

REVIEW ARTICLE

Cancer rehabilitation: A Nordic and European perspective

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Abstract

Background. The increasing incidence of cancer combined with prolonged survival times seen throughout the western world increases the need for rehabilitation. Diagnosis and treatment for cancer may have substantial effects on the patients' physical, psychological, social and existential well-being. The aim of this paper is to describe the current situation in cancer rehabilitation in the Nordic countries, the Netherlands and Germany. **Material and methods.** Description of the current situation in cancer rehabilitation in the Nordic countries and literature review. **Results.** Rehabilitation as defined by multiple organizations covers a multidimensional view on chronic disease and its effect on the patient's life. The rehabilitation systems in Denmark, Finland, Sweden, Germany and the Netherlands differ depending on the differing social security and health-care systems, but rehabilitation provided is largely based on a similar, multidimensional and multidisciplinary understanding of cancer rehabilitation. Research on rehabilitation efforts in European countries indicates that there is substantial evidence with regard to single interventions which can be part of cancer rehabilitation. **Discussion.** In order to assure patients and families continuing quality of life, rehabilitation should be an integral and continuous part of all cancer care.

The concept of rehabilitation in cancer care is part of the new situation characterized by a stable rise in incidence of cancer overall in most countries, concurring with a rise in the number of cancer survivors. More than half of European patients diagnosed with one of the common forms of cancers today will be alive after five years [1]. The mean age-adjusted relative five-year survival for breast cancer is almost 80%, for prostate cancer 75% and for colorectal cancers almost 55% [1]. Early diagnosis, modern combination therapy and sophisticated individualized treatment options have resulted in a high prevalence of cancer survivors in most industrialized countries.

Cancer patients may be in continuous need for rehabilitation during their entire life following diagnosis

of the primary cancer, although requirement for rehabilitation efforts may vary over time. Cancer patients are a heterogeneous group with respect to medical as well as sociodemographic factors, and as a consequence, rehabilitation needs vary considerably. Lymphoedema [2], urinary and fecal incontinence [3], and sexual problems [4] are examples of some of the more common chronic problems that patients may face depending on type of cancer and treatment. In addition to these physiological problems, it has been estimated that some 25% of patients are emotionally distressed during and after treatment for cancer [5]. Fatigue is the most prevalent cancer-related symptom and has a significant adverse impact on patients' functional ability [6].

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The period after completing primary and adjuvant cancer treatment, usually labeled “Survivorship”, also challenges the entire health-care system through the transition between speciality oncology care and primary care, a phase where responsibilities of care may be unclear for both patients and health-care providers [7]. The Institute of Medicine (IOM) [8] has recommended that all cancer patients in the US completing primary treatment should be provided with a “Survivorship care plan” addressing surveillance of cancer spread, recurrence or second cancers as well as late effects, and intervention that addresses the consequences and symptoms as well as psychological, social and financial consequences of cancer. Finally, an essential part of the survivorship care plan should be coordination between health-care providers to ensure that all survivors’ needs are met [8].

The aims of this paper are to provide a description of the current situation in cancer rehabilitation, to give an overview of the state of science of cancer rehabilitation and to describe availability of professional resources within the general health-care systems in the Nordic countries, the Netherlands and Germany.

Definition of cancer rehabilitation

The World Health Organisation (WHO) has defined rehabilitation as “the use of all means aimed at reducing the impact of disabling and handicapping conditions and at enabling people with disabilities to achieve optimal social integration” [9]. The Model of Functional Health as established in the WHO’s International Classification of Functioning, Disability and Health (ICF) [10] is considered to provide a theoretical framework of rehabilitation [10,11]. The ICF comprehends health condition, body functions and structures, activity, participation, personal and environmental factors (Figure 1) and offers a new

foundation for the understanding of functioning, disability and health [12]. The ICF complements the ICD (International Classification of Diseases) and provides a conclusive conceptual framework which incorporates the biological as well as the individual and the social aspects of health conditions [13]. In terms of the ICF-model, rehabilitation can be defined as a coordinated process which enhances “activity” and “participation” [14].

