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Consultation Program for Patients with Cancer-Related Fatigue: A Systematic Evaluation of the Experiences of the Bavarian Cancer Society

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Keywords

Cancer-related fatigue: diagnostics, treatment, counseling · Fatigue, cancer · Consultation hour · Management

Background

Cancer-related fatigue (CRF) is a subjective condition of atypical physical, affective, and cognitive tiredness and exhaustion [1]. Hampering daily life [2], CRF can be a relevant problem for such patients and CRF is also associated with a shortened overall survival [3]. Despite availability of evidence-based treatment options [4–6], many patients with CRF feel insufficiently cared for [7, 8]. As, to date, there is no International Classification of Diseases (ICD) code for CRF, the most suitably way to close this care gap is through a nonprofit organization such as the Bavarian Cancer Society e.V. (BKG).

Thus, together with the 'Institut für Tumor-Fatigue-Forschung' (ITFF), the BKG has started to develop a health care structure in Bavaria by offering free special consultation hours (CHS). These are currently available at the psychosocial cancer counseling centers (PCCC) Bayreuth, Kempten, Nuremberg and Munich, and with an external cooperation partner in Fürstenfeldbruck [9]. More facilities are being planned. Except at Nuremberg, all CHS are directed by physicians with oncological and psycho-oncological experience. Before the start, all took part in an extensive CRF management training. This paper provides information about CHS procedures, the patients and their problems with CRF, the results of a systematical evaluation and the challenges connected with the establishment of regular CHS.

Methods

CRF Consultation Hour at the BKG e.V.

The BKG is a non-profit organization with 19 outpatient PCCC and psycho-oncological services, and carries out approximately 23,000 counseling sessions per year. Patients who express serious complaints of exhaustion on this occasion will get an appointment for the CHS.

At the first consultation (duration 60–90 min) (differential-)diagnosis is made mainly by standardized anamnesis (compiled with a modified version of the anamnesis guideline of the German Fatigue Society [10]), the Brief Fatigue Inventory (BFI [11]) and inspection of the patient's records. The standardized anamnesis includes the topics: symptoms and intensity of CRF, impairment, beginning, course, earlier states of exhaustion, differences as compared to normal tiredness, cancer anamnesis, co-morbidities including depression, current

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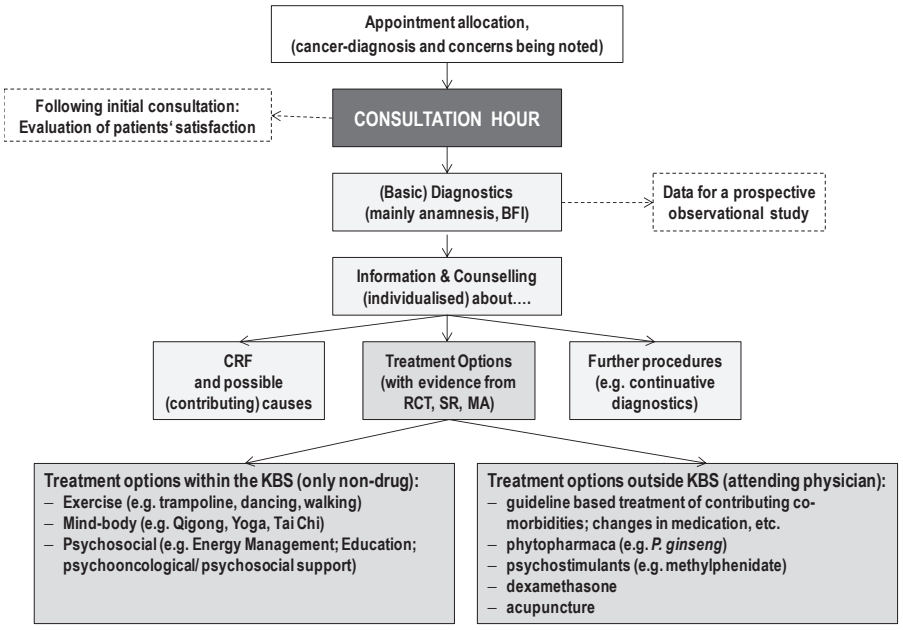

Fig. 1. Cancer-related fatigue (CRF) consultation hour of the Bavarian Cancer Society e.V. (BKG): Procedure.

medication, vegetative anamnesis, and social anamnesis. The BFI comprises 9 items with a numerical analogue scale from 0 to 10 to determine severity and impairment of the CRF (0–3 low, 4–7 moderate, 8–10 serious severity or impairment).

