

CANCER PATIENTS WITH NEED FOR PSYCHO-ONCOLOGICAL REHABILITATION

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Summary

In addition to the healing and alleviation of primary somatic cancer symptoms, the comprehensive psycho-oncological treatment of cancer patients is an important and fundamental component of oncological rehabilitation in Germany.

Rehabilitation treatment encompasses medical, physiotherapeutic, psychological, and creative therapeutic methods, as well as psycho-educational interventions within the framework of an individualized therapy plan. Psycho-oncological interventions within rehabilitation are governed less by individual therapeutic schools of thought, and more by a supportive, patient-centered approach that integrates various psychotherapeutic methods. Adapted methods and techniques from various psychotherapeutic approaches (*behavioral therapy, psychoanalytical psychotherapies, systemic family therapy, or hypnotherapy*) are currently used in the treatment of cancer patients.

A total of N=116 patients of the Paracelsus Clinic am See in Bad Gandersheim were able to be included in the study. In summary, this study shows that about two thirds of the patients admitted to the oncological rehabilitation clinic exhibit middle to high degrees of distress in the areas of anxiety and/or depression. Moreover, it appears to be particularly important to assess not only the mental distress of cancer patients but also their degree of information with regard to psycho-oncological treatment when performing screening for psycho-oncological treatment outside of the rehabilitation clinic setting. Here it is particularly important to accommodate for a differing need for differing forms of treatment (need for counseling, care, or treatment).

KEYWORDS: *cancer, psycho-oncology, rehabilitation*

POTREBA ZA PSIHOSOCIJALNOM REHABILITACIJOM OBOLJELIH OD RAKA

Sažetak

Sveobuhvatno psiho-onkološko liječenje bolesnika s rakom važan je prilog u liječenju i ublažavanju primarnih somatskih simptoma te temeljna komponenta onkološke rehabilitacije u Saveznoj Republici Njemačkoj.

Ova vrsta rehabilitacije obuhvaća medicinske, fizioterapijske, psihološke te kreativno terapijske pristupe, ali i psiho-educacijske intervencije u okviru individualiziranih terapijskih programa. Psiho-onkološki rehabilitacijski postupci manje su određeni kognitivnim psihoterapijskim metodama, a više potpornim, pacijentu usmjerenim pristupima koji obuhvaćaju različite psihoterapijske tehnike. Prilagođene metode i tehnike iz različitih psihoterapijskih pristupa (*bihevioralna terapija, psihoanalitička psihoterapija, sistemska obiteljska terapija ili hipnoterapija*) predstavljaju suvremeni koncept u liječenju onkoloških bolesnika.

Ova studija provedena je na uzorku od 116 pacijenata *Paracelsus Clinic am See* u Bad Gandersheimu. Rezultati studije pokazali su da dvije trećine pacijenata uključenih u onkološku rehabilitaciju pokazuje srednji do visok stupanj poremećaja u području anksioznosti i/ili depresije. Osim toga, osobito je važno da se u uvjetima definiranja psiho-onkološkog liječenja u izvankliničkim uvjetima ne procjenjuje samo vrsta i stupanj psihičkog poremećaja, već također i razina informiranosti o

psiho-onkološkom liječenju. U tom smislu posebno je važno različite oblike liječenja prilagoditi različitim osobnim potrebama bolesnika (npr. potreba za savjetovanjem, njegovom, liječenjem).

KLJUČNE RIJEČI: rak, psihoonkologija, rehabilitacija

INTRODUCTION

In addition to the healing and alleviation of primary somatic cancer symptoms, the comprehensive psycho-oncological treatment of cancer patients with mental problems is an important and fundamental component of oncological rehabilitation in Germany. Chronic illnesses such as cancer are characterized by numerous different and frequently severe symptoms as well as by familial and social difficulties, and the development of mental problems is seen in a substantial proportion of these patients. Stressors seen in cancer patients include, for example, the effects of the primary medical therapy, subsequent therapies and the side-effects of the therapies, pain, fatigue, psychosomatic symptoms, intense preoccupation with the diagnosis, uncertainty about the progression of the illness associated with a recurrence of the illness or a progression of the cancer, changes within the familial and social situations, restricted employment capacity, or long-term dependency on medical health care institutions (1). Epidemiological studies on the frequency of comorbid mental disorders in cancer patients show prevalence rates between 2% and 52% for adjustment disorders (2, 3), between 1% and 49% for anxiety disorders, and between 1% and 50% for depression, depending on the stage of the illness and the survey methods used (4).

