigue Inventory (BFI) score

^dReferring to the Patient Health Questionnaire, depression module (PHQ-9) score

^eBased on dichotomized barrier variable

Discussion

This study demonstrated gaps in the patient–physician communication about CRF and offered important insights into patient-perceived communication barriers. Our results suggest that CRF is often not discussed at all between patients and physicians. Furthermore, if a conversation about CRF

takes place, patients experience the quality of communication as unsatisfactory. For example, patients reported that physicians did not feel responsible for CRF, could not give competent advice or did not respond appreciatively to questions about CRF.

Patients reported that a minority of physicians addressed CRF by asking them whether they felt exhausted. Physicians

Table 5 Patients' perceived quality of the communication with physicians about cancer-related fatigue^a

Item	Strongly disagree		Disagree		Agree		Strongly agree	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
My exhaustion is not taken seriously by my physicians. (<i>N</i> =627)	249	39.7	212	33.8	119	19.0	47	7.5
My physicians are appreciative and understanding of my questions about exhaustion/fatigue. (<i>N</i> =600)	126	21.0	145	24.2	249	41.5	80	13.3
My physicians take time to address my questions about exhaustion/fatigue. (<i>N</i> =595)	142	23.9	158	26.6	227	38.2	68	11.4
My physicians do not feel responsible for fatigue. (<i>N</i> =574)	211	36.8	200	34.8	120	20.9	43	7.5
My physicians can give me competent advice on fatigue. (<i>N</i> =577)	143	24.8	206	35.7	185	32.1	43	7.5

^aThese statements were only rated by the participants who sometimes, often or always felt extremely exhausted since cancer diagnosis

seemed more likely to raise the topic with patients who had either completed or were currently undergoing chemo-, radio- or immunotherapy. Older individuals or those with depression were, on the other hand, less likely to be asked about CRF. Besides, only 13% of the participants recalled that their treating physicians conducted a CRF screening by means of a questionnaire or a rating scale, and only one quarter of the participants received education on CRF. The quality of education about CRF did not appear to be satisfactory. These findings point out that guideline recommendations including regular, structured screenings and routine education about CRF have not yet been translated into clinical practice in Germany. Previous research conducted in different countries yielded similar results (Berger and Mooney 2016; Harrington et al. 2022; Schmidt et al. 2021). For example, in a German study, 41% of the 2,508 surveyed patients were not asked about CRF by their physicians and only 13% of those experiencing severe fatigue were screened using a questionnaire. As in the present study, older age seemed to be associated with a lower likelihood of being approached by physicians with regard to exhaustion (Schmidt et al. 2021). However, it could be that some elderly individuals were actually asked about CRF by their treating physicians but did not recall correctly due to cognitive impairment. Alternatively, since elderly people often face multimorbidity differential diagnosis is challenging and physicians might tend to normalize exhaustion, thereby bearing the risk of overlooking CRF. Similarly, due to sharing symptoms, diagnosis might also be difficult in individuals with comorbid depression (Horneber et al. 2012). Given physicians' knowledge gaps regarding CRF one might carefully assume that some physicians avoid discussing the issue (Jones et al. 2021; Pearson et al. 2015). Thus, to increase knowledge but also confidence in dealing with CRF, specific trainings for physicians and relevant HCPs might be important. Apart from that, because of structural barriers like limited temporal and staff resources, physicians perhaps prioritize issues which are directly brought up by the patients (Jones et al. 2021; Smith et al. 2019).

Overall, the here presented results indicate that in most cases physicians do not initiate communication about CRF. But, a previous study demonstrating that half of the patients with CRF did not raise the issue with their physicians, suggests that patients too might perceive barriers making it difficult or even impeding them to address CRF in medical consultations (Stone et al. 2000). Indeed, we found that almost two thirds of cancer patients perceived ≥ 1 communication barrier, with 17% perceiving even five or more. Among those feeling impeded by exactly one communication barrier, the most frequently mentioned barriers were either of structural nature, e.g., because there was no opportunity to discuss CRF or they did not know who to turn to, or patient related, e.g., the fear of being perceived as weak. A considerable number of participants also felt time constraints in medical consultations or thought that their physicians consider CRF not to be important. Additionally, a quarter of the patients believed that their physicians do not have sufficient knowledge about CRF.