In an individualized counseling interview, the patient is informed about CRF, potential contributing factors, further diagnostic procedures if necessary and symptomatic treatment options with evidence from randomized controlled clinical trials (RCT), systematic reviews and meta-analysis. Following a shared decision-making approach, possible treatment options are discussed and defined with the patient. The procedure for the CRF consultation hour of the BKG is shown in figure 1. Diagnostics and counseling are systematically documented.

Potential treatment within the PCCC is restricted to psycho-oncological supervision and non-pharmacological symptomatic treatment. For this purpose, the BKG offers amongst other things special courses, e.g. Qigong. For causal treatment of contributing factors (e.g. therapy for comorbidities) and symptomatic treatment options that cannot be provided by the PCCC (e.g. acupuncture), the patient is referred to his physician, who can contact the original counselor at any time. As part of a Swiss study, suitable patients could stay 3 weeks without costs in the oncological REHA Clinic Sokrates at CH-Güttingen, which is specialized in the treatment of CRF.

Evaluation Design

We performed a prospective, observational questionnaire study to evaluate patients' perception of the consultation program for CRF. The project was reported to the Academy for Ethics in Medicine (Göttingen), which responded favorably on 21 July 2013. All patients gave their informed consent that their data can be used in anonymous, statistical analyses.

After the initial consultation patients were asked to fill in an anonymous evaluation questionnaire about the CHS, which was sent to the office of the tumor center of the University of Erlangen-Nuremberg for analysis. Because there is no assessment tool for the evaluation of a CRF-CHS, we developed a questionnaire with 12 closed-ended questions, 4 open-ended questions and 1 pitch to note question. All questions had a high face validity.

Analysis

All the data collected in the CHS were systematically documented and descriptively evaluated. The answers to the open-ended questions on the evaluation questionnaire were evaluated according to a content analysis, which belongs to the qualitative methods. The approach is described below.

Results

From September 2013 to December 2015, 269 patients with CRF visited the CHS (pilot phase Nuremberg in 2013–2014, n = 51; follow-up stage 1 at 5 sites in 2015, n = 218) [12]. Most of the patients came from the local area (62% within 0–25 km, 18% within 26–50 km, and 18% withing 51–100 km). According to the BFI, nearly 2/3 of the patients had a moderate and 1/3 a serious CRF. 21% of the patients felt too tired to follow their doctor's recommendations (table 1).

In the majority of patients the exhaustion began close to the time of the initial tumor diagnosis or initial therapy, but there were also patients who dated the beginning many years before their initial tumor diagnosis or many years after successful curative treatment. However, in order not to overlook treatable contributing factors, it has been found useful to examine at what date and in what specific situation the problems began. For example, there may have been a major depression, which has been observed more frequently in our patients with CRF (44%) than reported in the literature [13], or any other problem.

Evaluation

Completed questionnaires were returned by 251 of 269 patients. Taken together patients were very satisfied with the pattern, duration and content of the CHS. Figure 2 shows the results of the (closed-ended) statement questions. In addition, 4 open-ended questions were asked: (a) What did you like about the consultation hour? (b) What did you not like? (c) What did you miss? And (d) What could we do better?

The answers were verbatim transcribed in the office of the tumor center of the University of Erlangen-Nuremberg and subsequent content analyzed by I. Fischer (ITFF) according to Mayring [14]. For this purpose, for each question, similar statements were classified into empirically derived categories, which were then

Table 1. Patient characteristics

Total, n (% female)	269 (78)
Age, years (mean)	24–87 (55.3)
Most common types of cancer, %	
Gynaecological (mainly breast (85%[a]) and ovaries)	53
Hematological (mainly NHL, HD, MPN)	15
Gastrointestinal (mainly colon, stomach)	10
Urological (mainly prostate, kidney)	8
Sarcoma	5
Disease and treatment situation (most frequent situations), %	
Tumor locally limited	49
Locally advanced	9
Only lymph node metastasis	20
Distant metastasis	18
Situation unclear	4
Currently no cancer treatment	54
Average fatigue (BFI, past 7 days)[b],%	
0–3	5
4–7	64
8–10	31
Impairment of general activity (BFI, past 7 days)[c],%	
0–3	3
4–7	57
8–10	40
First manifestation of CRF[d],%	
Time before primary cancer diagnosis	
6–65 years	4
3–5 years	3
2 years	4
1 year	7
During year of cancer diagnosis	47
Time after primary cancer diagnosis	
1 year	15
2 years	4
3–5 years	8
6–21 years	8
Number of days with fatigue (past 4 weeks)[e],%	
Every day	55
21–26 days	8
16–20 days	14
11–15 days	13
< 10 days	11

