Research in Rehabilitation

Joint Research Programme “Rehabilitation Science” by BMBF and the German Pension Insurance
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In view of the increasing medical and economic importance of rehabilitation in the treatment of the chronically ill it is necessary to improve and update rehabilitation techniques continuously. Current developments in this branch of health care include a move to greater flexibility and individuality in patient care, an increasing demand for interdisciplinary networks linking the medical, social and work-related aspects of rehabilitation treatment, as well as an increased awareness of the need to make efficient use of limited resources. In such a rapidly evolving field it is imperative to use scientific research to find solutions to current challenges and further develop rehabilitation therapies and strategies.

To strengthen rehabilitation science in Germany, the Federal Ministry for Education and Research (BMBF) and the German Pension Scheme have initiated a joint research programme, in which eight regional research networks are supported with a total of 80 Million DM. These research networks, which were the winners of a nationwide competition for funding, have a promising infrastructure, and address important questions in rehabilitation research through specialized projects.

The joint research programme aims to improve the quality and international competitiveness of rehabilitation science, as well as promoting its transformation into a fully fledged field of research and teaching within the scientific community. This requires the establishment of lasting structures in the scientific landscape and the integration of rehabilitation research in universities as well as in the rehabilitation institutions. To this end, the German Pension Insurance Institutes have furthermore-endowed professorships, and involve their own rehabilitation centres in the research networks.

The regional networks embrace university and rehabilitation institutes as well as the funding organizations. Scientists and other experts from different disciplines can effectively collaborate. This comprehensive approach covers the medical, psychological, occupational and social consequences of chronic disease. Special attention is paid to the practical relevance of research results, and whether they would give rise to a significant improvement in patient care and its underlying structures. Cooperation between a major provider social security institution and the Federal Ministry provides very good framework for a fast transfer of scientific results into everyday patient care.

This brochure aims to bring the reader closer to the varied and interesting research field of rehabilitation science. It shows how research can contribute to the optimisation of rehabilitation therapy, and it introduces the eight research networks supported by the joint research programme. Selected examples of research projects from the networks bring to life in individual chapters what rehabilitation research really entails. The preliminary research results presented in this brochure strengthen our view, that, in pursuing the joint research programme, we are on a road to success.

Edelgard Bulmahn
Minister for Education and Research

Prof. Dr. Franz Ruland
Federation of German Pension Insurance Institutes
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The Joint Research Programme “Rehabilitation Science” Opens New Horizons

An important milestone was reached in 1996, when the Federal Ministry for Education and Research (BMBF) and the German Pension Scheme initiated the joint research programme “Rehabilitation Science.” The programme has an overall budget of some 80 Million Mark, funded equally by the BMBF and the German Pension Scheme. It is the first wide-ranging research initiative in this field to be supported by both the federal government and a social security institution.

The BMBF funding is being used to promote cooperation between rehabilitation centres and universities, with the aim of establishing a research culture in rehabilitation science capable of competing at the highest international level. Competition between research institutes is being stimulated and a scientific network connecting academic and non-academic institutions started. In the long run this should facilitate a world-wide commercial and scientific exploitation of the basic research. In this sense the federal government funding can be seen as the initial stimulus for the restructuring of rehabilitation science in Germany.

Similarly, the State Pension Scheme aims with the establishment of the programme “Rehabilitation Science” to move away from awarding research contracts on specific topics to individual institutions to a more systematic funding. The programme is hallmarked by the funding of research networks instead of single projects. Each network has a common research theme and is organized as to guarantee a close cooperation between pension insurance institutes, universities, scientific institutes as well as specialised rehabilitation centres.

Competent Networks for the Rehabilitation of the Future

In each of eight regional networks scientists with different research backgrounds are collaborating in interdisciplinary projects connecting academic institutes within and outside universities, rehabilitation centres and funding agencies. This regional concentration of activities establishes the basis for mutual support and criticism in the form of “networks of competence”, an infrastructure greatly facilitating the transfer of knowledge into rehabilitation practice. The new lines of communication not only foster new research results, but also promote the dissemination of existing knowledge. Therefore, the research networks provide the primary impulse for the “rehabilitation of the future”.

A basic premise of rehabilitation science is that it should be independent of institutions. In the research funding programme “Rehabilitation sciences” this is ensured by an independent committee of experts which determines the funding of the projects.

Research as a Way of Facing Future Challenges

Rehabilitation Science is a young field, with many open questions. Some of them are discussed in Section B of this brochure, where examples of research projects are described.

• How do chronic diseases evolve, and what are their prognoses? Which diseases tend to become chronic and which social and working life conditions lead to such a development?

• Diagnostic methods specific for rehabilitation have been developed which allow an early identification of insured individuals in need of rehabilitation and an estimation of the extent to which these persons can readjust to working life. How efficient are these methods?

• What results would a more flexible timing of rehabilitation bring?

• Which concepts would be likely to induce permanent changes of behaviour? What are the effects of patient training courses, health education and prolonged intensified patient after-care?

• The main goal of medical rehabilitation financed by the German Pension Insurance is to sustain or regain participation in working life. Are work-orientated elements of rehabilitation treatment effective in this regard? For example, some research projects are investigating the effects of work hardening and work motivation programmes.

• How do chronic diseases evolve, and what are their prognoses? Which diseases tend to become chronic and which social and working life conditions lead to such a development?

The overall objectives of rehabilitation research are to increase the flexibility of the rehabilitation system and to connect different areas of treatment, with the long term aim of establishing a more efficient system. Naturally, while pursuing these goals, an adequate treatment of chronically ill patients must be strictly maintained. The more we understand rehabilitation methods and their effects the sooner we will be in a position to optimally integrate chronically ill and handicapped people back into our society.

Research Funding Safeguards Standards of Patient Care

In the past, rehabilitation research was primarily concerned with the gathering of evidence for successful treatments. But today the focus has switched to scrutiny of the treatment methods themselves, especially of the interplay between diverse therapeutic components. The more scientific results concerning such components become available the easier it will be to identify and implement truly successful therapeutic strategies.

As the principal provider of resources for medical rehabilitation the State Pension Scheme has a clear interest in promoting research in this field and ensuring that treatments reflect advances in scientific knowledge. Consequently, the organization has been funding specific rehabilitation research projects since the mid seventies. By establishing professorships, collaboration with universities and regional funding associations, rehabilitation science in the Federal Republic has been sustained, and today has considerably improved perspectives. The annual Congress on Research in Rehabilitation of the Federation of German Pension Insurance Institutes (VDR) and the annual Forum on Rehabilitation of
Introduction

Happily, interest in questions related to rehabilitation science has considerably grown within the medical community in the past few years. This has led, for example, to the establishment of several university departments for rehabilitation science. Furthermore, a widespread distribution of institutes and professorships specialising in the field have recently been established, for instance in Berlin, Luebeck, Hamburg, Ulm and Bremen. This development reflects the attainment of one of the main goals of the German Ministry for Education and Research (BMBF), namely to establish rehabilitation research in universities and specialist institutes as a permanent feature of the scientific landscape.

Rehabilitation differs markedly from the medical care provided in hospitals and by general practitioners, which concentrates on the relief and cure of complaints. By contrast, rehabilitative therapy aims at removing—or at least alleviating—occupational and social impediments arising through illness. Not always can a complete cure be achieved – this is unrealistic in many cases – but the aim in these cases is the reintegration in social life at home and at work. This can be a source of appreciation and satisfaction for the chronically ill individual despite of physical impediments.

Depending on the individual disease, further treatment components may be required, such as psychotherapy, speech therapy or ergotherapy. For instance, patients with chronic heart disease need to concentrate on supervised physical exercise and health education, whereas patients with rheumatic diseases require the whole spectrum of physical therapy. Special tuition takes priority for diabetic patients and psychotherapy for patients with psychosomatic illnesses. In each case the choice and scope of treatment elements is tailored to the patient’s specific needs and capabilities.
Rehabilitation is based on a holistic view of the human being, in which body and soul are inseparable. Therefore, treatment requires a close collaboration of specialists from a variety of disciplines under the leadership of a medical expert. A rehabilitation team could be comprised of many professions. To be attended by a strongly interacting group of experienced and qualified therapists, encompassing such disparate professions is advantageous for the patient, who feels accepted as a complete person and treated accordingly.

**Self Help: Active Involvement as a Basis for Success**

Successful treatment of chronic disease depends on the active involvement of the patient. Nobody can be rehabilitated against their will. A lifelong and active cooperation is particularly crucial to prevent any further deterioration in the wake of chronic disease. Rehabilitation is all about self help.

Accordingly, modern rehabilitation medicine promotes an active rather than a passive patient participation throughout the entire course of therapy. Active engagement rather than passive treatment is stressed. This means for instance that orthopaedic rehabilitation is focussed on exercises rather than massage. And a healthy diet is not just a concept taken from lectures, but is put into practice in the kitchen in special cooking courses.

Rehabilitation does not end with discharge from the rehabilitation centre. Rather, it should provide the initial impulse to put the newly found knowledge into practice at home. Depending on the illness, various activities, such as training or relaxation exercises, or participation in an outpatient group for sufferers from heart disease could be a possibility.

**Rehabilitation as a Complement to Out- and Inpatient Care of Acute Disease**

Following the WHO model for the aftermath of illness (impairment, disability, handicap), rehabilitation is the holisitic biopsychosocial treatment concept. Rather than restricting itself to the treatment of the body, it embraces the psychological condition and social environment of the patient. Especially in times of cutbacks in the duration of hospital stays and very limited (time) budgets of doctors this holistic approach to rehabilitation is becoming indispensable. Rehabilitation can thus be said both to complete and complement hospital treatment and that of practitioners.

The effectiveness of rehabilitation therapy for patients with chronic diseases is well demonstrated by the example of the widespread disease diabetes. Preventive measures like weight reduction, dietary counseling and behavioural changes play an important role in the long term containment of this illness. Patients monitoring and regulating their blood sugar actively contribute to the prevention of further disease following on from diabetes, and can lead a normal life. This is also an example of how – by averting future visits to hospital – rehabilitation saves the patient money as well as distress – and the health system costs.

**Diversity and Quality – the Rehabilitation System in Germany**

Germany offers a broad spectrum of rehabilitative measures. There is a distinction between medical, vocational and social rehabilitation. This brochure mainly deals with research on medical rehabilitation. Medical rehabilitation is mainly conducted in specialised rehabilitation clinics. In the last years the out-patient and the part-time in-patient care has considerably grown. The most important areas of activity are - after musculoskeletal disorders - psychological illness and cardiovascular disease.

