Rehabilitation for Cancer Patients

Joachim Weis and Jürgen M. Giesler

Abstract

Rehabilitation for cancer patients aims at reducing the impact of disabling and limiting conditions resulting from cancer and its treatment in order to enable patients to regain social integration and participation. Given current trends in cancer incidence and survival along with progress in medical treatment, cancer rehabilitation is becoming increasingly important in contemporary healthcare. Although not without limitations, the International Classification of Functioning, Disability, and Health (ICF) provides a valuable perspective for cancer rehabilitation in understanding impairments in functioning and activity as the result of an interaction between a health condition and contextual factors. The structure of cancer rehabilitation varies across countries as a function of their health care systems and social security legislations, although there is a broad consensus with respect to its principal goals. Cancer rehabilitation requires a careful assessment of the individual patient's rehabilitation needs and a multidisciplinary team of health professionals. A variety of rehabilitation interventions exist, including psycho-oncological and psycho-educational approaches. Research on the effectiveness of cancer rehabilitation provides evidence of improvements in relevant outcome parameters, but faces some methodological challenges as well.

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1 Increasing Relevance of Rehabilitation in Cancer

As has been well documented (Bray et al. 2012), cancer incidence continues to rise worldwide as does the number of cancer survivors. For the year 2008, e.g., the International Agency for Research on Cancer (IARC) estimates that about 12.7 million people have been diagnosed with cancer all over the world (Cancer Research UK 2011; Ferlay et al. 2010). For the same year, the 5-years-prevalence of cancer worldwide has been estimated with 29 million persons (Cancer Research UK 2012). By the year 2030, the number of persons newly diagnosed with cancer is annually expected to rise to about 22 million (Cancer Research UK 2012). Irrespective of considerable variation between different countries in these parameters, these trends reflect the effects of various factors. Among these, advances in medical treatment and early detection of cancer during the past three decades as well as the increasingly higher life expectancy of the population play a significant role. In addition, changes in life-style associated with the development of modern industrialized societies have to be taken into account here. As a consequence of these trends, an increasing number of persons will require medical treatment for cancer, long-term surveillance, and eventually palliative care in the future. Thus, cancer has turned into a life-threatening chronic condition for a large proportion of patients that poses new challenges for comprehensive cancer care. These include, among others, a change in patient role toward more active participation in treatment decisions and treatment itself depending on the individual patients' needs and expectations.

Oncologic treatment typically includes surgery, chemotherapy, and/or radiation which in general have become increasingly more complex, long lasting as well as more invasive. That is, treatment may produce significant toxicities which cause substantial short- and long-term side effects, functional loss in various behavioral and life domains (physical, cognitive, emotional, social, and vocational) as well as psychosocial distress. Quality of life and functional status for a considerable proportion of patients will thus be substantially reduced. Against this background, cancer rehabilitation may generally be defined as the coordinated efforts of health

care professionals to help patients overcome, minimize, or compensate the functional impairments and activity limitations brought about by the disease and its treatment. Due to the different developments described above, the importance of cancer rehabilitation has steadily increased during the past decades. Thus, rehabilitation has become an increasingly essential part in comprehensive cancer care covering the entire continuum from early detection, diagnosis, primary and adjuvant treatment, survivorship, and aftercare to end-of-life phases.

2 Focus and Basic Concepts of Cancer Rehabilitation

If one follows the WHO's definition of rehabilitation in general (WHO 1981), cancer rehabilitation may be understood as the "use of all means at reducing the impact of disabling and handicapping conditions" associated with cancer and its treatment with the aim of enabling patients to regain physical, social, psychological, and work-related functionality and "to achieve optimal social integration" (see also Gerber 2001; Gerber et al. 2005, Meyer et al. 2011). This process starts already during or immediately after the end of the primary treatment in terms of secondary and tertiary prevention.

Basic to this understanding of cancer rehabilitation is a concept of functional health that the International Classification of Functioning, Disability, and Health (ICF) of the WHO (2001; German version: Deutsches Institut für Medizinische Dokumentation und Information 2005) builds upon. From this perspective, a person would be considered functionally healthy if his/her body functions are in accordance with accepted norms, if he/she can do what a person without a health condition would be expected to be able to do, and if he/she could live his/her life in personally important life domains in a way as it would be expected of a person without functional impairments and restrictions to activities and participation.

