CONCEPTS AND STRUCTURES OF CANCER REHABILITATION IN GERMANY: PRESENT AND A POSSIBLE FUTURE

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INTRODUCTION

If one wants to influence the health structures in one's country, it is essential to know the problems and structures in the other countries of the European Union. The way they handle health problems and implement interventions is of major importance for their national development. This includes the knowledge of rehabilitation measures for cancer patients.

Concepts and implementations are the result of numerous influences (Outline 1). They may change over time. To consider these changes may be as important as the knowledge of present concepts and structures. Apart from medical needs, there are many other factors which will influence the course of cancer rehabilitation. It will change and adapt to feasibility, practicability, needs, priorities and the interests of the society.

I will give a short overlook of the present situation in Germany, adding some remarks how the implementation of cancer rehabilitation may change in the future.

Outline 1: Factors influencing concepts, implementation and evaluation of cancer rehabilitation in Germany
- Need of consumers
- Changing epidemiology of cancer diseases
- Side effects of curative and palliative cancer therapies
- Economic situation
- Financial power of health insurance companies and of pension funds
- Lobby groups of medical doctors, self help groups, hospitals, pharmaceutical companies, politicians etc.
- Legal and social conditions in other European countries

QUANTITATIVE NEED

Although orthopaedic rehabilitation still constitutes the most frequent use of patient rehabilitation in Germany, cancer rehabilitation is becoming more and more important. There are now more than 300 rehabilitation clinics specialising in cancer rehabilitation.

The quantitative need will increase in the future. This will be the consequence of demographic changes. Improvement of diagnostic and therapeutic procedures, prolongation of survival times and better compliance will be additional reasons for the increasing demand for rehabilitation interventions. Many rehabilitation clinics for orthopaedic or other medical disabilities already are already being converted into rehabilitation clinics for cancer patients.

QUALITATIVE NEED

The majority of patients rehabilitated for cancer have breast cancer or malignant tumours in the gastrointestinal and urologic area. Although bronchial cancer is the most frequent cancer disease in Germany, only 6.3% of these patients make use of inpatient rehabilitation. This is in contrast to breast cancer, where almost every third patient benefits from stay in a rehabilitation hospital (28.5%). One of the reasons for this disparity may be the still existing idea that rehabilitation should be reserved for cured patients. Most cancer rehabilitation clinics are located in a nice surrounding and far away from home towns and cancer centres. This dates from a time when cancer rehabilitation was considered to be more like a cure. It is a remainder of former coping strategies to displace the cancer problem.

Social measures to avoid impairments of activities and performance will be given priority because an essential factor affecting quality of life is independence. Furthermore, social independence will reduce the costs of health insurance companies.
Many more palliatively treated patients will ask for rehabilitation. Curative, rehabilitative and palliative interventions will be performed simultaneously. Active, problem oriented coping strategies will dominate. Social support, individual or group cognitive behavioural treatments and other psycho-educational interventions, education and discussion groups, and ergotherapy will be more important than the recreation concept.

More patients will ask for rehabilitation measures close to their families and their treating cancer centres. There will be more rehabilitation departments affiliated to big hospitals and cancer centres. The need for outpatient rehabilitation structures will increase. On the other hand, the tendency to shorten the hospital stay and to shift to outpatient treatment will affect the demand for stationary rehabilitation. This shift and the more frequent occupational activity of rehabilitation partners will increase the demand for stay in rehabilitation hospitals.

CONCEPTS OF INTERVENTIONS

Rehabilitative care does not focus on influencing the illness, but rather on reducing disabilities due to the tumour and the therapy. The negative effects of the disease and corresponding therapy in physical, psychological, social and vocational areas should be eliminated or at least mitigated by rehabilitation. To improve the quality of life is the goal.

Officially, most European countries support the biopsychosocial approach to rehabilitation, but in reality, in most countries physical interventions or wellness have priority. In Germany, the holistic approach to rehabilitation is a reality in stationary and also in outpatient cancer rehabilitation. Nevertheless, there are still some remains of the concept to recover from physical and psychic stress during a stay in a rehabilitation hospital. Some patient groups, such as the majority of breast cancer patients, ask for a more cure-orientated rehabilitation (through distance and recreation) whereas some pension funds ask for a more vocationally orientated rehabilitation.

Rehabilitation and not cure will be the main task even in distant rehabilitation hospitals. The fact that wellness is not being considered to be a rehabilitative indication does not mean that wellness measures do not exist. There will be even more wellness clinics doing rehabilitation and wellness, but these clinics will work on a private basis.
It may be that vocational measures play a less important role in the rehabilitation process.

LEGAL BASIS OF REHABILITATION

In Germany, each cancer patient has the legal right to claim medical rehabilitation. These rights are found in the Sozialgesetzbücher V, VI, IX and XI.

Every cancer patient has the lawful right to a period of inpatient treatment of about 21-26 days after completion of primary treatment. This right is independent of age, stage of the disease, type of cancer, financial status and curative or palliative treatment. Need of care, most probable deterioration of the disease during the stay and lack of compliance are the exclusion criteria. One in three cancer patients makes use of the opportunity for inpatient rehabilitation. Furthermore, all cancer patients are entitled to a legal certificate which makes them eligible for special advantages. This certificate must be renewed at least once every five years.

Hopefully, these advantageous entitlements will be mitigated. The financial burden for the stay in a rehabilitation hospital is already enormous and increases every year. Dependence on need for rehabilitation or being in the least stage of the disease would be a more reasonable criterion.