Central tasks of the oncological rehabilitation of cancer patients include support for patients in coping with the effects of their illness and, to the greatest degree possible, the reestablishment of physical health, mental and social capacity, and the maintenance or reestablishment of occupational capacities and social integration. Rehabilitation treatment encompasses medical, physiotherapeutic, psychological, and creative therapeutic measures, as well as psycho-educational interventions within the framework of an individualized therapy plan. Psychological treatment approaches are designed to correspond to the psychosocial problem areas of cancer patients and have the following effects as their goal: reduction of anxiety,

depression, helplessness and hopelessness; improvement of self-esteem and patients' mental attitude towards the illness; mediation of self-control strategies; encouragement of active participation and involvement in treatment and rehabilitation; assistance in clarifying biographical conflicts; relief for the patient through the expression of negative emotions; development of active coping strategies; improvement of communication between patients, partners, relatives and friends; improvement of occupational and social integration; and improvement of individual areas of functioning, such as fatigue or sleeping disorders (5).

Psycho-oncological interventions within rehabilitation are governed less by individual therapeutic schools of thought, and more by a supportive, patient-centered approach that integrates various psychotherapeutic methods. Adapted methods and techniques from various psychotherapeutic approaches (*behavioral therapy, psychoanalytical psychotherapies, client-centered, systemic family therapy, or hypnotherapy*) are currently used in the treatment of cancer patients. Relaxation techniques and guided imagery methods, as well as art therapy approaches and psycho-educational measures are of particular significance. Therapy is generally performed in both individual and group settings.

Numerous international, controlled intervention studies substantiate the effectiveness of psycho-oncological treatment offers, particularly with regard to various dimensions of health-related quality of life (6). These studies have primarily examined behavioral therapy interventions. Behavioral therapy interventions center on influencing the side-effects of medical treatment or symptoms of the illness, as well as on emotional problems in the course of the illness. They have the goal of improving the patient's quality of life and assisting the patient in adjusting to the illness. The basic effectiveness of rehabilitative treatment for cancer patients in Germany, which has been established nationwide in a primarily indication-specific, inpatient setting over the past thirty years, can now be considered well-documented (7). The empirical studies available focus primarily on the improve-

ment of coping with the illness and addressing quality of life through oncological rehabilitation measures, in addition to changes in mental well-being (8, 9, 10, 11, 12, 13, 14, 15, 16, 17).

CONCEPTION OF A SPECIFIC PSYCHO-ONCOLOGICAL REHABILITATION TREATMENT

Treatment offers for oncological rehabilitation have been refined in recent years. Outpatient treatment forms are currently being tested in the framework of individual models (14). A further development concerns studies on the question of whether and to what degree the effectiveness of specific treatment measures for specific subgroups of cancer rehabilitation patients can be improved. This primarily concerns cancer patients that exhibit a high degree of mental comorbidity. In light of this, the Institute for Medical Psychology of the Hamburg University Medical Center developed a specialized psycho-oncological rehabilitation treatment offer (18) in cooperation with the medical directors of the Paracelsus Oncological Rehabilitation and Psychosomatic Rehabilitation clinics in Bad Gandersheim (Clinic am See and Roswitha Clinic). This treatment was implemented in the Paracelsus Oncological Rehabilitation Clinic in 2004.

This specifically behavioral therapy oriented treatment is designed for cancer patients who are very mentally burdened. The oncological rehabilitation clinic expanded its previous rehabilitative offer by installing an additional department specialized for psycho-oncological rehabilitation with 30 beds. The specialized, behavioral therapy treatment offer is integrated into the clinic's previous oncological treatment concept; however, it specifically targets patient groups with particular need for psycho-oncological rehabilitation. The target group encompasses both patients receiving rehabilitation measure directly following acute cancer treatment as well as those participating in rehabilitation measures later in the course of the illness. The guidelines for this specific treatment concept consist of an individual therapy plan achieved through a comprehensive assessment at the beginning of therapy, the use of evidence-based diagnostic and therapeutic methods, an adaptation of the therapy plans through routine progress assessment, the integration of measures to prepare the patient for reintegration into occu-

pational activity, the patient's participation in planning and decision processes, and a routine evaluation of the process and outcome quality. Indications on the somatic level include new malignant formations in the digestive organs, skin, mammary glands, and female genitalia. On the level of mental impairments, prominent factors include depression, phobias and anxiety disorders (especially fear of progression), adjustment disorders, and somatoform disorders (in particular chronic pain syndrome).