**Financing Medical Rehabilitation**

The most important providers of financial resources for medical rehabilitation are the State Pension Scheme (GRV), the State Accident Insurance (GUV) and the State Health Insurance (GKV).

- The GRV is responsible for the establishment of earning capacity and the prevention of early retirement of patients. It funds vocational and medical rehabilitation therapy for the work force. This funding amounts to over 60 per cent of all medical inpatient rehabilitation in Germany.
- The GUV is responsible for medical, vocational and social rehabilitation therapy related to disease or accidents which are incurred at work or are work related, such as those incurred while travelling between home and work.
- The GKV is responsible for those without employment. Rehabilitation measures help to prevent the onset of handicaps and dependence on home care or, if this situation already exists, to reverse them or to avoid a worsening.

**The Spectrum of Diseases Treated in Medical Rehabilitation**

- Musculoskeletal disorders continue to dominate demand for medical rehabilitation. The number of cases has increased in the past years.
- Other quantitatively important diseases in the context of rehabilitation are, in the order of frequency, psychological illnesses, for instance addiction and psychosomatic disease cancer and cardiovascular disease.
THE MOST EXPENSIVE SYMPTOM OF THE INDUSTRIAL NATIONS

Back-Pain: How Effective are Active therapies?

Do you have back-pain today? If posed on any day to a random sample in Germany, this question would be answered in the positive by about a third of respondents. Back-pain may well be a penance for our lifestyle, with some 80 percent of the population admitting to having experienced it at least once in life. For most, it is just a temporary problem, from which recovery ensues within two months independent of the form of the treatment, if any, that was undertaken. However, about half of the afflicted are consigned to living in fear of another episode of back-pain.

The majority of patients with back-pain suffer from chronic unspecific pain. A minority not only has tensed up back muscles and painful irritations of the nerves where they enter the spine, but a disc prolapse. In such cases the springy discs between the vertebrae have become brittle and cracked so that their jelly-like content extrudes and presses on the nerve. Frequent consequences, in addition to severe pain, are that movement and sensibility of the legs are impaired. As a rule, these symptoms are treated conservatively – that is with drugs and physical therapy. How-ever, if there is a risk of permanent damage the disc material has to be removed in an operation.

Unfortunately, for many patients with a disc prolapse, intensive treatment or an operation does not close this painful chapter in their life. Often, bad posture, tension and muscle weakness can maintain pain. Faced with this situation, rehabilitation may be the only remedy, just as it is for the large majority of cases involving chronic unspecific back pain which has no obvious link with the spine. Men are more often afflicted than women by this complex syndrome of clinical signs and symptoms. Experts also make use of the Anglo-American term “chronic low back-pain” to characterize pain in the lower spinal region. However, pain is often not consigned to the back, but is also felt in the neck and other joints. Such severe somatic symptoms are strongly correlated with psychological problems like anxiety, depression and exhaustion.

Eventually, the muscles become permanently hardened and the muscle tissue wastes away. This muscular atrophy is enhanced by the patient avoiding any form of physical activity for fear of aggravating the pain. With the removal of support from the back muscles, the spine is no longer adequately stabilised, and the patient follows an increasingly sedentary lifestyle, finally even avoiding social contact. The ever present fear of a recurrence of pain and the social isolation rob him of his zest for life and he becomes depressed. Rehabilitation strategies emphasise the reactivation of the patient to release him from this vicious circle and prevent a relapse into pain-induced passivity, taking third place with women. The main cost burden is accountable to a minority of patients who are prescribed sick leave over long periods due to back-pain. A quarter of the entire rehabilitation funding, amounting to some 1 Billion DM per year, is earmarked for the treatment of back-pain considering only the budget of the pension insurance.

The efficiency of various therapy concepts has been investigated in a multitude of studies, mainly abroad but also in Germany. The concepts differ greatly. There are patient classes (the so-called “Back School”) of a preventative character, purely physical exercise programmes, and complex programmes involving psychological treatment. Because of their diversity, it is difficult to compare the concepts and make specific evaluations and recommendations for clinical practice.
An important step towards a successful standard therapy is therefore a harmonisation of the evaluation criteria in studies of the different rehabilitation therapies for back-pain. The research programme “Rehabilitation Sciences” has issued recommendations which should clarify the situation regarding the treatment of back-pain and other therapeutic areas. There is general agreement between rehabilitation scientists and the funding organizations that the main shortcoming in Germany has been the lack of a valid standardised treatment concept for chronic back-pain. Unlike traditional therapies, such a concept should not entirely focus on somatic symptoms, but also take the psychological and social dimension of the disease into account.

Research
Example 1: Physical Exercise Instead of Massage

One therapy approach which, according to scientific studies, has had variable success, is the so-called “Functional Restoration! This is an intensive training programme developed in the United States which could be readily assimilated into clinical rehabilitation treatment in Germany. The main aim is not the reduction of pain (although pain killers might be used at first), but the activation of the patient, so that he can escape the vicious circle of pain, passivity and lack of exercise. Traditional passive therapy elements such as massage are expressly excluded in order to encourage the active involvement of the patient. Instead, the programme incorporates physical exercise for the back and for the whole body, behavioural therapy for coping with stress, and occupational exercises to help with reintegration in the workplace.

A similar programme is currently being evaluated by the Bavarian Rehabilitation Research Network. This is investigating the efficiency of a certain “work hardening” programme, known as GRIP (“Goettinger Rückenschule Intensive Programme”) or “Goettingen Intensive Back Training Programme”).

GRIP is one of the first German therapy concepts which might be able to satisfy the complex demands placed on a treatment for chronic back pain. It distances itself from traditional therapy concepts not only through the inclusion of active elements of therapy, but also through its exceptionally high level of intensity. 120 patients are being monitored, each undergoing one of two therapy schemes. After 3 and 12 months measurements are made of bodily parameters such as spine mobility and enhancement of muscular strength, and of psychosocial indicators concerning the patients’ well-being, their satisfaction with the therapy and their return to professional and social life. When the study is finished it will become clear whether GRIP is really superior to standard treatment.

Example 2: Individual Risk Profile Determines Choice of Therapy

Which patient should receive which treatment for his back-pain? This question is being tackled by a project of the Research Network Saxony-Anhalt / Mecklenburg-Vorpommern. Although risk factors for back-pain are well known, particularly those of a biomedical nature, their influence on the prognosis for the further development of the disease is rather uncertain. In particular, there is barely any knowledge regarding the role of psychosocial factors for the diagnosis and development of chronic back pain. Such knowledge would have far-reaching consequences. A successful therapy would have to take into account any link between specific psychological factors and a hardening of the symptoms. Therefore, one aim of the study is the development of a patient questionnaire which describes the actual need for rehabilitation whether the pain has already become chronic, what the prognosis for chronicisation is and which therapy has the highest chances of success.

The project consists of several successive study steps, each building on the results of the last. Firstly, medical and psychosocial data are collected from 400 patients with chronic unspecific back-pain. The “chronification prognosis” formed on the basis of this study is then verified on two further groups of patients. Lastly, the efficiency of criteria for an optimal choice of therapy, made on the basis of each individual risk profile, is explicitly tested. To this end one group of patients receive different kinds of therapy, varied according to the individual risks, while members of a control group receive treatments according to traditional criteria. Preliminary results indicate that patients which tend to take on special responsibilities at an earlier stage in their life and try to “see the pain through” need specific therapeutic approaches.
Rehabilitation Research
Investigates Loss of Mental Functions and Depression after Stroke

It didn’t come out of the blue. Later, after the worst was over, Martin S. realised that there had been some early – very early – warnings of the impending stroke – the temporary weakness in the arm, the inexplicable loss of concentration, and the double images in the newspaper. When he had rested a little these always went away, but a feeling remained at the back of the mind that something was not quite right. What worried him more was his general practitioner entreating him to give up smoking, go onto a low fat diet, and take lots of exercise. This should also improve his high blood pressure and blood sugar. In any case, he should go onto medication.

Desperately, he tried to make himself heard. Thank god, she had seen him – and had immediately done the right thing. Ambulance and paramedic rushed to the spot, and brought him – now unconscious – to the next university hospital where he immediately received treatment.

Most Common Cause of Invalidity in Adults

Each year about 350,000 people in Germany suffer a stroke – almost always without warning and too often without immediate and comprehensive help. The sudden decrease in circulation in the brain can have fatal consequences; every fifth person dies after a stroke. A survivor who got to hospital and treated sufficiently quickly has however got a good chance, through rehabilitative therapy, to recover at least some of his lost functions and return to his working life. It all depends on which part of the brain was temporarily deprived of oxygen and how extensive the resulting damage is. It is estimated that some 1.5 Million people in Germany are handicapped as a result of a stroke. Strokes are the most common cause of invalidity in adulthood, accounting for 25 percent of the total.

The further fate of stroke patients depends on the prompt commencement of carefully selected and dosed rehabilitation therapies. These patients have had their lives literally torn away from them. A return to an everyday routine is a long and stony path for them and their relatives, requiring medical and psychosocial guidance and support.

Active Cooperation of the Patient is Essential

Martin S. recovered quickly in the Intensive Care Unit and was quickly transferred to a neurological rehabilitation clinic. His doctor explained early on to him that drugs alone would not suffice to improve his condition. Any improvement would depend on an active involvement and determination from his side, which would be supported by the rehabilitation team. Martin S. still couldn’t move his right arm and leg. The 54 year old was often lost for words, and had seemed to have lost the ability to read and write. This had shaken him to the core. His wife tried to encourage him, but was herself in a state of despair because of the lack of a breakthrough in her husband’s condition.

Stages of Rehabilitation

Stoke patients undergo several stages of rehabilitation. Following acute treatment (Stage A), rehabilitation therapy is commenced at the stage for which, according to the severity of damage, therapy is both effective and relevant. If the patient is unconscious, or if his consciousness is dimmed because a greater part of his brain is injured, he must first of all be brought back to consciousness (Stage B). Only then can “true” rehabilitation treatment, in the narrower sense of the word, be begun.

How a stroke develops

Training of sensory and motonic capabilities

Phases A to F, following the Phase Model of Neurological Rehabilitation

Acute event (e.g. stroke)
Immediate treatment, restitution of vital functions
Medical diagnostic and treatment, early rehabilitation, individual rehabilitative support
Professional life
Long-term nursing care, permanent support
Occupational promotion, retraining
Comprehensive rehabilitation after completion of early mobilisation
Early mobilisation, comprehensive rehabilitative therapy combined with substantial medical and nursing effort
Stroke

Stage C is a transition phase into the ‘true’ rehabilitation, in which patients are attended to who have maintained consciousness and a willingness to cooperate, but for whom daily routine presents difficulties. Here, the restoration of important functions such as speech faculty or the use of limbs takes precedence, after which the patient is able to move on to stage D, the so-called “follow-up” rehabilitative treatment phase. This stage is tailored to the patient, for whom a team of medical doctors, nurses, physiotherapists, psychotherapists, and speech and occupational therapists will draw up an individual therapy plan.