[a]Base: n = 114 with gynecological cancers.
[b]Base: n = 213 of 218 (BFI not used in the pilot phase); mean: 7.1.
[c]208 of 218 patients answered question (BFI not used in the pilot phase); mean 6.6.
[d]253 of 269 patients answered question.
[e]244 of 269 patients answered question; mean: 22.4 days.
NHL = non-Hodgkin disease, HD = Hodgkin disease, MPN = myeloproliferative neoplasias, BFI = Brief Fatigue Inventory (0–3 low, 4–7 moderate, 8–10 serious severity or impairment), CRF = cancer-related fatigue.

grouped into empirically derived main categories. The number of patients who made a statement relevant to each category was counted. To quantify the main categories, net values were established, i.e. each patient was counted only once, regardless of the number of statements in the sub-categories. The determined frequency was subsequently figured in percentage for the whole group. Table 2 shows the most important categories for question (a), answered by 83% of the patients, as well as the share of the patients in the individual categories.

The feedback to the 'critical questions' (b), (c) and (d) showed that only 8% of the patients expressed dissatisfaction. The most frequent complaint was that the session was too short. The answers to question (c) (what did you think was missing?) reflect only individual needs. Considering question (d), 15% of the patients made suggestions for improvements: mainly that the CHS should be made more popular, and that follow-up sessions be offered. The average mark for all CHS was 1.2.

Discussion

CRF is a debilitating condition of atypical exhaustion in the context of cancer and its therapy. During cancer therapy most cancer patients suffer from CRF, and during aftercare 20–50% are affected [15], women slightly more often than men [16]. CRF is not only a problem for the patient but also for the family. Being a predictor for return to work after cancer, CRF has consequences for the health economy [17]. However, many patients feel that the care standard for their condition is insufficient [7, 8]. Thus, the BKG, together with the ITFF, is planning a comprehensive health care structure in Bavaria by offering free CHS, which is currently available in 5 Bavarian cities. In the first 2 years 269, mostly female, patients had appointments. Of these patients, 64% had a moderate, and 31% a serious CRF. On average, patients have felt exhausted on 22.4 days per month and for 4.2 years (range 2 months to 67 years), predominantly beginning at the time of initial cancer diagnosis or primary treatment. 57% of the patients feel that their everyday activities are moderately and 40% severely impaired by CRF. That CRF prevents every fifth patient from following his doctor's recommendations could be clinically relevant and should be investigated further.

The CHS are being evaluated continuously. Up to now, 93% of the patients have participated in the evaluation. The CHS are judged to be very good and helpful. Nevertheless, the number of CRF patients who have had an appointment in the CHS up to now is surprisingly low, considering that during tumor therapy nearly every patient, and during aftercare 20–50% of patients, suffer from CRF [15]. There can be several reasons for this imbalance: cancer patients who contact a PCCC to get psychosocial support get an appointment for the CHS only if they express serious complaints of being exhausted. The term 'fatigue' is not known to every patient and they do not connect their tiredness or exhaustion to CRF. Thus, they see no reason for an appointment. Others may not be aware of the CHS, have simply resigned themselves to their condition, already have a helpful contact person for this problem or do not suffer from CRF to such an extent that they feel a need to seek help for it. International study results also point to other barriers, which prevent adequate treatment of CRF, e.g. the belief that CRF inevitably belongs to the cancer illness and its treatment, and that no therapy for CRF is available [18, 19].

Table 2. Categories identified by content analysis of all answers to the open-ended question: What did you like about the consultation hour?