The rehabilitation clinic's supplemental psycho-oncological intervention program is based on a treatment concept founded in a behavioral therapy approach, with a broad range of evidence-based, psycho-oncological intervention methods. These include cognitive-behavioral individual therapy, group therapy (basis group / coping group, optional indicative groups, depression group, fear of progression group), relaxation therapy and methods for the improvement of body perception, sport therapy, exercise therapy and physiotherapy, occupational therapy, and medical-occupational treatment offers.

This psycho-oncological treatment plans for a differential indication and precise allocation of the patients to appropriate therapy measures. Patients with primarily cancer-specific physical problems are to receive general oncological rehabilitation measures. Patients with significant cancer-specific somatic and mental problems, on the other hand, will receive specialized psycho-oncological treatment. In accordance with the treatment concept, the identification of patients with specific treatment needs can occur by different means: a) The patients are assessed as having a particular need for psycho-oncological treatment by social workers or physicians in the acute care hospital setting. To aid them in their evaluation they will use a short assessment form developed by the Institute for Medical Psychology. This form consists of the Hospital Anxiety and Depression Scale (HADS) (19) and questions on a willingness to participate in treatment. This form of access to the patients is oriented exclusively towards patients who have the option of beginning rehabilitation measures directly following active cancer treatment; b) Identification of patients by the cost carrier (the ARGE) based on their files. This means of access to patients is generally oriented towards patients who have undergone repeated rehabilitation measures; c) Clinic-internal identification of

patients. This currently occurs on the basis of clinic files, the introductory meeting with the physician at admittance, and with the use of the short assessment described in point (a).

Access to treatment by way of the acute care clinics currently only exists to a very limited extent. It remains to be seen whether a specific assignment of patients to specific treatment forms is realistic in this setting. It is fundamentally conceivable that within the setting of access to treatment by way of the cost carriers, the decision of a transferal to psycho-oncological care be supported by an assessment questionnaire that is sent to patients by a given clinic prior to their admission to that clinic. Since the amount of time between the sending of the patient files and the admission of the patients to the clinic is not currently sufficient to allow for such a procedure, this method cannot currently be practiced.

The primary path of referral for patients to both outpatient rehabilitation and health care measures of the specific psycho-oncological program thus currently consists of the clinic-internal identification by way of the process described above. Within the framework of the initial diagnostic procedures a rehabilitation-oriented, psychotherapeutic exploration is performed in addition to the medical-oncological examination. On the basis of this exploration, an individual, behavioral-therapeutic/oncological treatment plan is drawn up in an interdisciplinary patient-admission conference.

AIM

The oncological rehabilitation clinic's psycho-oncological treatment concept has been the object of a large, multi-centered, prospective evaluation study in which further rehabilitation clinics are involved, in part as comparison clinics, in part with other interventions. The study examines the question of whether intensive psycho-oncological treatment contributes to a clear improvement of the rehabilitation success on the whole, and in particular of the psychosocial results of the illness, mental comorbidity, and occupational reintegration, in line with its goals. The prerequisite for the performance of a precise referral of patients to such an intervention study is the examination of the patient's degree of mental distress and ac-

ceptance of the illness, the degree of information concerning treatment and treatment options, and the willingness to participate in treatment. Prior to the implementation of the extensive evaluation study, several questions relating to the planning of the project were examined in an initial feasibility study. In addition to testing the instruments to be used, the focus of this feasibility study was on the question of the proportion of oncology patients who exhibited severe mental distress and a need for psychological support at the time of admission. The following individual questions were examined: How high is the percentage of patients with mental distress? How great is the willingness for participation in psycho-oncological support offers? How can patients with a specific need for treatment be validly identified? Which path of access to treatment is most appropriate?

MATERIALS AND METHODS

From the beginning of April to May 2003, data was collected among the oncology patients of the Clinic am See in Bad Gandersheim. A total of N=116 patients were able to be included in the study. The patients had a median age of 58, and were predominantly married and retired. About one third of the patients was employed, most of them were on sick leave. The socio-demographic characteristics of the sample are described in Table 1.

The most frequent diagnosis groups in the sample examined included locations of the cancer in the breast (32.2%), skin (20%), gastro-intestinal region (13%), and rectum (12.2). Gynecological tumors (6.1%) and urological tumors (6.1%) were equally present, followed by hematological illnesses (4.3%) and illnesses of the bronchial tubes and lungs (3.5%). Other illnesses were seen in the liver, thyroid gland, and larynx (Figure 1).