Based on the bio-psycho-social model of the WHO and a holistic approach of rehabilitation, cancer rehabilitation comprises multidisciplinary efforts including, among others, medical, psychological and physiotherapeutic treatment as well as occupational therapy and functional therapy, depending on the patient’s functional status.

Rehabilitation of cancer patients in the Nordic Countries

Denmark

In Denmark cancer rehabilitation has been subject for review by the national committees formed to establish nationwide cancer plans. This initiative was part of a general priority of all aspects of cancer treatment initiated by the government in 1998 in order to address needs for improvement in diagnostics, treatment and as the last priority – rehabilitation. Part of this activity was the decision of the National Board of Health to conduct a systematic review by a medical technology evaluation. This report focused on studies, which investigate interventions to combat depression, increase physical activity or address some of the known late effects in breast, prostate and colorectal cancer. The conclusion highlight the lack of evidence and the almost complete uniform need to clarify which interventions to offer, when these interventions should take place in the treatment trajectory, the duration and intensity as well as aspects

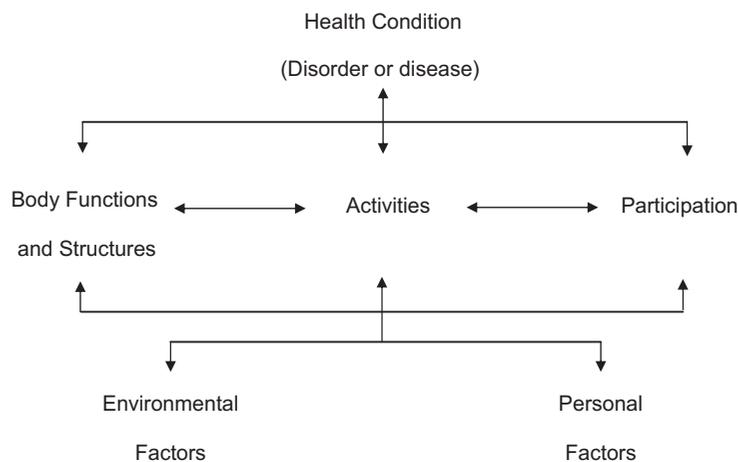


Figure 1. Interaction between the dimension of the International Classification of Functioning, Disability and Health (ICF).

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related to the integration of rehabilitation efforts taking care of other morbidities.

Since January 1, 2007 the responsibility for the rehabilitation of chronic disease, including cancer, has been assigned to the 98 municipalities of the country. Currently (June 2010) only a small number of municipalities has established cancer specific rehabilitation clinics and offer non-specific treatment such as physiotherapy or dietary counseling. Despite formal legislation it still needs to be clarified which parts of the rehabilitation problems faced by cancer patients that is the responsibility of the specialized cancer department at the hospital or the municipality. One example of a rehabilitation program is run by the municipality of Copenhagen, which in 2007 established a rehabilitation center dedicated to cancer patients. Another example is the medieval castle Dallund, which is operated by the Danish Cancer Society, offering a week long rehabilitation retreat, which consists of, for example, dietary counseling, physiotherapy and social support. Data from this rehabilitation center has illustrated the high prevalence of late effects in cancer survivors but also that the intervention did not show long lasting effects with regard to overall quality of life, change in health behaviors or distress following this short course [15,16].

Two research programs are currently focused on cancer rehabilitation. One is situated at Southern University Denmark funded by the Danish Cancer Society (1.7 million Euro) and another program supported by NOVO Nordic and the Danish Cancer Society (4 million Euro) currently under review. In addition the National Strategic Research Council has launched grants in the field of rehabilitation.

Sweden

In Sweden, many specialist clinics that treat cancer patients employ social counselors as a means to offer patients socioeconomic counseling and psychological support, and physiotherapists are often available for basic mobilization and rehabilitation in specialist clinics. Counselors, psychologists, physiotherapists and dieticians may, to some extent, be available to cancer patients through primary health-care services.

According to a recent survey made by the Swedish association for psychosocial oncology and rehabilitation (SWEDPOS), two larger multi-professional teams focusing exclusively on rehabilitation of cancer patients exist today: The Department of Psychosocial Oncology and Rehabilitation at the Karolinska University Hospital and the Department of Rehabilitation and Support at the University Hospital of Skåne. In addition, two smaller teams exist in the south of Sweden (Gothenburg and Kristianstad), and one in

the north (Umeå). Another small team is currently starting in Halmstad, on the south-west coast.