Categories (identified by content analysis)[a]	%
1. OPINION ABOUT THE CONSULTATION HOUR/APPROACH (nv)	66
1.1 (VERY) GOOD/OPEN/SOLUTION-ORIENTED/HELPFUL CONVERSATION (nv)	32
- good/well performed/balanced/intensive/objective conversation	10
- open/trustful atmosphere	10
- individual concern of personal situation	5
- good to know that, after all, there is help/a contact point; I am not alone anymore	5
1.2 (HELPFUL) TIPS/TREATMENT ADVICE/GOOD IMPULSES; DO SEE A PERSPECTIVE NOW (nv)	30
- was (very) helpful; tips/learned about treatment options	26
- gave me hope (for improvement)/gave me courage	6
1.3 GOOD/COMPREHENSIBLE INFORMATION OBTAINED (nv)	20
- many (good) information/(received understandable) explanations	15
1.4 ENOUGH TIME (DETAILED CONVERSATION POSSIBLE) (nv)	16
- enough time/no time pressure/lot of patience	14
1.5 THOROUGH, COMPREHENSIVE DIAGNOSTICS (WITHOUT PREJUDICES) (nv)	6
2. REMARKS ABOUT COUNSELOR (nv)	49
2.1 COUNSELOR COMPETENT/EXPERIENCED/WELL PREPARED (nv)	26
- Counselor (very) competent/experienced/well advised	25
2.2 COUNSELOR EMPATHIC/ATTENTIVE/SYMPATHETIC (nv)	31
- counselor sensitive/empathic	17
- counselor understood me/the disease/my situation/took me seriously	14
- counselor was attentive/listened to me	6
2.3 COUNSELOR NICE/FRIENDLY/EXUDES CALMNESS; PLEASANT NATURE	9
3. STATEMENTS ABOUT GENERAL FRAMEWORK (nv)	7
- pleasant/quiet atmosphere; nice room	6

[a]Base: total (n = 251 questionnaires; only categories ≥ 5% shown).
nv = net value.

That such attitudes also play an important role in connection with the CRF-CHS of the BKG was evident in the pilot survey of 63 self-help group leaders. It seems that those affected often doubt if their tiredness is really CRF, maybe due to the experience that persons in their social environment also often complain of being tired. Otherwise, it is often the exhaustion itself that prevents the patients from seeking treatment, especially when a longer journey to the treatment center has to be considered [20].

Almost certainly such a project takes more time than 2 years to get going, which was also seen at the Cancer Fatigue Clinic at MD Anderson Cancer Center [21], by which we have been inspired.

Conclusion

CRF-CHS at the BKG are currently being offered in 5 Bavarian cities. They are accepted and generally judged by the patients to be very positive. Therefore, we plan to establish CHS (in addition to Bayreuth, Fürstenfeldbruck, Kempten, Munich and Nuremberg) also in Augsburg, Ingolstadt, Passau, Regensburg and Würzburg. In the final stage, all of the CHS should be directed by physicians with oncological and psycho-oncological experience. To reduce the risk of CRF chronification, more attention will be paid to relevant risk factors, like loneliness or anxiety [22]. To evaluate possibly positive long-term effects of the CHS, a longitudinal study over a year is being planned. In order to change the general opinions about CRF, the barriers that seem to block the CHS need to be lowered. This can be achieved by CRF training courses for doctors, nurses, self-help group leaders and patients, which will be offered by the BKG. Special attention should be paid to the presence of CRF in the PCCC of all regional cancer societies.

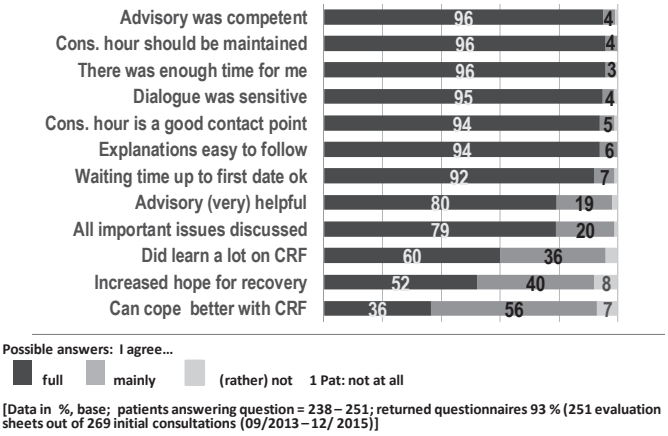

Fig. 2. Patient's evaluation of the consultation hour by means of statements (closed-ended questions) [9] with kind permission.

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Disclosure Statement

The authors declare no conflict of interest.

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