Next, the patient is prepared for his return into his social and professional surroundings. In stage E the extent to which the patient can withstand pressure in the workplace and his ability to do his job are established. Where necessary, work skills are practised, and he is prepared for out-patient treatment. Phase F stands for the long-term care of patients whose condition could not be improved through extensive rehabilitation therapy.

The consequences of a stroke can certainly be rather complex – as complex as the brain itself and its various functions. Obvious impairments like hemiparesis shape the picture society has of this group of patients. However, less obvious degradations in concentration, memory and perception pose the real barriers to a successful return to society and to work. For stroke patients it is said that perception “is cracked like a mirror”. Anyone whose environment is perceived only partially or in fragments, whose memory is incomplete and unreliable must find even minor everyday tasks, never mind life as a whole, extraordinarily difficult to systematically plan and act out. Bearing in mind the importance of planning and implementation skills, it is astonishing that so far the impairment and rehabilitation of these faculties have received such scant scientific attention.

The Brain – a Complex System

During a stroke, the supply of blood to the brain is interrupted. This can have serious consequences, as the brain controls all movements, gives us perception, and produces thoughts, images and emotions. The consequences of a stroke depend on the area of the brain involved. Perception and sensory faculties are mainly located in the cerebral hemispheres. These are connected with each other by over a million nerve fibres.

In most people the left hemisphere is responsible for speech, calculation and logical thinking. Stereoscopic vision and intuitive thinking as well as creativity and certain personality features are situated in the right hemisphere. Both hemispheres process perceptions of the sense organs which reach the brain via nerve connections. Both transmit commands via nerves to muscles in the opposite body half. Thus, if the right half of the body is paralysed the damage is most often located in the left half of the brain. Once dead, brain cells cannot recover. Nevertheless, the brain has an astonishing “plasticity”: Nerve connections can be activated or newly developed so that previously lost functions can be taken over by healthy brain areas and be regained.

Example 1: Planning and Acting Out Ability after Stroke

A project of the Research Network Ulm is studying impairments in these areas and their wide-ranging consequences. The scientists aim to find out what consequences a loss of planning and acting-out ability has on social and occupational rehabilitation. Another question to be answered is the benefit of in-patient and out-patient rehabilitation. Finally, they are investigating whether criteria can be found which would allow an objective measurement of the effectiveness of rehabilitative therapies. Quite possibly, certain diagnostics, such as data from computer tomography or from psychological tests, might allow prognoses about the probability of recovery. Final results will only be available in a few years time, because productivity and the extent of social reintegration can still evolve months after in-patient or partial out-patient treatment in a rehabilitation centre.

The research programme “Rehabilitation Sciences” is investigating such questions.

Scientifically based knowledge concerning the efficacy of a given rehabilitative therapy and the type of case for which it is suited can only be gained if studies are conducted on the effect of specific treatment methods on clearly defined bodily dysfunction. Several projects within the research programme “Rehabilitation Sciences” are investigating such questions.

Perception is “Cracked like a Mirror”

The consequences of a stroke can be rather complex – as complex as the brain itself and its various functions. Obvious impairments like hemiparesis shape the picture society has of this group of patients. However, less obvious degradations in concentration, memory and perception pose the real barriers to a successful return to society and to work. For stroke patients it is said that perception “is cracked like a mirror”. Anyone whose environment is perceived only partially or in fragments, whose memory is incomplete and unreliable must find even minor everyday tasks, never mind life as a whole, extraordinarily difficult to systematically plan and act out. Bearing in mind the importance of planning and implementation skills, it is astonishing that so far the impairment and rehabilitation of these faculties have received such scant scientific attention.
Stroke

Example 2: Depression after a Life-Threatening Event

A severe stroke comes as a shock to people who, in the main, are subjectively completely healthy individuals. It almost invariably triggers a trauma. In the worst cases it is experienced as an acutely life-threatening event, arriving without warning, and one feels entirely at its mercy. On top of all this, anxieties about the uncertain future arise. Often patients become depressive and apathetic, a state of mind which can enhance or superimpose itself over the actual cerebral loss of mental functions. At least 50 percent of all stroke patients suffer from some form of depression, which brings with it its own demands for treatment.

The Research Network Ulm is tackling the topic of depressive reaction through a project to investigate the significance of psychological changes following stroke. What is the influence of psychological illness – in addition to medical and socioeconomic factors – on the effectiveness of rehabilitation therapy? How can the collective effect of various risk factors be better understood and described? Does psychotherapy as a integral part of the treatment of neurological rehabilitation have any impact on depression? Which patients need intensified psychotherapy with a higher number of specific interventions and stabilising therapeutic elements? How do the results of rehabilitation, reintegration at work and into the social environment differ for different patients?

About 200 Patients admitted to a rehabilitation clinic following a stroke were divided equally into two groups. One group is receiving treatment in a normal rehabilitation ward whereas the other is being treated in a special ward for psychotherapeutic neurology. First results of this study show that there are depressive disorders after a stroke which are neither recognised by the patient nor the therapist, because they are quasi-hidden behind unspecified symptoms. Only distinctive diagnostic methods which in particular take into account the individual’s way of coping with the disease, can uncover these disorders and pave the way for a specific treatment.

Example 3: How much can Relatives Bear?

The success of rehabilitation largely depends on the therapy and the patient him/herself. However, the influence relatives can have should not be underestimated. The chronic disease of a member of the family makes them suffer themselves and often they find it difficult to provide the necessary support. Most patients return home and are dependent on relatives to take over part of the treatment and provide motivation. Changes of personality, perceptive disorders, lack of self criticism and self perception make the company of a patient with cerebral damage difficult. Social contacts are therefore avoided; psychological and somatic symptoms are the result.

How do relatives cope with this strain? What can they do to come to terms with the situation in the long term? A study conducted by the University of Leipzig on 80 relatives is elucidating how they survive living with stroke victims that have lost a fraction of their mental capabilities such as speech faculty. Interviews, diary entries, questionnaires and measurements of the stress hormone Cortisol are being used to construct a pressure profile.

Just how big the burden is, is shown by the first results of the study. At the time of admission to the rehabilitation clinic the relatives estimate a higher level of impairment in the patients than the patients in themselves. At this stage, about a third of the relatives would like to have more discussions with information and explanations about the disease, its therapy and the chances of recovery. After discharge from the rehabilitation centre and the return to home the relative’s and the patient’s estimation about the severity of the disease approach each other. The subjective burden of the relative depends on his judgement of the patient’s situation. The more physical and psychological impairment he estimates in the patient, the more physical complaints and depressive feelings he has himself.

Further information about research projects can be gathered at the individual Research Networks (Section C).
How Long-Term Results can be Improved after a Heart Attack

It is the most common cause of death. Every year about 130,000 people in Germany have a heart attack. 55,000 survive and must adjust to a life changed by the consequences of the first attack and overshadowed by the threat of a further one.

Each year, 100,000 people undergo bypass surgery. Rehabilitation after a heart attack or bypass operation is a core area of rehabilitation medicine in Germany. Some of the patients are men or women under 50 or younger who were suddenly thrown out of their daily life at work and at home and are trying to find a way back.

Many risk factors contribute to the narrowing of the coronary blood vessels and the consequent lack of oxygen in the heart muscle: smoking, bad diet, diabetes, high blood pressure, high blood cholesterol and psychosocial stress are the most important factors leading to coronary heart disease. The good news is that scientific studies have shown that coronary heart disease can be prevented. The bad news (for many concerned) is that a positive development is only possible if risk factors are constantly avoided. This is of immediate concern to some 5 million patients in Germany who already suffer from coronary heart disease and therefore are at risk of a heart attack, as well as to those patients recovering from a heart attack or bypass surgery, preparing for their return home in a rehabilitation centre.

Coordination of Acute Phase and Rehabilitation Treatments

After a heart attack patients are already mobilised in the intensive care unit at a very early stage. In order to prevent dangerous complications like thrombosis, pulmonary embolism and pneumonia, physiotherapy and getting up exercises are started in the first few days after an uncomplicated attack. If all goes well, transfer to a rehabilitation clinic can be made as soon as the second week because the risk of complications and another myocardial infarction is substantially lowered nowadays by lysis treatment of the underlying blood clot and the early instigation of heart catheters to investigate and widen the narrowed arteries (PTCA). Then, the so-called “associated rehabilitative treatment” in a rehabilitation clinic can begin. This has to be closely linked with the treatment of the acute phase. The starting point for all treatment are accurate diagnostic results of the physical state of the patient’s body. What are the functions of the damaged heart? Are there any specific risks like arrhythmia? Can it withstand exercise? When can the patient take up physical exercise?

After the medical examination come the psychological tests. Heart attack is a life threatening event with which the patient has often not been able to cope emotionally with and is surrounded by fears of another heart attack. Many patients are searching for a way out of their depression: The illness is suppressed as a “temporary engine failure” which can be “repaired” in hospital in order to return to the daily routine as quickly as possible. Or the patient gives himself up to the fate of a seemingly unavoidable invalidity. An adequate strategy of coming to terms with the illness and its consequences requires that the patient accepts his illness emotionally and tries to plan his life on a rational basis. Psychological treatment in a rehabilitation clinic therefore on the one hand relies on the reduction of fear and insecurity; while on the other hand endevouring to foster a positive, healthy conscious behaviour by providing the necessary information, and by motivating and training the patient.

Research

Example 1: Intensive Aftercare Preserves Effects of Rehabilitation

Rehabilitation in centres can improve major risk factors like blood pressure, body weight and cholesterol levels, as many studies have shown. However, it is unknown how long-lasting these positive results are. There are indications that improved cholesterol and blood pressure levels are fading as soon as six months after discharge from the rehabilitation centre. Even the so-called "Heart Groups" for out-patients - devoted to exercise training and of which several thousand exist in Germany - were not able to preserve the effects of the initial rehabilitation care long enough.