The larger teams consist of medical oncologist and/or psychiatrists, nurses, physiotherapists, dieticians, psychologists and social counselors making up a staff of around 20 full-time employees at each site. They mainly see patients on an out-patient basis. Both teams accept referrals for families with under-aged children where one of the parents has a cancer diagnosis, and both offer structured multimodal rehabilitation programs to patients and families.

In the past 20 years, a number of studies of multimodal rehabilitation programs, supported by the Swedish Cancer Society, have been published (e.g. [17–20]). These have typically been performed in a group setting, incorporating psychosocial as well as physical aspects of rehabilitation. Results from these studies are mixed, possibly reflecting inclusion of patients on the basis of cancer diagnosis rather than based on rehabilitation needs.

Norway

During the last 5–10 years, Norwegian politicians and health-care authorities have had a strong focus on rehabilitation in general. A national strategy for habilitation and rehabilitation was launched in 2007, and cancer is listed as one of the diseases that will increase the need for rehabilitation services. In the national cancer strategy for 2006–2009/10, rehabilitation is pointed to as an important area for development of new services. The practical consequences of these strategies in terms of service development must be considered relatively limited.

The Norwegian Cancer Society has for several years strongly advocated the need for service development within cancer rehabilitation and has supported several local initiatives throughout Norway's four health regions.

Both out- and in-patient rehabilitation services are at present available for Norwegian cancer patients. The in-patient services are mainly given at private rehabilitation institutions located in all four health regions. These institutions offer stays of normally three to four weeks duration to patients with different medical conditions also including cancer. There is a lack of information on how many cancer patients these institutions receive, the content of the services they offer and the effects of the stays in terms of health-related or social outcomes.

Out-patient rehabilitation services are offered at both oncology departments and at local hospitals. Some of these services are designed for specific groups of cancer patients or for cancer patients with specific needs. The oncology departments also offer supportive cancer care with somewhat different

content between the departments. These supportive services include physical therapy, physical training, psychological support or counseling on nutrition or social security benefits.

Since 1990, one national center, the Montebello-center, has run courses of 5–10 days duration for cancer patients and their relatives [21]. The main goal of the courses is to improve the patients' coping with their disease and its consequences. Information, physical activity and peer-support are core elements in the courses.

For all these different services there is, with a few exceptions [21–23], a lack of data on their effects both short-term and long-term. Research has until now mostly addressed the effects of single interventions and not of multi-disciplinary programs. Cancer patients' return to work life has been rather extensively researched. The present main challenges are therefore to evaluate the diversity of services in terms of contents and effects and initiate research.

Finland

The development of rehabilitative activities among cancer patients in Finland started in the early 1970s by the cancer societies, focusing mainly on patients with laryngeal cancer who needed peer-support after the surgery to learn the esophageal speech and help to cope with the change in their life. During the following decades cancer rehabilitation became synonymous with five to seven-day multidisciplinary courses arranged by one of the regional cancer societies or national patient organizations in rehabilitation centers across the country. In 2000, the Cancer Society of Finland widened this view into rehabilitative services to include all activities aiming to improve the psycho-social well-being and quality of life of cancer patients and their families. The perspective was changed from pre-defined means into processes and goals. The rehabilitative services include a wide variety of activities (Table I) arranged both by the public health care and NGO's.

The more intensive and targeted out-patient rehabilitation and psycho-social courses are financed mainly by the National Social Insurance Institute (for those under 65 years of age) or through grants from the National Slot Machine Association (65+ years). There are over 100 courses annually mainly in five rehabilitation centers. Currently about 10% of the 27 000 new annual patients participate on one of the longer courses and many more take advantage of the shorter or less intensive courses or services.

In 2005 the National Social Insurance Institute (KELA) published the first national guidelines for cancer rehabilitation. These set the content and procedures for the activities financed by KELA. This also

Table I. Principles forming the base for Finnish cancer rehabilitation model.