The number of patients who took part in rehabilitation measures directly following active cancer treatment (53%) and those who participated in rehabilitation at a later point in the course of their illness (47%) are evenly distributed. The costs of the rehabilitation were assumed by the ARGE in 51.8% of the patients; regional insurance institutions financed the patient's stay in the hospital in 41.2% of the cases. With an average age of M=60.6 (SD=12.7), the patients whose treatment was financed by the ARGE had a significantly

Table 1.
DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE (N=116)

Age (in years)	M=58.3 (SD=12.9) (Range 26-90)	
	%	n
Family status		
single	4.3	5
married	73.3	85
divorced	6.9	8
widowed	15.5	18
Partner relationship		
steady relationship	73.3	55
no steady relationship	26.7	20
Education		
9 years of primary and secondary schooling	74.4	84
10 years of primary and secondary schooling	17.7	20
university level degree	5.3	6
Employment		
employed	10.7	12
employed but on sick leave	25.9	29
unemployed	5.4	6
retired	43.8	49
housewife (house man)	12.5	14
other	1.7	2

higher age than those financed by the regional insurance institutes (M=54.4; SD=11.6) ($p < .05$). The Federal Insurance Agency for Employees carries the costs for 1.7% of the patients. The remaining cost carriers, labeled as "other" (5.3%), include

mandatory and private health insurance providers (Figure 2).

RESULTS AND DISCUSSION

Mental distress

The patients were surveyed concerning anxiety and depression using the standardized self-assessment questionnaire "Hospital Anxiety and Depression Scale" (HADS-D), which assesses anxiety and depression in adults with physical ailments and illnesses. The HADS-D encompasses the two subscales of "Depression" and "Anxiety" with 7 items each, which are answered with four predetermined response alternatives. A sum score of 0 to 21 can be calculated for each scale. The three score regions of 0-7 (not evident), 8-10 (possible diagnosis), and >11 (probable diagnosis) can be chosen. The patients exhibit a median score of M=7.8 (SD=4.1) on the anxiety scale, and a median score of M=6.5 (SD=4.0) on the depression scale.

Figure 3 illustrates the distribution of the sample across the three score regions: Slightly less than half of the patients have low scores on the anxiety scale (47.7%) and approx. two thirds of the patients have low scores in the area of depression (63.2%); 27.5% of the patients were seen to have a possible anxiety disorder, and approx. 21% had a possible depressive disorder; 24.8% of the sample showed high scores on the anxiety scale, representing a probable anxiety disorder, and 15.8% of the sample had a probable depressive disorder. There are no significant differences with regard to

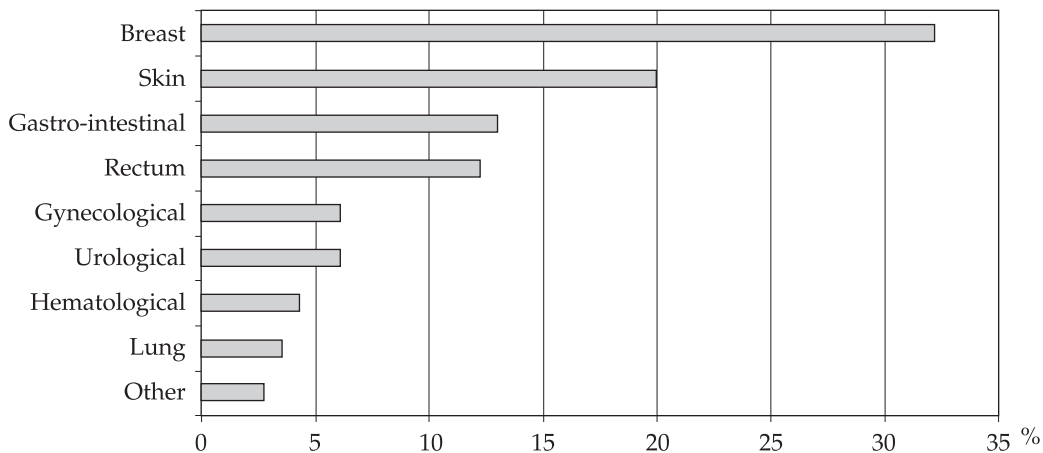


Figure 1. Oncological diagnosis groups (N=116)

