

CONCEPTS AND STRUCTURES OF CANCER REHABILITATION IN EUROPE

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Summary

There are several synonymous terms of cancer rehabilitation in Europe. They all have a common goal, e. g. improvement of quality of life. Quality of life is now the second parameter after survival used to evaluate the effectiveness of new potentially curative first line oncological therapies in Europe. Rehabilitation is a complex discipline that involves the interaction of many diverse medical health care providers.

The professional qualification of the personnel involved in rehabilitation and palliation varies greatly. Advanced training programs for the rehabilitation team exist in some European countries. In nearly all European countries outpatient rehabilitation measures are given priority, except for Germany. In some countries, such as Germany, special state sponsored and semi-state sponsored cancer counseling centers are available to the public. In other countries, charity institutions, self-help organizations, and support groups assume the social and legal aspects of outpatient patient care (such as the organization »Lutte contre le cancer« in France).

Rehabilitation does not aim to influence the actual disease, but focuses on reducing the disabilities due to the tumour and subsequent therapy. It does not lengthen the life of the patients but enables them to live their life in a manner which enhances the time they have left. The goal of rehabilitative treatments is to allow the patient to lead as normal life as possible thereby giving them a sense of dignity and purpose. The requirements for the necessary therapeutic methods during rehabilitation are dependent primarily on the limitations of quality of life, and not as with curative therapy on the extent, risk of recurrence and prognosis of the disease. Cancer patients seek to lengthen survival time and improve **quality of life** (table 1).

Table 1: Aims of follow up of cancer patients

To lengthen survival time: by medical after care including recurrence prophylaxis, early detection of recidivism, therapy of disease recurrence

To improve quality of life: by rehabilitation and palliation including alleviation of symptoms which are manifested in a physical, or a psychic affect. It also extends into the patient's social and/or vocational work life

The term »rehabilitation« refers to a process aimed at enabling people with disabilities to achieve and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to adapt their lives towards a higher level of independence. As a result rehabilitation is a multidisciplinary effort.

Evaluation of rehabilitation includes subjective parameters such as improvement of pain, dyspnea, physical fitness, appetite, overcoming fears etc., and objective parameters as well (such as improvement of physical fitness, improvement of functional capacities, resumption of work, reduction of required nursing care etc.). In general these parameters are not found in *outcome assessment and evaluation* (response, remission and length of remission) of primary therapy and medical after care. If rehabilitation induces a prolongation of life this is a desired side effect but far more important goal is to improve quality of life. It is a mistake to evaluate the value of rehabilitation, palliation and supportive care by the same parameters used in curative treatment.

The definition of rehabilitation procedures and measure can be confusing. There are several synonymous terms of rehabilitation in Europe. In practice the term of »oncological rehabilitation« is named very differently in various countries. Activities which are considered to be oncological rehabilitation measures in one country would not be named rehabilitation measures in other countries (table 2).

Table 2: *Synonymous terms of rehabilitation in Europe*

France: Soins de suite ou de réadaptation, médecine physique et de réadaptation, Rééducation fonctionnelle, Reinsertion Readaptation, Reconvalescence

Italy: Riabilitazione, medicina fisica e riabilitativa

The Netherlands: Revalidatie

Sweden: Rehabilitering

Slovakia: Rekondicionierung, Health spa, fyziatria, balneológia & liečebná rehabilitácia)

Great Britain: Aftercare, Support, Rehabilitation

Germany: Rehabilitation, Nachsorge, Kur

Rehabilitation is often confounded with wellness. Wellness is an important part of quality of life and improvement of quality of life is the goal of rehabilitation, but rehabilitation is more than physical wellness. Rehabilitation measures are often associated with physical therapy and mainly hydrotherapy. Physiotherapy, massages, and hydrotherapy are important rehabilitative measures but other measures such as psychosocial and vocational support may be more important. Many doctors have little experience with rehabilitation measures for cancer patients. They confound palliative care and supportive care with rehabilitation. Alleviation of symptoms, mainly pain therapy, is an important part of rehabilitation, but rehabilitation of cancer is more than pain therapy. The difference between rehabilitation and palliation can be found in

the fact that rehabilitation attempts to re-establish impaired functions, while palliation focuses on the alleviation of symptoms.