As can be seen from Fig. 1, the ICF distinguishes between health conditions and contextual factors. Thus, it provides a new perspective on disability and functional impairment which are now explicitly viewed as outcomes of an *interaction* between these health conditions and contextual factors. This perspective integrates a social and a biomedical model of disability into a biopsychosocial one. In addition, Fig. 1 shows that the ICF distinguishes between body functions and structures, activities and participation in order to describe levels of restricted functioning. *Body functions* refer to physiological functions of body systems (including psychological functions), whereas *body structures* comprise anatomical parts of the body such as organs, limbs, and their components. Problems at this level may take the form of significant deviation or loss and are termed *impairments*. On the next level, activity means the execution of a task or an action by an individual and difficulties in executing tasks are termed *activity limitations*. Finally, *participation* refers to a person's involvement in a life situation and problems experienced by the individual in this respect are referred to as *participation restrictions*. *Environmental factors* (comprising a person's physical, social

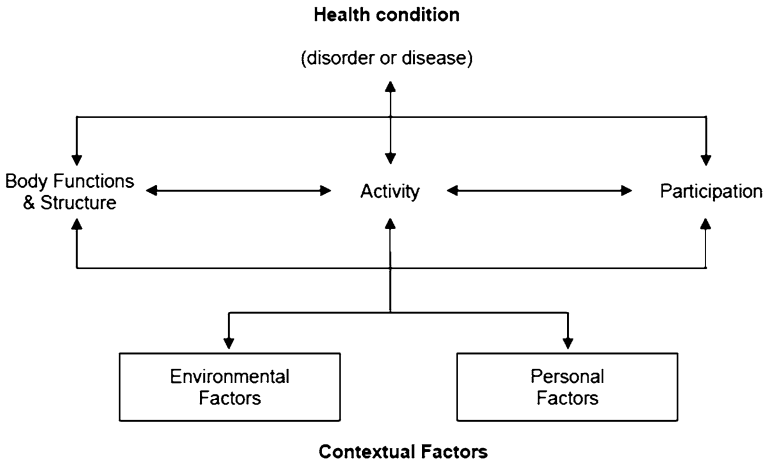

Fig. 1 Model of disability underlying the ICF (WHO 2001)

and attitudinal environment) and *personal factors* (e.g., a person's optimism) may moderate how a given health condition impacts on the three levels of functioning and activity and thus on the manifestation of disability. As an example in the field of cancer, one might consider the case of a patient with peripheral neuropathy and ankle weakness resulting from chemotherapy (Gilchrist et al. 2009). This might lead to a limitation in this patient's ability to walk. However, whether or not this would result in a participation restriction in the vocational domain as well would of cause depend on the person's vocation (e.g., if he were a fire fighter as opposed to a computer programmer).

Intended as a complement to the International Classification of Diseases (ICD), the ICF provides an extensive set of categories by which a person's functional impairments, activity restrictions, and limitations deriving from a health condition may be described in detail with additional reference to contextual factors. To be clinically useful, however, subsets of this extensive list have to be built which refer to specific health conditions and represent so-called ICF core sets. In the field of cancer, core sets for breast as well as for head and neck cancer have been developed and are currently undergoing validation (Becker et al. 2010; Brach et al. 2004; Glaessel et al. 2011; Leib et al. 2012; Tschiesner et al. 2009, 2010). This research lends support to the content validity of the respective core set categories on the one hand, but on the other also identifies the need for further amendments. Thus, there still is a need for additional development and further validation. Although the general perspective provided by ICF has been positively evaluated so far, it remains to be seen, then, whether core sets covering impairments and limitations associated with other tumor diagnoses will emerge. Furthermore, reservations concerning the applicability and practicability of ICF categories in the field of cancer rehabilitation (e.g., Bornbaum et al. 2013) will have to be resolved.

3 Structure of Rehabilitation Care

Considering the continuum of cancer care, cancer rehabilitation has its place at the interface of acute and follow-up or after-care. How rehabilitation services are delivered varies greatly from country to country as a function of the social security system into which they are embedded. In most European countries and in the United States of America rehabilitation services are mostly based in out-patient settings, whereas in Germany one finds a unique system in which rehabilitation services are provided predominantly through in-patient settings although out-patient rehabilitation services have partially gained importance there in recent years, too.

Hellbom et al. (2011) recently have provided a brief overview of the structures of cancer rehabilitation and the state of rehabilitation research in Nordic and European countries. As they point out, cancer rehabilitation ranges from primarily out-patient programs as in Sweden, Norway, and the Netherlands over 1-week courses as in Finland, Denmark, Iceland and, again, Sweden and Norway to (predominantly in-patient) 3-week programs in Germany (for Germany see also Koch and Morfeld 2004; Koch et al. 2000; Koch and Weis 1992).