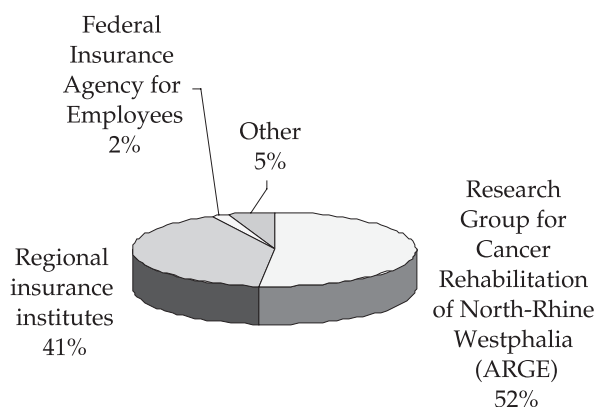


Figure 2. Cost carriers for oncological rehabilitation (in Germany)

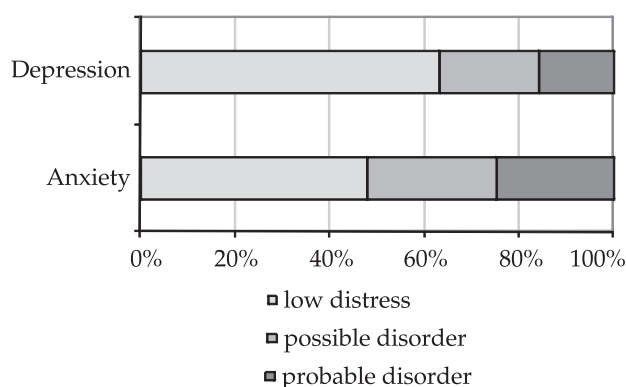


Figure 3. Prevalence of anxiety and depression (N=116)

anxiety and depression between the patient groups who take part in rehabilitation measures directly following their active cancer treatment and those

who participate in rehabilitation measures at a later point in the course of the illness.

Health-related quality of life

When asked to rate their health condition during the past week on a 7-point scale from “1=very bad” to “7=excellent”, the patients respond with a median score of $M=3.8$ ($SD=1.4$). The patients respond similarly when asked about their quality of life over the past week, which was to be rated based on the same 7-point scale. Here the responses had a median score of $M=3.9$ ($SD=1.5$). The patients’ scores for both their health condition and their quality of life are seen in the median region.

Need for psychological support

When asked whether they felt they had a need for psychological support with regard to their cancer illness, the patients respond on a 4-point scale from “1= not at all” to “4=fully agree” as follows: The patients predominantly agree that they would accept the offer of psychological support for coping with their cancer illness, with a median score of $M=2.6$ (close to “3=somewhat” on a 4-point scale; $SD=1.2$). For the statement “I think that psychological support would help me cope with my illness”, the patients respond with a median score of $M=2.4$ (between points “2=little” and “3=somewhat” on the scale; $SD=1.2$). The statement “I already have experience with psychological support (such as psychotherapy)” received the least agreement ($M=1.5$; $SD=1.0$).