The Finnish model for cancer rehabilitation is based on the following principles:

- the services cover the whole period from symptoms to post-treatment follow-up
- different needs are met with specific services
- all patients do not need all the services
- patients have individual needs for common problems
- effective rehabilitation is multidisciplinary teamwork
- rehabilitation is an integral part of treatment and recovery
- need for rehabilitation should be considered for all cancer patients

meant that any provider of rehabilitation services (center, clinic) could apply for KELA's financing. The Cancer Society of Finland agreed on collaboration with four private professional rehabilitation centers. The regional cancer societies became partners of these centers and gave up the role of organizers of the courses. The fifth center of cancer rehabilitation is owned and run by the largest regional cancer society.

The effectiveness of the rehabilitation courses has been evaluated in various studies published in Finnish. The results have shown immediate improvement of quality of life and physical well-being, but have not looked into the long-term effects. Such studies are currently on the way. The national guidelines require continuous evaluation with well established and validated instruments for measuring health related quality of life and psychological status. The use and usefulness of this data remains to be seen.

The national cancer plans have included some aspects of rehabilitation since the 1950s, but more emphasis will be given to this area in the current development of the latest plan scheduled to be ready in 2011. Some of the clinical guidelines for different cancers include a section of rehabilitation (e.g. breast), but it is still not the rule.

Iceland

Rehabilitation for cancer patients in Iceland has mainly been organized within Landspítali – the National University Hospital, where vast majority of individuals diagnosed with cancer receive their care. In January 2002 an outpatient rehabilitation center, offering physical therapy, occupational therapy and group support sessions for cancer patients was opened by a multidisciplinary team within the hospital. The referrals were mainly concerning breast cancer patients' but also covered a variety of other cancers. Two years after opening the center, organizational changes within the hospital led to a closing of the center, in spite of its well functioning services and positive results. Activities were transferred into the general rehabilitation center within the hospital, leading to changes in services provided. At present,

regular distress screening is being conducted among patients at the medical haematology and oncology outpatient center but no centrally run rehabilitation services are provided.

In 2005 a multidisciplinary team wrote a report on behalf of the hospital directors assessing the need of rehabilitation for cancer patient and outlining what resources were available. In conclusion they emphasized on the important role of a multidisciplinary team organizing and overseeing the rehabilitation program and emphasizing the importance of a public policy in the area of cancer rehabilitation.

Outside the hospital setting, there are at least two general rehabilitation centers that offer inpatient rehabilitation consisting of physical rehabilitation and psycho-social support for two to four weeks at a time. One privately run organization in Reykjavik has for the past five years offered a rehabilitation and support program for people with cancer and their families and the Icelandic Cancer Society offers support groups, information and counseling services.

Cancer rehabilitation has faced some obstacles in Iceland and some are difficult to avoid. Despite these problems there is genuine interest at all levels to improve rehabilitation for cancer patient. A clear policy supported by scientific data (e.g. clinical guideline) is essential in the restoration of its cancer rehabilitation.

Germany

In Germany, rehabilitation is an integral part of a comprehensive social security system which roots date back to the 19th century. Since then, many revisions and amendments of the social security system have been carried out, but the basic principles still apply to the current structured system, in which the statutory branches are organized independently of each other [24]. The statutory pension insurance agencies became the most important financiers of rehabilitation measures. Driven by their interest in the prevention of early retirements and the calculation that the postponement of early retirement for three to four months compensates for the average costs of a four week inpatient rehabilitation measure, the Pension Insurance Agency invested financially and played a key role in the development of the rehabilitation sector [24]. The slogan “rehabilitation before retirement” (Reha vor Rente) captures the idea of rehabilitation as a prevention of early retirement in a nutshell.

Based on the historical background of the German social security system, the German rehabilitation system evolved as a specific and independent system which is unique and distinct from the system in many other European countries where rehabilitation measures are part of primary health care [25,26].

Nowadays, based on the social laws, German patients have a legal right to rehabilitation if they meet explicit criteria for the need and prognosis of rehabilitation [26]. Rehabilitation measures are mainly carried out as inpatient programs in specialized rehabilitation clinics, which are staffed with multidisciplinary rehabilitation teams.