One of many interesting characteristics of the German rehabilitation system is that rehabilitation costs are primarily covered by the German statutory pension insurance scheme or the patient's health insurance–depending on whether or not the patient still is in the labor force. Different from patients with other health conditions, however, cancer patients in Germany generally are entitled to apply for rehabilitation measures. Rehabilitation of cancer patients not yet retired is guided by the aim of restoring their earning capacity (as a prerequisite of social participation) which is well captured by the official slogan "rehabilitation rather then pension". Another specific feature of rehabilitation in Germany is a special form of rehabilitation that is termed "post-acute rehabilitation." This refers formally to rehabilitation services that are about to begin not later than 2 weeks after discharge from the acute-care hospital. This type of rehabilitation measures represented about 35 % of all rehabilitation measures in 2011 (Deutsche Rentenversicherung Bund 2012b).

In 2011, the German statutory pension insurance scheme provided a total of 163,466 in- and out-patient cancer rehabilitation measures (Deutsche Rentenversicherung Bund 2012b). These represent 18 % of all its rehabilitation measures for adults in that year. 84 % of all rehabilitation measures in 2011 were in-patient measures and 13 % were out-patient measures (both for adults). The latter represents an increase of 7 % points over 16 years. This mainly reflects the efforts that have been taken during that time in order to develop out-patient services in Germany, too, in order to tailor services more specifically to the needs of some subgroups of the patient population. However, with respect to the total of in-patient rehabilitation measures provided in 2011 in approximately 120 oncologic rehabilitation clinics the proportions of women and men amounted to 21 and 16 %, respectively, while the proportion of patients with cancer in regard to the total of out-patient rehabilitation measures amounted to only 2 % in both women and men.

In the United States of America, the form of delivering cancer rehabilitation has undergone some notable changes during the past decades according to observations by Alfano et al. (2012). These authors note a shift in rehabilitation service delivery away from tertiary cancer centers to community centers coupled with a fragmentation of cancer care in community settings. In combination, these trends limit the potential of cancer rehabilitation. In order to improve this unsatisfactory situation Alfano et al. (2012) suggest to revitalize the link between primary treatment and rehabilitation services and also to consider the possibility to integrate some elements of the European forms of rehabilitation into the US system of health care. It remains to be seen how this will translate into practice. Nevertheless, these recommendations fit well with initiatives of the Institute of Medicine to establish the concept of a cancer survivorship plan that describes the tasks for survivorship care of any individual patient (Oeffinger and McCabe 2006; Salz et al. 2012; Stout et al. 2012).

So far, this section should have made clear that the structure of delivering cancer rehabilitation not only varies widely across countries, but also is undergoing dynamic processes of change in response to changes in medical care and society in general. Despite the marked variation in the delivery of cancer rehabilitation services across different countries, however, there appears to be a general consensus that cancer rehabilitation is a multidisciplinary task (for details see Sect. 7).

4 Rehabilitation Needs and Assessment

Physical and psychosocial sequelae of cancer and its treatment differ widely between patients and the stages of the cancer trajectory. Problems during the initial phase immediately after treatment are different from those that may arise in later phases, e.g., after a recurrence or at the end of life (Gerber 2001). More specifically, the spectrum of sequelae may include fear of recurrence, anxiety, depression, cognitive dysfunction, fatigue, pain syndromes, peripheral neuropathy, sexual dysfunction, problems with body image, balance and gait problems, various mobility issues, lymphedema, problems with bladder and bowel functioning, stoma care, problems with swallowing, and speech and communication difficulties (Alfano et al. 2012; Fialka-Moser et al. 2003; Stubblefield and O'Dell 2009). Given this broad range of potential impairments in combination with the wide variability between patients, each cancer patient requesting rehabilitation has to be assessed individually with respect to his/her rehabilitation needs (Gamble et al. 2011; Ruppert et al. 2010). This assessment will take place routinely at admission in terms of a medical examination and interview. It may be complemented by a short psychological assessment by a psychologist or on the basis of a routine distress screening procedure. Determining a patient's rehabilitation needs could be improved using standardized instruments designed to measure quality of life. These may be either generic or may focus on the specific problems and distress of

cancer patients. Aside from assisting in the assessment of rehabilitation needs before or at admission, these instruments may be used efficiently in evaluating the effects of rehabilitation programs at discharge or follow-up examinations as well. Schag et al. (1991) and Ganz et al. (1992) were among the first to develop a comprehensive instrument for assessing rehabilitation needs in cancer patients. Overviews of more recent instruments may be obtained from a variety of sources (e.g., Mpofu and Oakland 2010). Bengel et al. (2008) have provided an update of instruments available to assessments in rehabilitation in Germany, covering internationally established ones for which a validated German version exists as well as instruments available only in German. Table 1 illustrates some of the more frequently used instruments that are generally available to assessments in cancer rehabilitation settings.