A research project of the Rehabilitation Network Ulm is investigating how positive in-patient results might be extended into the long term through intensive aftercare. During their stay in the rehabilitation centre patients are prepared in seminars to follow the development of risk factors and to learn self-monitoring. The group is led by an experienced therapeutic exercise trainer and a doctor is present during therapy who can handle emergency cases. One feature of intensified after-care is the therapy chart to monitor the physical state, patient complaints and drug intake as well as important laboratory results and body weight. This enables, the doctor, the group leader and the patient to follow the development of a risk profile. The therapy chart also registers any additional training units recommended to the patients. Every three months participants attend an health education seminar covering the topics risk factors, diet and stress management. The scientists in Ulm compare the risk profiles of the intensive after-care participants with the corresponding profiles of patients undergoing the standard after-care. Although sound results are not yet available it is already clear to the scientists that patients in the new aftercare model were highly motivated and welcomed the health education seminars.

Coronary Heart Disease

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“Heart attack is a typically male disease.” This cliché is wrong, although women indeed have a much lower risk of heart attack prior to the menopause when they benefit from hormonal protection. Until the 45th year the relation between women and men regarding the incidence of heart attack is 1:6. From 75 years onwards women approach equality with men. However, if women have a heart attack, also in younger years, they are more likely to die than men. Furthermore, recurrence of heart attacks are more common in women. Almost all studies on heart attack have been conducted with male patients. Their results do not necessarily apply to women since coronary heart disease usually produces different signs and symptoms in women and takes a different course. In particular, old and very old women have highly specific demands on rehabilitation therapy.

A project in the Research Network Northrhein-Westfalia is investigating these issues. The research has to take account of the fact that the differences between men and women not only have a medical cause, and that other factors may be more important, as indeed international studies have shown. Women tend to withdraw from lengthy therapies and are less often prepared to continue with rehabilitative measures. Also, men and women have different perspectives towards health and disease. Men consider themselves to be healthy if they have no pain or other complaints and are “functioning” at home and at work. This different attitude also applies to rehabilitation: women value their own contribution to their health more and pay less attention to work ability, even if they are in working live. Women may also have other needs and expectations from rehabilitation; they need more emotional support, want less pain, not too much exhaustion through exercise and prefer other forms of training than just the ergometer bike. Social roles, standards and daily routine seem to determine which rehabilitative measures are employed. Women with family and a job have a worse prognosis than single women, whereas men seem to have advantages from having a family.

Example 2: Women Need Another Rehabilitation than Men

Gender specific treatment and rehabilitation after heart attack is also the subject of further studies in the North German and Bavarian Research Networks. Scientists from North Germany followed 400 men and women after their first heart attack, after a first PTCA (which widens the coronary blood vessels with a balloon) or after a first bypass operation. The Bavarian network is investigating 250 women and 350 men after first heart attack or acute coronary disease for gender specific influences on the short- and long-term effects of rehabilitative measures. Scientists want to find answers to the following questions: Are there any gender-specific differences in regard to recurrence of the disease, return to work and home, quality of life and changes in the classical risk factors for coronary disease? Are there biological, therapeutic or psychosocial factors which have different influences on the outcome of rehabilitation in men and women? Which factors or combinations of factors best determine the success of rehabilitation in men and women?

All patients undergo a thorough medical examination at admission and at dismissal from the rehabilitation clinic. They are also questioned about their occupational and social situation and their health behaviour. Questionnaires are answered about their subjective state of health and satisfaction with the treatment, both in the rehabilitation clinic and 18 months after discharge, at which point the interviews are repeated as well. First results from a small random sample show considerable gender differences concerning state of health and psychological condition. These are independent of the patient’s age and seem to indicate that more specific therapeutic measures for women are required than previously thought.
Rehabilitation and Psychological Disease: More Flexibility and Integration?

“Treatment after heart attack and stroke,” “rehabilitation after disc prolapse,” “integration of handicapped people.” If the man on the street hears the word “rehabilitation” he associates it with these and many other terms. Less well known is that psychosomatic medicine is a traditional area of rehabilitative medicine and is more closely based on scientific evidence than many other disciplines in that field. The spectrum of psychological disease is broad, ranging from neurotic to psychotic disorders up to psychological illness caused by underlying chronic or severe acute disease.

A Stony Path to a Diagnosis

For one group the way into a psychosomatic rehabilitation centre is often a long and winding path, especially if bodily symptoms like headache or back-pain prevail. Then the odyssey of the patient visiting one specialist after the other begins. Often doctor and patient persist too long with purely somatic diagnoses – often until a total break down makes admission to a rehabilitation clinic unavoidable. On average it takes about six years for a psychosomatic illness to be properly diagnosed and treated.

For patients being treated in a rehabilitation clinic diagnoses have long been established. Outpatient psychotherapy had not been able to improve their condition in their normal environment. Only a temporary distance from everyday life and the different therapeutic surroundings can give them the chance of a successful treatment. Another group of patients is embarking on rehabilitation therapy following treatment in a psychosomatic or psychiatric hospital. In the rehabilitation clinics they are generally preparing to return home to their family, into their social environment, and also to their professional environment.

Growing Demand for Psychotherapeutic Rehabilitation

Rehabilitation treatment for psychological disease is on the increase. About 15 percent of all rehabilitative therapies in Germany are prescribed for patients with a diagnosed psychosomatic illness. Additionally, there is a large outpatient programme. It is difficult to estimate the real need for therapy. Studies have shown that every tenth person in the federal republic suffers from a psychological illness each year, the vast majority of them receiving outpatient treatment. Furthermore, there are specific opportunities for rehabilitation treatment for special groups of patients, such as patients with psychosomatic disease, patients suffering from addictions or eating disorders, patients with cerebral disease who have developed psychosomatic problems after a cerebral trauma or a stroke, and patients suffering from psychosis.

Having existed for months or years, a psychological disease cannot be effectively treated in the space of three weeks. Therefore, treatment in a psychosomatic rehabilitation clinic generally requires a longer duration than treatment of other diseases such as heart attack and back-pain where bodily symptoms prevail. However, even six weeks can be often too short a period to break up encrusted psychosomatic barriers and to assimilate and put into practice new patterns of behaviour. Consequently, experts are looking for methods which guarantee a better link between outpatient and inpatient therapy and thereby lead to better long-term results.

Psychoanalysis and Behavioural Therapy are Complementary

The first psychosomatic rehabilitation clinics in Germany were mainly orientated towards psychoanalytic psychotherapy. They endeavoured to find the underlying causes of psychosomatic disease in childhood or adolescence and tried to counter these. In the eighties several rehabilitation clinics introduced behavioural therapy according to the principle “Talking is silver, acting is gold.” Today, many clinics cover both therapeutic schools and have the relevant treatment for each patient. The research project therefore seeks to find out whether additional therapy in the rehabilitation clinic after hospital discharge would be accepted by the patient, and how efficient such a strategy might be.

The Magic Mountain Study

The Magic Mountain Study (1983-86) proved the efficiency of the use of psychoanalytic therapy in clinical rehabilitation. About 350 patients participated in the study, most of them with a longstanding psychological disease. After three years the following results were obtained:

- Two thirds of the participants thought that their psychological and bodily state of health was better than before treatment and were satisfied with this result.
- More than half of the patients said that they had become more efficient and less susceptible to stress.
- The frequency of medical consultation and sick leave had decreased.
- Drug consumption and hospital stays had been reduced.
Projects can be gathered at the independent health clinics. Research and health insurance organizations providing finance, Questionnaires, interviews, and analyses of the patients’ files from the psychosomatic rehabilitation clinics will help to identify the risk factors for therapy interruption. Furthermore, scientists are looking at the long term consequences for a patient’s health and the likelihood of him applying for and receiving further treatment. Quite probably, the course of treatment must be carefully planned from the outset to prevent a premature end. The right choice of therapy, made on the basis of a correct diagnosis, presumably has a decisive influence on the acceptance of rehabilitation care – for the patient as well as the therapist.

Example 2: How can Short Cuts of Treatment for Psychosomatic Illness be reduced?

In 1998 less than 5 percent of all rehabilitative measures in rehabilitation clinics were prematurely ended, according to VDR statistics. By comparison the overall figure for psychosomatic rehabilitation was around 9 percent. This percentage varies according to the exact nature of the disease. Thus, patients suffering from anorexia or a personality disorder more often left clinic earlier than planned than patients with, for example, a neurotic depression. Furthermore, patients under the age of 30 were much more likely to cut short the therapy.

The Northrhine-Westfalia Research Network has instigated a project to investigate the causes and consequences of therapy interruption. Patients leaving the rehabilitation clinic prematurely are often disappointed and rather ill, a situation which might well not bode well for the future development of their disease. However, it should not be forgotten that the clinic and the therapists must also come to terms with what is often a rather unpleasant event.

The study designed to investigate these issues is following a group of 300 patients who had prematurely ended psychosomatic rehabilitation. Additionally, rehabilitation professionals have been questioned, including doctors, psychologists, as well as representatives from the health and pension insurance organizations providing finance. The pub, a family business, and looking after her father, a cancer sufferer, put Gerda K. under intense pressure. Relaxation was not possible. When her physician first suggested she apply for medical rehabilitation in a psychosomatic rehabilitation clinic, she indignantly rejected the idea. A little later, after a complete break down from exhaustion and an emergency admission to hospital she reconsidered the suggestion of her physician, and applied to her pension insurance, which duly arranged a stay at a rehabilitation clinic.

A Patient’s Tale of Woe

Gerda K. (65) couldn’t survive without pain killing tablets. She had deposited the pills everywhere - in her handbag, her coat, in different drawers in the house and in the pub where she worked together with her husband. When the headaches got too much for her she was able to pick up her “saviours” immediately. “Migraine”, “tension headache” - the diagnoses by her general practitioner, a physician, a neurologist and an orthopaedic surgeon hardly made a difference to her condition. The pub, a family business, and looking after her father, a cancer sufferer, put Gerda K. under intense pressures. Relaxation was not possible. When her physician first suggested she apply for medical rehabilitation in a psychosomatic rehabilitation clinic, she indignantly rejected the idea. A little later, after a complete break down from exhaustion and an emergency admission to hospital she reconsidered the suggestion of her physician, and applied to her pension insurance, which duly arranged a stay at a rehabilitation clinic.

The aim: to lead a “just normal” life.
Patient Education

Counter Chronic Disease?

Patients with chronic diseases need help to help themselves. Help means supplying information about the illness, its treatment and its everyday management. This applies not only to the patients themselves, but also to the relatives and carers who must often bear much of the burden.

The more they get to know about the disease and its treatment, the more responsibility they can take on for living with it. The patient comes to terms with his disease, develops practical skills, follows his own initiatives, and gets to understand the therapy plan designed by the rehabilitation team. The chances of success grow when he can pull his weight as a self-confident and informed partner.