In 2008, the German pension insurances paid for 804 006 inpatient medical rehabilitation measures in adults, 152 000 (19%) of those due to a cancer diagnosis [27]. Although quality criteria regarding content of the measures, staffing of the clinic, quality assurance programs, etc. are identical for inpatient and outpatient setting, currently only about 1% of all cancer rehabilitation measures are carried out in the outpatient setting [28]. Cancer rehabilitation measures normally last three weeks. If medically indicated, a prolongation can be applied for by the rehabilitation physician. During rehabilitation patients receive a combined multidisciplinary treatment program consisting of physical therapy, patient education, relaxation training, functional training, psychooncological treatment, group sessions, nutrition counseling, occupational counseling etc., depending on the patient's functioning and needs as assessed at the beginning of the rehabilitation measure.

Since the beginning of the 1990s, there have been some significant steps in the development of the rehabilitation sciences in Germany, namely the initiation of a mandatory quality assurance program and the implementation of a federal program for rehabilitation sciences [29]. In summary, the results of a number of German evaluation studies indicate that cancer rehabilitation leads to improved quality of life, physical functioning and general well-being in the cancer patient [e.g. 30–32]. Many of these studies, however, suffer from several methodological flaws, mainly the lack of control groups and randomized designs. However, the legal situation and the social security system in Germany as described above preclude the conduction of randomized controlled trials within the German rehabilitation system. Studies including a comparison group of rehabilitation non-participants find that non-participants indicate lower functional and psychosocial symptom levels at baseline [32], which indicates a well-functioning self-selection process with regard to the patients' self-assessment and their inclination to apply for and participate in cancer rehabilitation.

The Netherlands

In the Netherlands, the National Cancer Plan 2005–2010 [33] addresses integrated care, professional expertise and psychosocial care as subjects for improvement. The Dutch Health Board reported

serious innovations and more evidence are vital for the Dutch cancer follow-up and aftercare system to meet the needs of the increasing population of cancer survivors (4% of the Dutch population in 2015) [34]. In the 1980s, the Dutch government established Comprehensive Cancer Centres (CCCs) as expertise centers with regional offices to improve the quality of oncology and cancer/palliative care nationwide. Cancer aftercare and patient support is provided in hospitals, primary care settings and specialized centers for psychosocial cancer care. Psychologists, social workers, dieticians and physiotherapists are involved in this. Finances are (partly) covered by the national health insurance system.

Cancer rehabilitation was initiated in 1996–1997 by the CCCs who developed an outpatient multidimensional rehabilitation programme, named Recovery & Stability (www.herstelenbalans.nl). The 12 weeks program combines physical training (individual training & group sports) twice a week with psycho-education once a week. It is a group program designed for mixed groups of cancer survivors and based on individually tailored training plans. It aims at improvements in patients' quality of life, functioning, and cancer side-effects such as fatigue. The program is run in hospitals, rehabilitation centers and primary care centers, and multidisciplinary guided by rehabilitation specialists, physiotherapists, psychologists, dieticians and social workers. The positive short-term and long-term effects of the program on quality of life, physical functioning and fatigue were seen in a multicenter cohort study (n=658) [35] and a multicenter randomized controlled trial (n=209) [36]. In a program audit patients reported the integrated training, psycho-education and patient to patient contacts as a powerful combination [37].

The CCCs built a nationwide network to make the rehabilitation care available to all patients. By now, health-care centers all over the country (and some in Belgium) have adopted the programme; about 200 professionals are involved in this. To warrant the quality of the rehabilitation care at such a wide spread level, a quality care system is developed and supervised by the Foundation Recovery & Stability. It includes licences, professionals' education and web-based monitoring. Most health insurance companies adopted the licenses as a condition for financing. Since 2010, cancer rehabilitation is labeled by the government as structural financed care in the national health insurance system.

Due to improvements in cancer treatment the indications of patients for rehabilitation are increasing and become more diverse. To meet these needs the CCCs are improving the single concept Recovery & Stability program into a multi-modular rehabilitation

program for all phases of cancer care: during and after curative treatment and in palliative care. Inspired by positive trends in the effects of physical training during cancer treatment [38,39] multicenter randomized controlled trials in this field are carried out in the Netherlands [40].