5 Goals and Interventions

Given the multifaceted impairments and sequelae due to cancer and its treatment, cancer rehabilitation usually addresses a variety of goals. On a general level, cancer rehabilitation aims at restoring the patient's physical, emotional, social, role, and cognitive functioning as well as independence. This may also include re-integration into work life. Besides helping the patient regain functional autonomy, preventing further impairment of functioning may frequently represent another important task for rehabilitation of cancer patients. Following a suggestion by Bergelt and Koch (2002) rehabilitation goals may be classified as biomedical/treatment-related, psychosocial, educational, or vocational. Table 2 presents an illustrative list of rehabilitation goals covering these categories.

Specifying rehabilitation goals for the individual patient will take his/her individual needs into account as well as the results of all other assessments. In addition, the goals to be specified should be attainable within a reasonable amount of time. Based on this principle and the respective assessments an individual rehabilitation plan will be developed in close cooperation with the patient. Also,

Table 1 Illustrative selection of instruments and domains available to assessment in cancer rehabilitation

Domain	Instruments
Quality of life	*Cancer specific:* EORTC QLQ-C30, FACIT, *Generic:* NHP, SF-36
Health-related cognitions	IPQ-R, MHLC, SOC
Coping with cancer	CBI, COPE, FKV*, TSK*, WoCL
Social support	ISSS, SSUK*
Pain	MPI, PDI
Distress/co-morbidity	BDI-II, BSI, DT, GHQ, HADS

Note *Available only in German

Table 2 Types of intervention goals in cancer rehabilitation (slightly modified after Bergelt and Koch 2002)

Biomedical/treatment-related goals
To continue therapies as recommended after primary treatment
To identify and treat sequelae of cancer and its treatment (e.g., pain, fatigue, lack of endurance, peripheral neuropathy, sleep disorders)
To improve physical condition and performance status focusing on strength, endurance, and mobility
Psychosocial goals
To support the process of coping with the disease and the accompanying physical changes
To restore and improve social, emotional, and cognitive functioning
To enhance self help strategies, competencies and resources for disease management
To facilitate adaptation to irreversible limitations and help the patient develop compensatory skills and abilities
To help the patient stabilize with respect to his/her personal, familial, social, and vocational situation
Educational goals
To provide information on cancer, its treatment, and forms of psychosocial support
To provide information on risk factors and to initiate modification in health-related behaviors like dietary habits, exercise, smoking, or alcohol consumption
Vocational goals
To help the patient achieve vocational re-integration, resume previous occupation, or retrain in order to attain a position appropriate under given circumstances

patients and–wherever possible and indicated–their family will be encouraged to actively participate as partners in the rehabilitation process and thus contribute to attain its goals. In the end, the rehabilitation plan will combine a variety of medical and psychosocial interventions considered necessary to achieve the specified objectives. As an illustration, Table 3 presents an overview of the treatment options typically available in cancer rehabilitation programs.

In addition, specialized programs have been developed that address issues and sequelae of patients from a given diagnostic or treatment subgroup (e.g., patients with breast or prostate cancer or patients having undergone stem cell transplantation). Thus, rehabilitation programs designed specifically for women with breast cancer may, e.g., focus on comprehensive management of lymphedema, exercise, dietary counseling, post-operative management of breast reconstruction, psychological counseling or psychotherapy, and dance therapy in order to address problems with body image and self-esteem. Similarly, patients suffering from severe fatigue and decreased physical performance for a prolonged period of recovery after having received stem cell transplantation may also profit from a specialized program that might combine elements of physical exercise and psychoeducational interventions.