Patient education thus plays a central role in rehabilitation from chronic disease. It conveys knowledge about the peculiarities of the disease, and its effect on the body, cultivates certain patterns of behaviour, and lays down general guidelines for healthy living. In the last few years special teaching programmes have been developed, in particular for asthma, diabetes, and cardiovascular and rheumatic diseases. In fact, the education and training of asthmatics and diabetics has now become a standard treatment, even being adopted as an integral part of out-patient care funded by health insurance institutions.

Information Increases Motivation

Though not every patient is satisfied with his treatment, he is usually reluctant to talk openly about this with his doctor or another therapist. Drugs are not taken, active cooperation refused. In order to change this the reasons have to be known:

The patient:
- is not involved in the planning of therapy and in decisions,
- doesn’t understand prescriptions or frequently changes doctor and therapy centre,

The doctor:
- either doesn’t understand or ignores the patient’s needs and gives unclear instructions,
- involves drugs with side effects or is demanding, complex and lengthy,

A patient can be uncooperative for a wide variety of reasons. However, a common underlying feature is a lack of information and a feeling of helplessness towards the disease. More knowledge and self esteem can remove misunderstandings arising through instructions that seem too complex or are not understood, and prevent a relapse into a passive role. Ignorance is more widespread and dramatic than is generally supposed. Even the most basic facts are often missed. An American study has shown that two thirds of asthma patients were unaware that they might die of the disease. Three quarters of the patients had no inkling of the pharmacological mechanism of the drugs they were using, and only a third of the patients were able to use the aerosol spray correctly in an emergency. Similarly alarming results were found for other patient groups such as diabetics. These deficits of information can be removed by specific patient education. Participants are able to manage their disease in an adequate way. As a result rehabilitation is better accepted and more successful.

The attitude of a patient to his disease influences the success of rehabilitation, as studies of diabetes and asthma have shown. More knowledge, a positive attitude and adjustments in behaviour bring rewards in the short and long terms. There is less need for hospital stays or visits to the doctor, and fewer days are lost at work. All in all, the patient comes better to terms with his illness, while keeping down it’s overall costs.

Educational programmes also make up a sensible supplement to the therapy of rheumatoid arthritis, as a study of several treatment centres has shown. It was found that knowledge of the disease and the ability to fight pain could be increased. Patients were also more willing to participate in a self-help groups and were more likely to be able to continue or resume their professional life.

Research

Example 1:
Bechterew’s Disease: Trained Patients are more Satisfied Patients

The effect of educational programmes on patients suffering from spondylitis ankylosans (Bechterew’s disease - a chronic inflammation of the joints) has not been systematically studied until now. The Research Network Lower Saxony/Bremen has instigated a project to address this question. The project is scrutinising an educational programme developed by the German Society for Rheumatology. Are the patients being helped? And if yes, which patients benefit most? The programme is comprised of six teaching modules, each seminars of 90 minutes duration. The themes presented are the clinical picture of the disease, physiotherapy, pain management, therapy options, spine-friendly behaviour, and everyday coping techniques. Two groups of 150 patients are being studied as they undergo individual rehabilitation programmes. One group is being exposed to the six seminars whereas the control group is receiving six further instalments of the normal therapy programme.
What is Spondylitis Ankylosans (Bechterew’s Disease)?

Spondylitis usually arises between the ages of 15 and 30 years, and accompanies a patient for the rest of his life. Previously, it had been thought that mainly men are afflicted (in the relation 10:1), but today it is known that the gender preference is much less prominent and that the disease takes a less severe course in women. The first symptom is normally back-pain in the night which can cause agonizing interruptions in sleep. In some patients, the entire vertebral spine can become afflicted by inflammations of the small joints at a later stage. Pain and immobility are possible consequences, sometimes leading to a complete stiffening of the spine.

Some patients also suffer from uveitis and from inflammation of other joints and of tendons, for instance at the heel. For some, the disease may cease to further develop after a few years; for others, it may get worse in a series of flare ups. The earlier typical signature of a bent forward posture is nowadays almost unknown because modern therapy can snuff out this development early on. Therapy is built around physiotherapy, sport, analgesic physiotherapeutic measures, adaptation to everyday life (the correct posture in bed, use of special mattresses and chairs, etc), pharmaceutical treatment and, where necessary, occupational reorientation.

The aim of the project is to enhance the efficiency of in-patient treatment by complementing it with special education. The scientists are using medical and economic data as well as subjective statements from patients as criteria to judge the efficiency of the programme. The commencement of educative therapy at toddler age would lead one to expect that parents should be better able to cope with the disease and its consequences and recognise important symptoms early on. The training should also help children to quickly become involved themselves in the management of the disease. The intensive mediator training not only teaches how to avoid risks, but gives concrete instructions as to how everyday life should be restructured. And it gives guidance in mastering critical situations such as when siblings think themselves neglected.

When a child is admitted into a rehabilitation hospital it is normally accompanied by one parent, usually the mother. She participates there in information evenings and in so-called mediator training, which provides intensive training how to deal with the disease and how to influence it positively. However, the programmes which are currently being practised have rarely been evaluated systematically for their efficiency. Another project of the Research Network Lower-Saxony/Bremen is investigating the effect of intensive mediator training in comparison to education solely based on the transfer of information.

The rehabilitation of chronically ill children under the age of six poses special demands for educational programmes on both therapists and parents. Asthma and atopic eczema are the most common chronic diseases in childhood; about 4.5 percent of all children between six and nine years have asthma, and nine percent atopic eczema. These children suffer from lack of sleep, are rather anxious, too closely relying on their parents, and often show abnormal behaviour. Their parents are exhausted, feel left alone, and overextended. They must constantly play the role of „co-therapist”, ensuring that medical instructions with regard to diet or removal of allergens from the environment are adhered to.

Example 2: Parents as Co-Therapists: Educational Programmes for Children Prepare for a Life with the Disease

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Although the study is not yet completed, about half the participants have taken part in the seminars. Preliminary results show that the seminars are judged by the patients to be easy to understand and recommendable. Participants of the seminar were better informed than patients from the control group, as was to be expected. Furthermore, they were more satisfied with their therapy and placed more value on an exchange of experience with other patients. The more pain and impairment they had, the more they valued the modules “pain management” and “coping techniques.” In the long run educational programmes are expected to improve disease management.

Further information about research projects can be gathered at the Individual Research Networks (Section C).
Motivation is the Key to a Return to Work

Rehabilitation therapy as a prelude to retirement? Despite the best efforts, the real goal of the pension insurance institutions – the patients’ return to work – is not always realised. According to patient surveys from these institutions’ quality assurance programmes, about 25 percent of patients who have undergone rehabilitation therapy consider early retirement.

However, not only patients lose sight of what is a core issue from the standpoint of the pension insurance institutions. The primary aim of doctors, psychologists, in fact of the entire therapeutic team, is, quite naturally, the physical and psychological recovery of a patient. And this can be effected without special regard for his prospects for a return to professional life. Thus, also for the therapists, whether or not their patients ever make it back to work is only of secondary importance. Almost all rehabilitation clinics offer occupational therapy and counselling, but only relatively few offer occupational therapy or counselling. Fewer still offer occupational therapy and counselling.

The attitude of the rehabilitation doctor is, according to studies, also an important factor for professional reintegration. A pessimistic view can be transferred to the patient, bringing with it inability and early retirement. Equally important is the attitude of the employer and the appraisal and expectations of the partner.

Studies conducted by the pension insurance organizations have clearly shown that improving a patients’ condition, reducing his risk factors, and modifying his lifestyle are by themselves not sufficient to effect a successful return to the work place. What really counts is the patients’ attitude to his professional future. How would the patient answer the following questions for himself: What is expected of me at work? Am I sufficiently competent and resilient to satisfy these demands? Studies suggest that motivation must be nourished, and in some cases even rediscovered, to smooth the difficult path back to work. However, a failure to reintegrate into professional life can cause depression and loss of motivation, and may eventually lead to social isolation. In this way, the success of rehabilitation therapy as a whole can be threatened.

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Attitudes to career and the work place are topics which should not be left undiscussed until the end of a rehabilitation treatment. For years concepts have been tried out which link medical rehabilitation with occupationally-orientated elements like tests of psychological efficiency or ability to withstand stress. If necessary measures of vocational rehabilitation to promote a return to work at the earliest opportunity can be introduced. In this cases, loss of time at the boundary between medical and vocational rehabilitation, unnecessarily delaying reintegration into careers should be avoided. The tests undergone by the patient explore various aspects of his readiness for work. For example, what is his disease and which abilities has he lost? What would be expected of him at work? Which problems have to be solved in order to achieve an occupational reintegration?

Occupational Capacity Trial (OCT) for Psychosomatic Disease

1. On admission to hospital answers on a questionnaire are used to assess whether an OCT is called for. In addition to the patient’s medical and psychological history the questionnaire covers in detail the situation at work and career background.

2. Acute complaints are treated by a month long course of psychosomatic rehabilitation. In parallel the OCT is designed by a social educationalist. It involves, for instance the preparation of a documents for a job application and the job interview itself.

3. The patient takes up a four week occupational practical in a local firm, to fit his abilities and interests. He works at least four hours a day and is closely monitored by the social educationalist. Treatment in the clinic and the OCT are carefully co-ordinated by the rehabilitation team.

4. Experiences at work are discussed twice weekly in a group. The most important questions addressed are: Are the demands in the practical comparable with those of the former job? What effects do former conflicts and problems have on the new work situation? The patients learns how to influence the effect of the job on himself and plan periods of relaxation.

5. The patient and his job supervisor assess the work practice, at first independently of each other. Both reports are compared and discussed. The assessments are also followed up in a group discussion. This forms the basis for further vocational therapy, for instance further education or retraining.
Return to Work

Occupational Orientation and Practical Trial (OOPT)

The patient is expected:

- to analyse preferences and opportunities for a future working life, as well as ability to cope with stress
- to learn new behavioural strategies for anxiety and stress management and put these into practice
- to cope with demands and anxieties.

Research Network Bavaria is investigating whether such an "occupational capacity trial" (OCT) would indeed promote the rehabilitation of patients with psychosomatic illnesses. Further objectives of the study are to clarify which patients in particular would benefit from such a possibility, and identify common reasons for therapy to fail to enable patients to clear the last hurdle, the transition back to work.