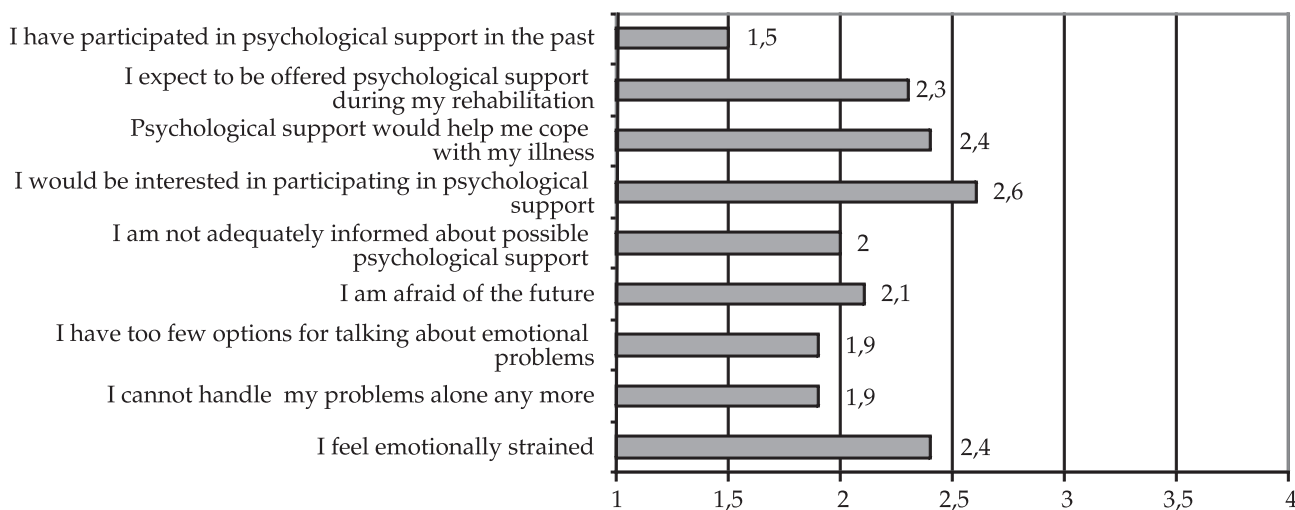


Figure 4. Subjective need for and acceptance of psychological support offers (N=116)

About half of the patients (51.3%) state that they feel mentally distressed. Nearly a quarter (19.1%) stated that they are hardly able or not at all capable of coping with the individually existing problems alone. About a third of the patients (28.8%) responded that they have too few options for talking about mental distress. More than a third of the patients (35.5%) indicate that they are afraid of the future. About 70% of the patients feel they are adequately informed about psychological support options for cancer patients. About a third of the patients (29.5%) feel, on the other hand, that they are not adequately informed. More than half of the patients (54.4%) would participate in psychological support with regard to the cancer illness if this were to be offered in the framework of their rehabilitation. Somewhat less than half of the patients (44.3%) expect specific psychological support within their rehabilitation, and 49.9% of the patients state that psychological support would help them cope with the illness. About 17% of the patients have participated in psychological support before. 59.5% of all the patients exhibit a possible or probable score in at least one of the two HADS scales, "Anxiety" and "Depression". Approximately 61% of these patients believe that psychological support would help them, and 64% would participate in psychological support.

CONCLUSION

In summary, the preliminary study shows that about two thirds of the patients admitted to the oncological rehabilitation clinic exhibit middle to high degrees of distress in the areas of anxiety and/or depression. Of these patients, approx. two thirds consider psychological support to be helpful and would participate in such support within the framework of the rehabilitation. The results of this survey thus provide information concerning the degree of distress in a substantial segment of the cancer patient population, as well as a positive disposition towards psycho-oncological care offers within the framework of the inpatient rehabilitation setting.

However, specific psycho-oncological intervention programs, such as those available in the described rehabilitation clinic, can only be effective once it becomes possible to successfully identify cancer patients with problems and distress

that require treatment. An important step in the development of a precise implementation of specific psychosocial interventions can be seen in the development and use of appropriate screening instruments that are adequately differentiated and valid, and can be practicably and economically implemented. The feasibility study showed that the HADS can prove its value as a screening procedure in the clinic at the time of admission. But other international procedures can also be considered, especially in their brief versions. Among these are the General Health Questionnaire (GHQ) (20), Brief Symptom Inventory (BSI) and SCL-90-R (21), or SF-36 Health Survey (22). Moreover, the German "Hornheider" questionnaire (23) is to be named here due to its specificity for cancer patients. Furthermore, US-American research groups indicate that the NCCN Distress Thermometer (NCCN Distress Management Measure) (24, 25). A German version by Mehnert et al. (26) is a particularly economical instrument for the screening of mental distress in cancer patients. The long-term goal should be not to undertake the identification of patients with an outstanding need for psycho-oncological treatment at the time of admission to the rehabilitation clinic, but rather to determine the need for such treatment prior to admission. A possible time point to assess this need can be seen in the inpatient hospital treatment setting when planning rehabilitation measures. A training course for social workers from various transferring acute care clinics was led in the framework of the above described project. It showed that this professional group has a high degree of interest in assisting patients with procuring psycho-oncological treatment. This group of trainees showed that an adequate competence in using a psycho-oncological screening instrument can be achieved through this training. It was seen, however, that motivation and training alone are not sufficient for implementing these skills under the conditions of daily clinical routines if the appropriate conditions, primarily with regard to time, do not exist for the hospital employees. Moreover, it appears to be particularly important to assess not only the mental distress of cancer patients but also their degree of information with regard to psycho-oncological treatment when performing screening for psycho-oncological treatment outside of the rehabilitation clinic setting. Here it is particularly important to accommodate for a dif-

fering need for differing forms of treatment (need for counseling, care, or treatment) (27).

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