In general, the finding that a large number of patients experienced communication barriers is mostly consistent with the literature (Henselmans et al. 2015; Noordman et al. 2017). Barriers to communication and participation in medical consultations are also reported by almost half of patients with other chronic conditions such as cardiovascular diseases or diabetes (Henselmans et al. 2015). As in our study, communication barriers commonly referred not only to patients' characteristics and HCPs' attributes, but also to external factors (van Bruinessen et al. 2013). Few older studies explicitly dealt with communication barriers in CRF management and described that the fear of being bothersome, the belief that CRF is inevitable, the experience that the physician never raised it as an issue and time pressure as relevant barriers (Passik et al. 2002; Shun et al. 2009; Stone et al. 2000). Interestingly, these barriers coincide well with those we found in our study. It can be concluded that, despite advances in CRF research that have led to the development of specific guidelines and raised awareness of the issue, clinical practice does

not seem to have improved as much as one would have expected over the past 20 years. There still appears to be an unfavorable interplay between structural, patient- and HCP-related barriers often resulting in the topic of CRF not being addressed.

In this study, we further tried to identify factors linked to the perception of communication barriers regarding CRF. We found that education has an impact on the perception of communication barriers. While participants with higher education were more likely to perceive the barrier ‘*no opportunity to discuss CRF*’, they were less likely to feel impeded by ‘*not knowing who to turn to for CRF*’. A previous, though not CRF-specific, study showed that individuals with low education and low health literacy were generally more likely to report communication barriers (Henselmans et al. 2015). Therefore, it is important to inform patients, particularly those with lower education, about responsibilities in healthcare and to explicitly encourage them to raise questions and concerns. Furthermore, major depression was related to a higher probability to report communication barriers, in particular the fear of being perceived as weak, the fear of dose reduction and the belief that there are no treatments for CRF. Depression-typical characteristics such as avolition or cognitive biases, e.g., dichotomous thinking, could enhance the perception of barriers and the feeling of being hindered by them. This finding is particularly concerning since, as mentioned earlier, physicians were reluctant to address CRF in individuals with depression. Instead, HCPs should be even more proactive in raising the topic of CRF in this subgroup.

Moreover, with regard to some barriers (e.g., ‘*physicians consider CRF not important*’, ‘*not knowing who to turn to for CRF*’) social support seemed to be protective. Similarly, in a qualitative study among cancer patients support from a companion facilitated patient participation (Henselmans et al. 2012), e.g., because caring relatives might motivate patients to take an active role in consultations or even accompany them for support. Additionally, more severe CRF was related to an enhanced perception of barriers, with regard to the global score (perceiving ≥ 1 barrier) and for all barriers separately. Based on previous studies in which patients experiencing higher levels of CRF interference with daily activities were more willing to report CRF, we expected that the distress and associated need for support resulting from stronger CRF symptoms might reduce barriers to communication (Shun et al. 2009). One possible explanation for our contrasting results could be the following: Individuals with severe CRF, who also have a strong need to discuss CRF and to receive support, are more aware of existing (structural) barriers. On the other hand, the barriers for patients with no/mild CRF, who have a lower need to address the issue, are hypothetical in nature. Their relevance might therefore be underestimated by this group.