Table 3 Interventions in cancer rehabilitation

Medical treatment including pain management and complementary medicine
Physical therapy and exercise programs
Diet counseling
Smoking cessation education
Psychological counseling/individual psychotherapy
Psycho-education
Art therapy/occupational therapy
Neuropsychological training

6 Psycho-Oncology in Rehabilitation

Psycho-oncological interventions are well recognized as an essential part of a comprehensive cancer rehabilitation program. They address the cognitive, behavioral, and emotional facets of the patients' (and their families') response to cancer and its treatment. During the past decades numerous psycho-oncological interventions based on individual or group therapy approaches have been developed (Newell et al. 2002; Holland et al. 2010), which are carried out also in rehabilitation centers. As meta-analyses and systematic reviews have shown, evidence of the effectiveness of these interventions is available at the high ranking EBM levels I or II (NHMRC 2003; Faller et al. 2013; Edwards et al. 2008). In a rehabilitation setting, psycho-educational group interventions are utilized to address the patients' psychosocial distress and to give participants the opportunity to share their experiences and find a solution to their problems. These interventions are frequently based on a cognitive–behavioral approach and include various elements as summarized in Table 4. They typically encompass 4 to 12 sessions with a maximum of 10 to 12 patients each. These interventions are operated on the basis of a structured agenda that focuses on the most prevalent issues of cancer patients and aim at initiating an active coping behavior.

Table 4 Elements of psycho-educational programs in cancer rehabilitation

Information about cancer and its treatment
Social and emotional support, sharing of experience
Stress management
Cognitive–behavioral self-instruction and self-control techniques
Relaxation, guided imagery

7 Cancer Rehabilitation: A Multidisciplinary Task

Due to the multifaceted nature of cancer and its treatment, cancer rehabilitation requires a multidisciplinary team of health care professionals (Alfano et al. 2012; Hellbom et al. 2011; Ruppert et al. 2010). The interventions provided by these professionals in accordance with an individual patient's rehabilitation plan have to be coordinated by a member of the team who in most cases will be the rehabilitation physician. The multidisciplinary cancer rehabilitation team may thus include members from the following professions: oncology, psychology, nursing, nutritional counseling, physiotherapy and physical therapy, occupational therapy, art therapy (including music therapy, dance therapy, etc.), social work/vocational counseling as well as spiritual care. As a team, these professionals work together very closely, thus requiring a regularly based professional interchange in terms of multidisciplinary case conferences across the course of rehabilitation. In addition, external supervision will support the work of the multidisciplinary cancer rehabilitation team as a well established instrument of quality assurance.

8 Evaluation of Cancer Rehabilitation

Cost-effectiveness has become a major issue in healthcare and rehabilitation services over the past years. As a consequence, evaluating the effectiveness and efficiency of rehabilitation in general and cancer rehabilitation in particular has also become a major field of research over the past three decades wherever health care systems are providing rehabilitation services. Efforts at addressing the effectiveness of rehabilitation services empirically may also be useful in providing a basis for attempts at implementing programs for quality assurance in rehabilitation settings.

Evaluation of cancer rehabilitation may be carried out at the level of single intervention modules of which a rehabilitation program is made up and at the level of multicomponent programs as whole. Thus, evaluation of cancer rehabilitation covers the whole spectrum from randomized controlled studies of specific interventions to health-services research addressing the effects of established programs at more complex levels. However, while randomization may be easily performed when evaluating single interventions, randomization may be difficult to perform at the level of evaluation a program as a whole.

For the majority of the countries focused upon by Hellbom et al. (2011), studies on the effectiveness of rehabilitation interventions for cancer patients are available. However, these authors also support the assumption that the level of available evidence of the effectiveness of single interventions in rehabilitation settings varies–with largely positive results for interventions like relaxation training or psychosocial counseling, whereas evidence levels are lower for effects of interventions like, e.g., lymph drainage or art therapy (Weis and Domann 2006). Similarly, higher levels of evidence appear to be available for interventions

targeting fatigue and physical exercise (Cramp and Byron-Daniel 2012; Mishra et al. 2012; Puetz et al. 2012; Spelten et al. 2003; Spence et al. 2007; van Weert et al. 2005, 2006, 2010). With respect to the rehabilitation of patients with prostate cancer, however, Hergert et al. (2009) report rather limited evidence of the effectiveness of the majority of the interventions investigated by the studies they reviewed. As a consequence, these authors suggest additional and methodologically stronger research in this field of rehabilitation.