The study is looking at two groups of men and women under 50 years of age, suffering from psychosomatic disorders. Thereby, it is tackling a particular problem of psychosomatic rehabilitation, as psychosomatic patients comprise 25 percent of all premature retirements. The patients in the study have suffered various degrees of impairment of ability to pursue their working life. The treatment group is made to undergo – additionally to the standard therapy – an occupational capacity trial. The study is being implemented at two rehabilitation clinics, one with a psychoanalytic orientation, the other specialising in behavioural therapy.

First results of the study suggest that participation in an OCT raises the chances of returning to an adequate job after rehabilitation. Participants showed a higher willingness to work and more stamina, as well as being less stressed than the patients in the control group.

Example 2: Back to Work after a Heart Attack?

Another scheme, this time referred to as an "Occupational orientation and practical trial (OOPT)", is being carried out by the Research Network Freiburg/Bad Säckingen. The occupational reintegration of men and women after a heart attack is a central task of the pension insurance institutions. Blue collar workers have a worse prognosis than white collar employees in this respect. The first step is to identify those patients whose return to work is threatened, but not ruled out on medical grounds. They are given the opportunity to size up their situation in a two day course at a local institute for vocational promotion and redirect their career, for instance by undergoing short trials in old and new areas of work. This course is already offered to them on admission to hospital, subject to an assessment of whether their psychological state would permit such an early confrontation with a continuation of professional life. This assessment includes psychological tests of intellectual abilities.

A psychological evaluation of the short stay at the institute for vocational promotion is made the following day in the rehabilitation clinic. The institute drafts a report with recommendations for the further process of reintegration. Patients having taken part in these trials, as well as patients from a control group are interviewed after discharge from hospital and answer a questionnaire about the further course of their rehabilitation.
Return to Work

Example 3: Is it Possible to Predict Occupational Reintegration?

Which patients are likely to profit from further rehabilitative support, for instance through tests to determine ability to withstand stress or through practical vocational reorientation courses? And for which patients would straightforward improvements in physical and psychological states be sufficient for a successful return to work? A project of the Rehabilitation Research Network Ulm aims to establish a predictive instrument which can reliably place patients with various diseases into one of these two categories. In a first step more than 1,000 histories of patients under 52 years of age are retrospectively examined to find distinctive factors pointing to one or other category. These distinctive factors are verified on a few hundred patients at several rehabilitation clinics and are complemented by data on the patients’ ability to cope with stress. Additionally, patients as well as doctors were interviewed extensively. Lastly, these data and the documentation should lead to the definition of various categories which could serve as a future basis for the classification of patients and their rehabilitation treatment.

Step by Step, the Return to Work

A stepwise return to work can ease the process of reintegration as the following example shows: The car varnisher Herbert K., 55, works in a small family firm of ten employees. He is married, has a grown up child, and his wife also works. For the past 20 years he has suffered painful immobility of the legs arising from a bad fall. Twice he had to have an operation and has been on painkillers for years in order that he might work at all. Mobility is a prerequisite for his profession, because he has to kneel down or bend forward much of the time.

Because of his long occupational disability the medical service of the health insurance recommended Herbert K. to undertake rehabilitative measures funded by his pension insurance organization. Herbert K. assumed that afterwards he would retire early. Actually, he would quite like to go back to work, but did not dare ask his boss for working aids or part time work. Former hobbies like bowling and his membership in the shooting association also had to be given up because of his disability. He had become socially isolated. But group discussion during his rehabilitation treatment made him realize that other patients have similar problems. Not only did he learn to identify his problems, but is now able to talk about them. Intensive physiotherapy and muscular training as well as specific drug therapy have freed him from pain. While still in rehabilitation, he contacted his employer to discuss possibilities for a step by step return to work, with a gradual increase of working hours. Therapy is now being continued as an out-patient at a local specialist. Four months after rehabilitation the patient is back at work fulltime, has taken up his hobbies and renewed old friendships. His job makes him confident, while his leisure and social activities allow him to enjoy life.

Active Planning and High Motivation

A 52 year old woman has worked at a large media centre for the past 20 years. As secretary she is a reliable help to many editors, answers questions, types articles and organizes. She lives alone, devoting time to a circle of friends and personal interests. She likes her work. When she was told she had cancer her immediate reaction was to obtain comprehensive information and to draft a plan together with the doctors for an operation, followed by rehabilitation. During the time in the rehabilitation clinic she discussed her reintegration at work with other patients as well as with the therapeutical team. There was enough time and leisure to come to terms with her illness as well as to plan her future life. While in hospital she made the decision to contact her employers, and heard that she would be welcomed back. At the date set for her return she resumed her fulltime job. The cancer has not recurred so far.

Further information about research projects can be gathered at the individual Research Networks (Section C).
Rehabilitation and Money

Rehabilitative measures not only improve the quality of life for patients, but also have a positive effect on the overall financing of the health system. After a successful rehabilitation general practitioners and specialists are less often consulted and drug intake is reduced. Furthermore, the incidence of hospital stays and sickness leave is considerably reduced.

In view of limited budgets and the ongoing discussion about health care costs, the institutions providing social benefits (the state health, accident and pension insurers) are bound to pay special attention to the cost-effectiveness of rehabilitative measures. What exactly are the effects and benefits of rehabilitation in relation to its costs? An important aim of rehabilitation research is therefore the analysis of its economic aspects.

Is Rehabilitation Worthwhile?

From the point of view of the Pension Insurance, rehabilitation treatment certainly represents a good investment. Savings are made through reduced liability to injury benefits via state accident insurance, and the Federal Employment Institute can reduce its unemployment benefits payments. Furthermore, successful rehabilitations alleviate the state pension scheme burden by reducing the number of early retirements. This latter aspect is also important from the higher point of view of a social market economy, since productive individuals will be retained in the job market. In turn this maintains a higher overall productivity and growth potential for the economy. In fact, more than two thirds of rehabilitation patients are able to resume their working life within five years of the treatment funded by the Pension Insurance, and are thereby still net contributors to the various state social benefit schemes.

Thus, quite apart from the direct benefit to the patient, the financial support of successful rehabilitation can be regarded as profitable for both the institutions providing social benefits and society as a whole.

On the other hand, the resources available for rehabilitation from the social security institutions and from society as a whole are not unlimited. The question of how to optimise the use of resources for rehabilitation in the health care system is therefore of great political importance. As with all decisions relating to the distribution of resources in the health system this is a question of the justification of allocations. Health economists aim to make a constructive contribution by providing information about the relative cost effectiveness of potential therapies. Economic evaluations thus consist of comparative studies of costs and effects of the various components of health care.

Research Costs and Benefits of Rehabilitation

Costs are categorised in terms of direct, indirect and non-monetary costs (table on the left).

The non-monetary costs can probably be best summarised by the term “loss of quality of life.” Health economists and rehabilitation scientists are trying to develop objective, standardised and therefore comparable evaluation instruments for the subjective “quality of life.” It is their aim – within the framework of cost effectiveness analyses – to confront the costs of a therapy with its benefits and make comparisons with other therapies.

This is exactly the concept being followed by the rehabilitation scientists of the Research Network Ulm, who are conducting an economic analysis of a therapy strategy as a follow-up to a clinical study. The project aims to determine whether an intensified psychological care of patients with back-pain can deliver better results than the conventional rehabilitation therapy. Thus, as well as studying the effectiveness of the alternative treatment, the additional costs and benefits of the intensified therapy are being examined in relation to the associated additional costs.

Scientists from the Research Network Lower Saxony/Bremen are evaluating the cost effectiveness of all projects undertaken by their network under the premise that costs and benefits of rehabilitative measures can be defined, measured and realised in relation to a single set of standards. This allows choices to be made between different therapeutic strategies on the basis of achieving low costs at the same time as meeting a reasonable level of effectiveness.

Rationalisation Rather than Rationing

How does the subjective attitude of the insured person influence his propensity to claim health care benefits? A project undertaken by the Research Network Berlin-Brandenburg-Saxony addresses this question. On the one hand, health costs may be reduced after a successful rehabilitation, but on the other hand they might heighten the health consciousness of those having undergone rehabilitation, which might in turn lead to increased health care expenditure. On the basis of comprehensive questioning of the insured, this inquiry is also investigating the influence of availability of support from the immediate social circle on the attitude of potential health care claimants. One hypothesis is that those in need of rehabilitation with supportive friends and relatives are more likely to opt for a (partially self financed) out-patient care, rather than applying for an extended stay in a rehabilitation clinic. This project again tackles the question of how limited resources can be used most efficiently. Nevertheless, it is recognised that the individual need of the insured person must take priority. Anything else would result in counterproductive rationing, rather than sensible rationalisation.
The defining feature of the research initiative “Rehabilitation Science”, jointly sponsored by the Federal Ministry for Education and Research (BMBF) and the German State Pension Scheme, is collaboration through networks. In supporting eight regionally organized networks, rather than a bunch of single projects, the initiative seeks to foster a long-lived inter-institutional cooperation that should continue to flourish long after the initial funding impulse. The networks embrace the principal research facilities from all over Germany.

The regionally organized networks promote interdisciplinary collaboration, bringing together scientists from university and non-university institutions, as well as therapists from rehabilitation centres and representatives of the funding institutions. The main task of all research networks is to plan and carry out research projects. The networks have established priority areas of research in order to focus the activities of their members on certain topics. These priority areas establish an individual profile for each network, as well as making the research more visible to staff at rehabilitation institutions, which in turn eases the incorporation of results into clinical practice.

Part of the funding of networks is directed at the establishment of the underlying infrastructure needed to sustain and further develop rehabilitation science as a strong and self-supporting discipline. All networks feature the basic facility of a central office to coordinate research and administrative activities. Furthermore, each network incorporates an advice service which provides counselling and help on scientific methods for the individual research projects.

Each research network undertakes a number of scientific projects investigating different aspects of rehabilitation therapy relevant to the main topic of the network. Here, in Section C, we do not describe individual projects in detail. Instead, the general areas of rehabilitation introduced in Section B are illustrated using research projects from the networks as examples. Cross marks of reference connect the research areas from Section B with the networks of Section C. In addition to projects supported by the research programme each network has associated projects complementing the main topic of the network by bringing in further aspects of research. More details can be requested through the network central offices or on their homepage (under www.reha-verbund.de).