Because of the lack of a systematic overview of evidence-based recommendations for optimal cancer rehabilitation, a multidisciplinary working group including patients' perspective and guided by the CCCs is developing a national evidence-based guideline for professionals. The guideline will be available (also in English) on the Dutch guideline website for oncology www.oncoline.nl by the end of 2010. Other evidence-based aftercare guidelines are available as well. Two guidelines provide recommendations for screening for psychosocial distress and support for work-reintegration after cancer. The guideline for cancer survivorship care recommends structural identification and treatment of patients' side-effects of cancer, supported by an individual survivorship care plan for each patient.

State of science in cancer rehabilitation

Cancer can cause multiple impairments and the biopsychosocial model as a core concept of modern definitions of rehabilitation support the interdisciplinary team approach to cancer rehabilitation [41]. Depending on the cancer disease patients may suffer from various functional symptoms such as for example loss of motor control, cranial nerve deficits, cognitive and speech problems, swallowing problems, and sensory loss [41]. Thus, evaluation studies related to cancer rehabilitation cover a wide variety of interventions and programs, ranging from specific treatments such as urinary incontinence training for prostate cancer patients to multidimensional rehabilitation programs covering several interventions from physical exercise to relaxation training and psycho-educational interventions.

In general, the existent body of research indicates that rehabilitative interventions reduce symptom distress in cancer patients and increase quality of life, functioning and general well-being. However, the evidence levels for rehabilitative interventions range from good (e.g. for relaxation training and psychosocial counseling) to low (lymph drainage and art therapy) [42]. Also, many reviews criticise the methodological quality of the existent studies [43] with regard to sample sizes, comparison groups (e.g. [44,42]), or definition of outcome indicators and stress the need for methodologically advanced research endeavors in rehabilitation research.

Discussion

The definitions of rehabilitation and the rehabilitation efforts described above illustrate that psychosocial support, supportive care and rehabilitation share many features together. Indeed, psychological and social support and to some extent supportive care are integral parts of rehabilitation.

Rehabilitation as defined by multiple organizations covers a multidimensional view on chronic disease and its effect on the patient's life. Thus, in contrast to acute care and other medical treatments, rehabilitation is based on a holistic view of the cancer patient, not only treating the disease but considering the side-effects and long-term consequences of cancer with regard to the patient's daily life, family, resources, occupational life, leisure activities, etc. Rehabilitation can be seen as an essential part of the continuing health care of all cancer survivors.

The description of the rehabilitation systems in Denmark, Finland, Sweden, Iceland, Germany and the Netherlands show that, depending on the differing social security and health-care systems countries, cancer rehabilitation is carried out in various settings and ranges from primarily outpatient programs (Sweden, Norway, the Netherlands) to weekly courses (Finland, Denmark, Sweden, Norway, Iceland) and three week-programs (Germany). However, all these programs are based on a similar, multidimensional and multidisciplinary understanding of cancer rehabilitation.

Research on rehabilitation efforts in European countries indicates that there is substantial evidence with regard to single interventions which can be part of cancer rehabilitation. However, rehabilitation consists of multiple efforts and further research should also take combined therapies into account. Even when rehabilitation is mainly carried out in the outpatient setting, patients may participate concurrently in several treatments (e.g. physiotherapy and psychological treatment). Thus, further research should account for concurring treatments and as a requirement consider outcome indicators not restricted to a single treatment-related outcome (e.g. physical capacity in exercise programs). Rather, they should include various and multidimensional outcome indicators, namely quality of life measures with their various sub domains on physical, mental, emotional and role functioning.

As pointed out by various review articles, rehabilitation research suffered from several methodological limitations in the past. Future research should focus on specific effects of not only specific treatments but multimodal programs. Future research should also address the problem of the identification of reasonable outcome indicators on multiple levels

of rehabilitation and apply advanced study designs such as randomized trials wherever this is possible.

To conclude, the increasing incidence of cancer combined with prolonged survival times seen throughout the western world call for immediate efforts to provide patients with evidence-based rehabilitation tailored to their needs. Diagnosis and treatment for cancer may have substantial effects on the patients' physical, psychological, social and existential well-being. In order to assure patients, and indeed the families of patients, continuing quality of life in all these domains rehabilitation should be an integral and continuous part of cancer care.

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