In Germany, efforts at establishing quality assurance and research programs in rehabilitation settings started in the 1980s. As a result, various means of quality assurance have been implemented (expert visitations of rehabilitation centers, expert reviews of discharge records and recommendations, and patient surveys) and are considered to be working successfully. Regarding the effectiveness of cancer rehabilitation at the program level earlier as well as more recent research in Germany provides evidence of patients improving with respect to health-related quality of life, subjective well-being and physical functioning or symptoms (Bartsch et al. 2003; Heim et al. 2001; Krüger et al. 2009; Schwiersch et al. 1994; Teichmann 2002; Weis and Domann 2006). In general, rehabilitation effects found for patients with cancer or other chronic conditions in Germany have been interpreted as clinically meaningful (Haaf 2005). That rehabilitation measures are cost-effective as well may probably also be assumed insofar as it can be shown that the costs for rehabilitation reach the break-even point if a person's retirement may be postponed for at least 4 months (Deutsche Rentenversicherung Bund 2012a).

As a comparative study by Weis et al. (2006) showed, patients with non-metastatic breast cancer receiving rehabilitation differed from a group of comparable patients not planning to have rehabilitation by lower emotional functioning, higher psychosocial distress, and more disease-specific impairments. This was taken to indicate that processes of (adequate) referral by health-professionals and self-selection by patients themselves were in operation as might have been expected in light of the objectives of rehabilitation. In addition, controlling for the influence of prior chemotherapy, Weis et al. (2006) found improvements in their patients with respect to health-related quality of life, anxiety, and depression as measured by the HADS, and in specific symptoms. When compared to the patients not attending cancer rehabilitation, effects of the factor "treatment/time of assessment" were mainly found to be of moderate size and higher for patients having received rehabilitation.

Although the available evidence thus suggests positive effects of cancer rehabilitation, there still are some unresolved issues and challenges to be addressed by future research. One of these issues concerns the question whether the improvements reported for various outcome parameters during rehabilitation are sufficiently stable beyond discharge. In fact, some studies have reported a decrease of health-related quality of life or well-being after discharge and initial improvements–in some cases to even lower levels than those observed at admission (e.g., Weis et al. 2006). Consequently, further research is needed in order to clarify whether improvement or deterioration across time vary as a function of the demands of the rehabilitation program, the transfer of newly acquired skills to

daily life, the disease, socio-demographic characteristics, and the patient's social and psychological status. Another issue, of course, is the fact that the majority of studies to date do not employ a randomized controlled design that alone would allow causal inferences. Therefore, setting up valid designs whenever randomized control is not feasible will continue to present a major challenge for researchers in the field of cancer rehabilitation who are interested in causal inferences. In addition, setting up a valid design in rehabilitation research implies the need to carefully select the variables of interest and operationalize them appropriately. These may be sampled from various domains of patient reported outcomes in terms of, e.g., quality of life and subjective well-being, or from biomedical or socio-economic domains covering outcomes such as frequency of re-hospitalization, survival, health behavior, health care costs, return to work, or others.

9 Summary and Outlook

This chapter presented a brief overview of some major features of cancer rehabilitation. The model of functional health as provided by the ICF served as a background for conceptualizing cancer rehabilitation as a system of coordinated efforts to overcome the functional impairments and activity limitations that have resulted from cancer and its treatment with the aim of restoring functional independence and participation of a patient at the highest possible level. Although countries obviously differ with respect to the way they organize cancer rehabilitation services, they widely share a consensus with respect to the goals of these services. Epidemiologic trends in cancer incidence and prevalence that have contributed to an increase in the importance of cancer rehabilitation thus far were described. It was further pointed out that cancer rehabilitation requires careful individual assessment and in the light of the multifaceted sequelae of cancer and its treatment is probably best provided by a multidisciplinary team. Next, a variety of interventions available to cancer rehabilitation were introduced. Finally, results from evaluation research on the effectiveness of cancer rehabilitation at the level of either single interventions or a rehabilitation program as a whole were discussed. This research suggests meaningful improvements of relevant outcome parameters like quality of life and functional status during the course of rehabilitation and there is also some evidence of cost-effectiveness. However, methodological challenges exist as well, e.g., with respect to the stability of improvements in the patients' quality of life, subjective well-being, and psychological status beyond rehabilitation and with respect to the feasibility of randomization. Nevertheless, future research in cancer rehabilitation will be able to effectively address issues like these and thus will continue to help refine and optimize cancer rehabilitation services. Furthermore, cancer rehabilitation will gain additional importance given the persistence of the epidemiologic trends illustrated in this chapter. Insofar as the utility of cancer rehabilitation programs could further be supported by empirical studies this would once more highlight that cancer rehabilitation serves both the individual patient and society as a whole.

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