Rehabilitation may be necessary in cured patients as well as those patients whose disease is not responsive to curative treatment. In Germany rehabilitation is often misunderstood as simply vocational rehabilitation. As stated earlier vocational rehabilitation plays an important role but most patients who need rehabilitation are in an advanced age and occupational problems are not as important.

Rehabilitation can be performed in both **inpatient and outpatient settings**. Outpatient clinic service enables treatments for ambulatory patients who can be treated in their home environment. In nearly all countries such outpatient rehabilitation measures are given priority, except for Germany where almost all rehabilitation measures are predominantly performed as inpatient programs in special cancer rehabilitation hospitals. In most other countries the inpatient rehabilitation units are located in cancer hospitals with an in-house physician on call and the various medical and surgical consultation services available at all times (table 3).

Table 3: *Synonymous terms for "Inpatient rehabilitation services" in Europe*

<p>Germany: <i>Nachsorgeklinik, Tumornachsorgeklinik, AHB-Klinik, Kurklinik, Sanatorium</i></p> <p>France: <i>Maison de repos, maison médicale, maison de moyen séjour, maison de retraite, maison de convalescence</i></p> <p>Netherlands: <i>Revalidatiecenter</i></p> <p>Slowakei: <i>Spa, Rekonditionierungsklinik</i></p> <p>Sweden: <i>Konvalescenzhemet, Kuranstalten, Rehabiliteringsklinik</i></p>
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The professional qualification of personnel involved in rehabilitation of cancer patients varies greatly. Even though England has nursing specialists for breast cancer, PEG artificial nutrition, colorectal, stoma care and a rehabilitation community for lung cancer and health supervisors (*these types of special skills have a very high degree of professional qualification and psychosocial competence and their own education and training programs*), these advanced training programs and specialists are not always available in most other countries.

Assistance in social care of cancer patients is available in most countries. Aid is offered to both patients and families in different forms in different countries. In France nearly all hospitals employ social workers («assistance sociale») who have high reputations and who are responsible for securing post-stationary social care. In some countries, such as Germany, special state sponsored and semi-state sponsored cancer counseling centers are available to the public. In other countries, charity institutions, self-help organizations, and support groups assume the social and legal aspects of outpatient patient care (such as the organization «Lutte contre le cancer» in France).

The social services of most clinics, as well as the health insurance organizations, have information on counseling services of the national cancer organi-

zations and self-help groups. These organizations will have names and addresses for the patient, the family, or the physician responsible for further outpatient care.

With the explosion of the internet many cancer centers and hospitals, news networks, pharmaceutical companies have websites on various featured topics. Many of these websites are dedicated to cancer therapy in general and focus on specific topics in various formats. Occasionally patients can become overwhelmed with all of the information. Therefore it is important for patients to use the information obtained as part of the shared decision-making process with their physicians regarding their treatment.

References

1. Barat M, Franchignoni F (edit) (2004): Assessment in physical medicine and rehabilitation. Maugeri Foundation books. PI-ME Press Pavia.
2. Bausewein C, Fegg M, Radbruch L et al (2005): Validation and clinical application of the German version of the palliative care outcome. *J Pain Symptom Manage* 30, 51 – 62.
3. Bundesarbeitsgemeinschaft für Rehabilitation (2003): Rahmenempfehlungen zur ambulanten onkologischen Rehabilitation. Bundesarbeitsgemeinschaft für Rehabilitation Frankfurt.
4. Delbrück H, Haupt E (edit) (1998): Rehabilitationsmedizin. Ambulant – teilstationär – stationär. 2. Auflage Urban & Schwarzenberg München.
5. Delbrück H, Witte M (2004): Vergleich onkologischer Rehabilitationsmaßnahmen und -strukturen in Ländern der Europäischen Gemeinschaft. Nordrhein-Westfälischer Forschungsverband Rehabilitationswissenschaften Wuppertal.
6. Delbrück H. (2007): Rehabilitation and palliation of cancer patients. Springer France (In press).
7. World Health Organization (2001): International classification of functioning, disabilities and health. WWW. WHO.int/classification/ICF.