The research networks present themselves in Section C, which follows. The area of regional cooperation is highlighted by the areas indicated on the small map. It should however be noted that some networks have cooperations and projects extending outside the indicated area.
Patients in Rehabilitation

Aims: Using Novel Research Methods

The Rehabilitation Research Network of Bavaria (RFB) follows the general theme “Rehabilitation for Patients: Disease-specific and generic approaches to questions of motivation, coping with illness, intervention and evaluation”. Its particular characteristics are its proximity to clinical treatment and its use of novel research techniques. In particular, wherever possible, projects make use of randomised controlled designs, comparing treated with untreated groups. Such randomised controlled studies are well suited to evaluate the efficacy of therapeutic or other treatments and to link effect with cause. Account must however be taken of clinical constraints, which may not always be fully compatible with this approach. In rehabilitation research this type of research study is still relatively rare. The Bavarian Research Network has adopted randomised controlled designs in several studies – so far with very good success. This demonstrates the feasibility of utilizing advanced research methods in a practical field like rehabilitation research.

Organization and Structure

The network covers three project areas, embracing ten research projects in all, with many associated projects and working groups. The scientific questions addressed are summarised below.

Project Areas

Project Area A: Diagnostics and Predictive Factors

Project area A is concerned with questions relating to disease management and the prediction of the success of various rehabilitation treatments. Three studies, each using a different methodological approach, are aiming to determine predictive factors for successful rehabilitation. The individual projects are looking at gender-dependent factors for short- and long-term rehabilitation, the subjective view of patients about the effectiveness of their treatment, and patient’s fear that the disease may get worse. The studies are carried out on samples of patients which have suffered either from heart attack, from diabetes, or from rheumatic disease, low back-pain, or cancer.

Project Area B: Evaluation of Therapy Programmes

This area is comprised of intervention studies investigating the effects of new or adapted patient training concepts for certain diseases (chronic back-pain), psychosomatic disease, chronic kidney disease, and chronic obstructive bronchitis. Projects aim at developing or evaluating structured intervention methods or concepts for implementation into routine patient care following the research programme. Special emphasis is consequently placed on randomised controlled studies. The investigations also seek to identify any gender-specific or health economic effects.

Project Area C: Problems with the Interface to Rehabilitative Care

Interfaces of rehabilitation medicine exist between rehabilitation and the return to work or between acute treatment and rehabilitative care. Two psychosomatic hospitals are investigating whether specific vocational-orientated treatments facilitate the transition from rehabilitation (back) to the professional and former social life.

A comprehensive planning of rehabilitative care requires an admission procedure which ensures that rehabilitative therapy is tuned to individual need. Different socio-medical evaluation systems used by Bavarian pension insurance institutes are analysed and compared. Furthermore, the interface between general practitioner and rehabilitation clinic, an important element of admission control, is investigated.

Networking and Long-Term Effectiveness of the Bavarian Research Network

A central office in Würzburg coordinates the activities of the network. Scientists are supported by a counselling office for scientific methods in Würzburg, which also is responsible for quality control of all research and the centrally organised randomisation of studies. An office in Munich handles questions relating to health economics.

In March 2000 a professorship at the University of Würzburg, also belonging to the network, was inaugurated by the pension insurance institutes. The extensive channels of cooperation and collaboration opened up by the network across Bavaria guarantee that newly proven concepts of clinical intervention are incorporated into standard rehabilitation treatment.

Activities and Further Information

The research network holds meetings about recent topics in medical rehabilitation. So far, the topics covered were disease management, gender specific aspects, patient education and occupational measures.

Further information can be obtained from the homepage of the network which is updated regularly.

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Theoretical and Practical Foundations of the Organization and Economics of Rehabilitation

### Aims

With its central theme “Theoretical and practical foundations of the organization and economics of rehabilitation,” the network Berlin-Brandenburg-Saxony aims to improve the organization, management procedures and results of the rehabilitation system. The network is concerned not only with improving basic knowledge, but also its transfer into practice, and considers rehabilitation from a systemic rather than an economic point of view. Functional and procedural aspects of rehabilitation, as well as the level of results achieved, are evaluated from an organizational standpoint. The results should lead to a more rational utilisation of managerial control mechanisms in rehabilitation organizations.

Emphasis is laid on nationwide analyses of organizational structures encountered in different rehabilitation institutions and the potential mutual interdependence of informal organizational issues within institutions and external factors. Special emphasis is placed on the investigation of overlapping aspects of funding institutions and of the rehabilitation institutions themselves. This approach is especially responsive to research at BBS; the participation in the network of the Federal Insurance for Salaried Employees (BfA) and a cooperation with regional pension insurance institutes allows research on aspects regarding different funding institutions.

To avoid the network simply being a summary of unconnected research projects, synergy is achieved by:

1. Structuring research projects in the network in a common way
2. Providing centralised organizational facilities readily accessible to each project
3. Building up long-lasting infrastructure

Interdisciplinary collaboration has a favourable influence on the organization of research, as does the use of a variety of research methods, and the cooperation of projects with each other and with research institutions or clinics outside the network. Intercommunication between the many diverse branches of rehabilitation science, the funding organizations, and the various practising institutions is also beneficial from a purely scientific standpoint.

### Organization and Structure

The network has its central office at the Humboldt University in Berlin, and is also represented at the Free University of Berlin, the Technical University Dresden and the University of Leipzig. It works closely together with the BfA and with the pension insurance institutes in Berlin, Brandenburg, and Saxony. Basic decisions about the direction of research and the structure of the network are taken in the project council, which is made up of all the project leaders. Each research project belongs to one of three main areas:

- **Project Areas**

  **Area A: Problems of Nationwide Control of Institutionalised Forms of Rehabilitation**

  Projects in this area investigate from various viewpoints problems associated with the control of rehabilitation. They form the conceptual link to a planned nationwide, wideranging organizational review. Particular emphasis is placed on the investigation of institutionally organized rehabilitation, through consideration of their management of information and treatment, and their quality control. Economic aspects are also investigated, as are interfaces between medical and vocational rehabilitation.

  **Area B: Adaptation to Aids, Remedies, and Prostheses in Rehabilitation**

  This area investigates control processes in rehabilitation, especially those concerning patient adaptation to artificial aids, remedies and prostheses, which often constitute a cost intensive treatment. Research focuses on the relation between institutionally organized rehabilitation and the cooperation of projects with regional institutions and of the rehabilitation system. The network is also beneficial from a purely scientific standpoint.

  **Area C: The Role of Relatives in Rehabilitation**

  Relatives play an important role in rehabilitation, for example in the social reintegration of family members. This project area is looking at factors which might be relevant. The analysis is not restricted to the psychological dimension; relatives are viewed as an integral element of institutionalised rehabilitation care and organization. Thus, relatives are not merely “appendices” of rehabilitation, but an innovative stimulus to rehabilitation which must be exploited.

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Rehabilitation Research Network
Freiburg/Bad Saeckingen

Goal-orientation in Diagnostics, Therapy and Evaluation

The rehabilitation research network Freiburg/Bad Saeckingen (RFV) pursues an interdisciplinary approach, embracing various departmental facilities. In all, 15 individual projects, covering separate topics, are coordinated by the RFV. The network was founded on initiative of the Department for Rehabilitation Psychology of the University of Freiburg, the Hochrhein Institute for Rehabilitation Research in Bad Saeckingen, and of the Department for Quality Management and Social Medicine of the University Hospital Freiburg.

Aims

The individual projects aim to establish a scientific and organizational basis for the integration of the wide variety of activities, disciplines, and personnel involved in rehabilitation. The central concept for this integration is the establishment of an individual goal-orientation in the following broad areas of activity:

- Recognizing specific problems of individual patients as basis for subgrouping of patient populations
- Determination of specific objectives for therapy
- Attainment of individual goals as a basis for measurement of outcomes.

Individual projects probe the central theme of the network – "Goal-orientation in Diagnostics, Therapy and Evaluation" – from different perspectives. The projects can be categorized as belonging to one of the following four research areas:

1. interface problems
2. differential indications
3. methods and health economics
4. interventions and their evaluation.

In addition, two cross section projects provide facilities and services needed by all the participants in the network – a Central Office for Project Management and an Counselling Office for Research Methods. These support individual projects by advising on scientific methods and providing information and reports. They also play an important role in establishing the organizational pre-requisites of the collaboration. The research aims of the network are comprehensively described in Bengel, J. & Jäckel, W.H. (Hrsg.)(2000). Zielorientierung in der Rehabilitation – Rehabilitationswissenschaftlicher Forschungsverbund Freiburg/Bad Säckingen. Regensburg: Roderer.

Organization

Structural Aims:

The network strives to establish organizational structures for rehabilitation science which will facilitate long-term collaboration and cooperation between the participating institutions beyond the initial funding period. The foundations for this were laid through the inclusion of practicing rehabilitation centers, academic research institutes, and the funding pension insurance institutes in the network. In establishing the network, care was taken to ensure that the various interest groups were properly represented at all decision-making levels.

Thus, the continuous working group "Rehabilitation Sciences" has developed into a discussion forum for representatives of health and pension insurance organizations, physicians in in- and out-patient rehabilitation institutions, research scientists, professionals working in out-patient care, and self-help groups. The inclusion of a large number of rehabilitation centres from the region is a crucial factor in facilitating the adaptation of research results into clinical practice. More than 120 such units have agreed to cooperate in return for receiving various services such as a regular newsletter of the network, information via its homepage, and advice on specific issues on request.

The integration of research results into the practice of rehabilitation is further supported by a hospital and exchange programme promoting communication between scientists and clinicians.

Professional training and Young Scientist programmes

Seminars for graduates are an ideal forum for the dissemination of research results from rehabilitation research. The RFV has its own professional training programme: It regularly organizes one- or two-day trainings, according to the need in the research projects of the network and also for regional rehabilitation centres interested in it. In addition, a lecture series on rehabilitation provides an overview of progress in other areas of rehabilitation science.

To promote a scientific careers in rehabilitation, two PhD scholarships in Medicine and Psychology are awarded to young scientists, through application and expert review. Many further dissertations and doctoral thesis are integrated in the context of the network.

Quality Management within the Network

Quality improvement begins with the process of choosing among applicants the individual scientific projects belonging to the RFV, and is continued for each project through a system of regular internal reports. These reports are checked by the Counselling Office for Research Methods before being forwarded to the board of directors. This procedure helps to define the need for external help in order to safeguard the high standard of research in a project. All these single measures are integrated into the Network’s Quality Management.

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Rehabilitation Research Network
Lower Saxony/Bremen

Rehabilitation Outcomes: Prediction, Method Optimization, Costs

Aims

Operating under the general theme “Rehabilitation Outcomes: Prediction, Method Optimization, Costs” this network focuses on the effectiveness of therapy and the adoption of research results into clinical practice. Studies relating to the theme element “Prediction” are designed to elucidate case characteristics predictive of a successful rehabilitation. The theme element “Method Optimization” is addressed by comparisons of different intervention programmes, while the third element, “Costs”, relates to cost-efficiency analyses which includes economic as well as psychosocial parameters.