STRUCTURAL CHARACTERISTICS

Rehabilitation can be performed in both inpatient and outpatient settings. In contrast to all other European countries and to other physical and psychosomatic disabilities, inpatient rehabilitation is given priority for cancer patients in Germany. Only those rehabilitation hospitals are entitled to rehabilitate cancer patients that fulfil strict criteria (e.g., room settings, medical and technical equipment, qualification of personnel). These criteria are controlled by the financing funds. Presently, there are about 300 cancer rehabilitation hospitals. Most clinics work quite independently from cancer centres and the treating hemato-oncologists who visit the patients at home.

The initiation, coordination and surveillance of rehabilitative measures are mainly directed by physicians who must hold a diploma in medical oncology and rehabilitative medicine as well. The cooperation between primary cancer centres, rehabilitation follow-up care and rehabilitation centres is poor.

Self-help groups exist for almost all cancer diseases. Treatment deficits, such as in osteotomy care, led to the establishment of these cancer patient groups. Many patients say they want to use the association's information and activities.

Outpatient rehabilitation structures and departments for cancer rehabilitation in hospitals will increase in number and size. The cooperation and exchange of information between primary treatment settlings, follow-up care and rehabilitation structures will hopefully improve.
There will be specialisation among cancer rehabilitation hospitals. Apart from hospitals for particular cancer diseases, there will be hospitals specialised in needs such as pain problems, nutritional problems, and psychosomatic problems. Rehabilitative interventions and measures to avoid worsening of the cancer disease will be possible there. Other rehabilitation hospitals will simultaneously undertake palliative care.
While treatment deficits once led to the establishment of cancer self help groups, theses groups are more and more frequently formed for psychosocial reasons, as well as for the gain of political influence. Internet will replace guide books and self help groups as the main source of information.

INTERVENTIONAL CHARACTERISTICS

Theoretically, all cancer rehabilitation hospitals simultaneously perform rehabilitation and cancer prevention. In reality, rehabilitation has high priority, and help in occupational reintegration has a very high rank among the different rehabilitation goals. In the case that curative treatments have to be performed simultaneously, rehabilitation measures can only be carried out if curative treatments do not disturb rehabilitation.

Actually, assessment of rehabilitative needs is mainly performed by rehabilitation hospitals and not by cancer centres.

There will be more possibilities to simultaneously carry out curative medical and rehabilitative measures in cancer centres and rehabilitation settings.
How to assess rehabilitation needs and carry out interventions will be an important part in the training of physicians specialising in hemato-oncology. Preventive rehabilitation will rather influence primary treatment. Restorative, supportive and palliative rehabilitation will be the main task of rehabilitation hospitals whereas patient education and counselling programs will be the main challenge for outpatient structures.
Rehabilitation-related assessment will be performed in primary hospitals. Their outcome will decide between in- or outpatient rehabilitation and what rehabilitation setting is the best for the patient.

FINANCING CONDITIONS

Pension funds – and not medical insurances – pay more than 80% of the costs for a stay in a cancer rehabilitation hospital in Germany. This is unique on world scale, since elsewhere medical insurance companies cover the costs of medical rehabilitation. Pension funds pay regardless of age or stage of disease, and they also pay for dependent persons. They pay not only for the hospital stay, but continue to pay the salary as well (unless the patient is still working). This is in contrast to all other medical disabilities in Germany. On the other hand, pension funds pay less than 25% of the costs for outpatient rehabilitation measures for cancer patients.

The actual cost of stay in a rehabilitation hospital is 98-108 Euro per day.

Hopefully, there will be one single financing institution for in- and outpatient rehabilitation.
The costs for one day in a rehabilitation hospital will increase; but considering the probable shortening of such a stay from the average of 23 days to about 14 days, the total costs will not rise dramatically.

QUALITY CONTROL AND EVALUATION

There are guidelines that exclusively concern oncologic rehabilitation. However, these guidelines are only applicable to inpatient rehabilitation and not yet to outpatient rehabilitation of cancer patients. The guidelines guarantee a certain quality of structures and interventions. Guidelines for outcome evaluation are still in the process of being developed. Up to now there, are only few objective parameters that evaluate the outcome of interventions.

Outline 2: Quality control and evaluation
- *Quality of structures*
- *Quality of diagnostic and therapeutic interventions*
- *Quality of outcome (evaluation)*

The overall evaluation of rehabilitative interventions in cancer patients is not directed at survival, but rather at quality of life criteria. In principle, improvement in quality of life pursued in rehabilitation is attained when (1) less nursing care is necessary (main outcome aspired by medical insurance companies and (2) the patient can be vocationally reintegrated and his/her physical handicaps and functional limitations are at a minimum (main outcome aspired by pension funds).

Guidelines will be developed for outpatient rehabilitation as well. Rehabilitation settings that do not follow these guidelines will have difficulties in being financed unless the patients pay themselves. Documentation of assessment, therapeutic interventions and outcomes will be an important matter.
In addition to subjective parameters, there will be more and more objective parameters to evaluate outcome of rehabilitation interventions.
High quality and moderate price of rehabilitation measures will be the most important criteria for competing rehabilitation settings. Subjective and objective parameters will be developed to define quality of life and assess quality of life in rehabilitation.

RESEARCH

Since 1996, the German funds have been financing research programs in medical rehabilitation. Few of them deal with cancer rehabilitation. In one of these supported research projects we tried to compare the different rehabilitation structures in Europe (Delbrück 2000).

Quality of life and how to assess, improve and evaluate the outcome of rehabilitation interventions will be the main topic of research in cancer rehabilitation.

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