Clinical implications

To improve patient–physician communication about CRF, several actions are required to reduce barriers at the system, patient, and physician level. According to the framework suggested by Feldman-Stewart et al. (2005), communication is determined by needs, skills, values, beliefs, and emotions on the part of both, the patient and the physician, which mutually influence each other. In the context of CRF, knowledge gaps among physicians (skills) and a tendency to underestimate the burden caused by CRF (beliefs) might contribute to physicians being reluctant to address CRF (Jones et al. 2021; Pearson et al. 2015; Williams et al. 2016). Therefore, to increase feelings of competence and self-efficacy in dealing with CRF, physicians should be provided with the relevant information and skills in CRF-specific trainings. On the patients’ side, the fear of being perceived as weak or of being bothersome (emotions) and the belief that there are no treatments for CRF seem to be possible reasons for not bringing up CRF (Passik et al. 2002; Stone et al. 2000). Patients might not even be aware that their exhaustion is a common condition for which there is a medical term: Fatigue. Thus, measures to raise patients’ awareness of CRF and to reduce communication barriers are manifold. First, following guideline recommendations, HCPs should initiate the dialog about CRF by conducting a CRF screening, by introducing the term fatigue and by providing information about CRF (Fabi et al. 2020; National Comprehensive Cancer Network 2023). Second, a reflective communication style, i.e., taking time for explanations, using understandable everyday language instead of medical jargon, asking if everything has been understood, etc., will further make it easier for patients to process information during the medical appointment (van Bruinessen et al. 2013). Moreover, physicians should support patients to be active in consultations by encouraging them to self-monitor CRF symptoms using fatigue diaries and to prepare question prompt sheets (Henselmans et al. 2013; Milzer et al. 2022). To further promote the shift toward self-management and patient empowerment, it is also important to structure medical consultations in a way that makes patients feel comfortable, encouraged and empowered to assume an active, participatory role. For example, previous studies have described that the longer the patient–physician relationship and the more familiar they are with each other, the more willing patients are to raise own concerns (Henselmans et al. 2012). Therefore, if possible, a certain consistency should be ensured within the treatment team.

Strengths and limitations

A strength of the present study is the large, diverse sample including numerous different cancer types. Additionally, a

clearly defined phase in the cancer continuum, namely the acute phase approximately six months after diagnosis, was considered, minimizing the risk of a recall bias. Regardless, some limitations have to be noted. When looking at the recruitment flow one might notice that the participation rate was relatively low. However, from telephone conversations with patients who were invited to participate or with their relatives, we know that a considerable number did not meet the inclusion criteria (e.g., sufficient German language skills). Since patients with language barriers were excluded from study participation it can be assumed that the actual communication problem is even more pronounced in clinical practice. Furthermore, participation in the survey required effort and time which increases the likelihood that primarily motivated and interested patients were included. Thus, a selection bias cannot be excluded. In addition, only patients living in the German federal state of Baden-Wuerttemberg were included in the study, which may limit the generalizability of the findings. Moreover, our data do not allow us to draw clear conclusions about how many patients experienced communication barriers, but still addressed CRF. Additionally, we were unable to verify the validity of the self-reported data by, e.g., linking patients' reports to those of their physicians using a matched-pairs approach. Therefore, it could be possible that more physicians raised the issue after all, but that patients did not recall it correctly. Finally, the logistic regression analyses have to be considered explorative and future studies investigating determinants of communication barriers should also take other factors such as patient activation, health literacy, and cognitive abilities into account.

Conclusion

This study identified gaps in the patient–physician communication about CRF. Due to structural, patient-, and HCP-related barriers, CRF is often not discussed at all between patients and physicians, and when it is, the quality of communication is insufficient. To improve patient–physician communication about CRF, structural barriers need to be reduced. Furthermore, physicians should routinely address CRF and learn, e.g., in specific communication trainings, how to adopt a communication style that encourages patients to also seek a dialog about CRF and express their questions. These measures could empower patients to take an active role in CRF management.

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Author contributions IM, KS, MES: conceptualized and designed the study. Material preparation and data collection were performed by MM, ASW, SK, in close cooperation with IM, KS, MES. SH: significantly contributed to the recruitment of patients. The Cancer Registry of Baden-Württemberg (S. Schneider and S. Bergbold) performed the cohort matching and data preparation. MM and MES: completed the statistical analyses. The first draft of the manuscript was written by MM and all authors commented on previous versions of the manuscript. All authors read and approved the final version of the manuscript.

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Data availability Data can be made available to scientific cooperation partners upon reasonable request.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The study complied with the principles of the Declaration of Helsinki and approval was granted by the Ethics Committee of the Medical Faculty of Heidelberg University (S-526/2018).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent to publish N/A.

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