Organization and Structure

The Research Network Lower Saxony/Bremen (RFNB) is jointly organized by the Centre for Rehabilitation Research of the University of Bremen, the Medical School of Hanover (MHH) and the Department for Medical Psychology at the University of Hamburg. The RFNB has investigated seven specific projects “cross-section” projects. All projects are performed interdisciplinary involving physicians, psychologists and economists.

28 cooperating hospitals and a number of medical practitioners participate in the studies in which various rehabilitative measures are implemented and evaluated. Cooperation between the universities and the continuous exchange of information with clinics ensure that scientific results are transferred into university teaching and clinical practice.

Project Areas

The three “cross-section” projects provide conceptual and methodical support to the seven specific projects in the form of a central scientific office, and study groups (clinical methods and health economics). In addition, they are responsible for special problems, such as cost-efficiency studies. The other projects of the RFNB research in the areas “Evaluation of Patient Education” (A), “Access to Rehabilitation and Rehabilitation Concepts” (B) as well as “Rehabilitation of Children and their Relatives” (C).

Specific projects of area A aim at evaluating the efficacy of patient education programmes (or pedagogical programme elements) on adults with spondylitis ankylosans, asthma, or atopic eczema. One project focuses on the effect of the patients’ willingness to participate in therapy actively (Compliance).

Project area B aims at identifying predictors for the socio-medical development of patients in particular their inability to work) and their availsment of rehabilitation treatment. This research is conducted on patients with chronic polyarthritides, with the aim of identifying circumstances in which early clinical intervention might reduce the risk of adverse long-term developments, such as an inability to resume working life.

Project area C is mainly concerned with rehabilitative measures for children and their relatives, for example the comparison between inpatient and modern outpatient therapy with children with psychosomatic diseases. The area also includes the psychometric evaluation of questionnaires for children, with the aim of improving the feasibility of evaluation in children. The development and evaluation of training programmes for chronically ill children, and for parents of young children complete this project area.

In all three project areas the outcome indicators are in accordance with the recommendations of the “inter-research network” study group on clinical methods. The evaluations include psychosocial variables as well as data relating to the development of the disease and economic factors. The research results should help to optimise patient education and rehabilitation programmes. Up to the present the rehabilitation of children has been somewhat neglected in comparison to adulthood rehabilitation, a fact that highlights the importance of project area C.

Activities and Further Information

Further information can be obtained from the homepage of the RFNB (www.frb.uni-bremen.de). References for meetings and offers for further education from the RFNB can also be found there. For example a symposium held in January 2000 on the perspectives of patient education has received widespread attention. Further symposia on this topic will take place annually.
Optimization of Rehabilitation: Needs Assessment and Ensuring Effectiveness

Aims

The North German Network (NRVF) starts its work with an analysis of major strengths and weaknesses of the German rehabilitation system to provide suggestions for further development. Current concerns focus on the identification of rehabilitation needs, the practice of medical rehabilitation (overcoming problems with health care interfaces) and the limited evidence for the efficacy of rehabilitative interventions. In short, the NRVF aims at developing an empirically-derived basis for the planning of rehabilitative care that meets the populations needs and provides treatments as effective and efficient as possible.

Organization and Structure

The projects of the NRVF are located at three universities (Lübeck, Hamburg, Kiel) and at one rehabilitation clinic (Bad Malente). Furthermore, many associated projects and rehabilitation centres from all over Schleswig-Holstein are involved. The network is cooperating closely with the regional associations for the promotion of rehabilitation science, which have been instigated by the pension insurance institutes of Schleswig-Holstein and Hamburg (e.g. “Verein für die Förderung der Rehabilitationswissenschaften”, vfr). In contrast to the NRVF, the vfr supports more basic projects in the specific areas of rehabilitation research. A hospital-based working group on rehabilitation science in Schleswig-Holstein provides a further basis for the NRVF.

The network has two central projects which advise and monitor the other projects of the NRVF:

- The central office is responsible for administrative coordination and scientific support of the NRVF. It organizes meetings, workshops, assemblies of the members and committee meetings, and keeps in contact with the other networks, and to the funding institutions.
- The central method counselling office helps the projects planning and evaluating statistical studies. The office also carries out its own research.

Project Areas

The NRVF combines the following two areas of research:

Area I: Identification of Rehabilitation Demand and Needs in Populations of Insured Persons and Patients

Projects in this area are concerned with questions relating to the rehabilitation need – assessing and meeting this need – from different points of view, such as from the viewpoint of rehabilitation law. The project addresses the question of whether the present rehabilitative legal framework is sufficient, or whether (and where) it must be enhanced by further legal regulations.

Another perspective is the attitude of general practitioners and their patients to rehabilitative therapy. Projects seek to obtain information on the criteria adopted by general practitioners and patients to decide whether to undergo rehabilitation treatment, and to ultimately estimate the effectiveness of that treatment. Furthermore, the influence of doctors’ attitudes towards the counselling of potential rehabilitation candidates is investigated.

Two projects deal with the question of the rehabilitation need from individuals insured under the state pension insurance scheme. How many insured persons need medical rehabilitation? How many actually undergo treatment? And what is the effect of rehabilitation on the state of health? These questions are investigated for certain groups of diseases.

Another study in this area is looking at the reasons for the premature ending of psychosomatic in-patient rehabilitation treatment. The risk of a premature end of treatment, the circumstances of the break, and the medical and economic consequences are examined. The project should identify ways of reducing the percentage of patients breaking off treatment and of reducing costs.

Area II: Evaluation and Determination of the Effectiveness of Traditional and Novel Rehabilitative Intervention Methods

In this area a project studies the long-term outcome of rehabilitation for women and men after their first heart attack, balloon dilatation or bypass operation. The study focuses on the question of whether the success of rehabilitation therapy in women is determined by other factors than in men.

Information about NRVF, its projects and activities can be found on its homepage (http://www.rehabverbund.de).

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### Future Strategies in Rehabilitation

**Aims:**
Effective and Economically Justifiable Rehabilitation

The development of scientifically based strategies for effective and economically justifiable rehabilitation is the main aim of the research network Northrhine-Westfalia (NRW), jointly worked out by its members. New knowledge in specific areas gained from basic science and subsequently adapted to clinical practice should form the basis for the rational planning and organization of medical rehabilitation. To this end, the network has identified several key research issues, which are categorized into two different areas of research according to whether they are related to medical or organizational questions: “Predictors of Efficacy” and “Control and Management.” These two areas of research are linked by so-called cross-section projects.

### Organization and Structure: Close Cooperation with Supporting Organizations

The scientific work of the network is based on close interdisciplinary cooperation involving the regional pension insurance institutes, rehabilitation hospitals and scientists working in rehabilitation hospitals, in scientific institutes or in the regions’ universities. Three funding pension insurance institutes are situated in the area – the Federal Insurance Fund for Miners, and two regional Pension Insurance Institutes – LVA Rheinprovinz and LVA Westfalen. Furthermore, some 150 rehabilitation hospitals, many health insurance institutes, various professional associations and four universities – Bielefeld, Bochum, Muenster and Witten/Herdecke – belong to the network. There are also a number of cooperations with other networks, hospital carriers and institutions situated outside Northrhine-Westfalia. Considering this background the A “Society for Rehabilitation Science in Northrhine-Westfalia” was founded. This society funds, for instance, further research projects of network members as associated projects, concordant with the aims of the network.

Currently, the network has 50 scientifically active members working in nine network projects and four associated external projects. An advisory committee and a strategic planning group monitor the network’s research. The advisory committee ensures an external quality control and advises members of the network on further development and in course of the applications for new projects. Internal quality control is provided by a centre for research methods and counselling. The strategic planning group aims, in close contact with the projects, to translate research results into practical forms of therapy, and thereby derive strategies for the future.

### Research Areas

**Predictors of Efficacy**

This project area is marked by the requirements of the patient: How successful is the rehabilitation of a patient with a specific disease in a chosen hospital setting a specific form of therapy likely to be? The answer to this is found via predictors identified from analysis of the initial medical and psychosocial state of the patient. Special attention is paid to gender-specific differences in rehabilitation care. Furthermore, projects in this area investigate different patterns of disease management as the disease evolves, and intercompare various indicators.

### Control and Management

This project area investigates the system of rehabilitation care. What are the structures and processes and their frameworks? The area is comprised of research projects investigating issues of interface or of quality control. This context legal, system-analytical and international topics are discussed.

### Intra-Network Projects

**The intra-network (or “cross-sectional”) projects constitute a network by themselves.** They gather and bind together research results and methodologies from the various participating projects and disciplines.

- The project “further education in rehabilitation” aims to establish, through the utilization of scientific concepts, the conceptual and organizational basis for the establishment of a long-lived institution for further education in rehabilitation. Above all, the project seeks to promote interdisciplinary cooperation between different types of rehabilitation professionals.

- The other intra-network project “disease management for rehabilitation” is concerned with the analysis of patient histories. It seeks to improve the cost/benefit relationship for specific diseases. This project not only looks at the phase of acute or chronic disease, but also at times before and after. It should lead to the development of statistically founded guidelines which, as such, could be adopted by all rehabilitation institutions.

### Activities of the Network

- The network was founded in 1996. Currently, the network has 50 scientifically active members working in nine network projects and four associated external projects. An advisory committee and a strategic planning group monitor the network’s research. The advisory committee ensures an external quality control and advises members of the network on further development.

- The network has organized in the framework of the EXPO 2000 a workshop on the topic “The Future of Work and Rehabilitation” in Dortmund, in cooperation with the Federal Institute for Work Protection and Vocational Medicine (BAuA).

More information about the NRW network, its members and projects is available on the homepage given below.

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Rehabilitation Research Network Saxony-Anhalt/
Mecklenburg-Vorpommern

Interfaces in Medical Rehabilitation – Development and Evaluation of Practice-Oriented Solutions

Aims

The projects initiated by the research network Saxony-Anhalt/Mecklenburg-Vorpommern aim at the identification of weaknesses in the rehabilitation system and the care it provides, and at the evaluation and implementation of steps to improve the system in these regards.

Organization and Structure

Institutes and hospitals of the University of Halle’s medical faculty, the medical faculty of the University of Magdeburg, and the Law and State Sciences faculty of the University of Greifswald cooperate in the network. Additionally, nine rehabilitation hospitals and four institutions involved with out-patient or in-patient rehabilitation are also members of the network. The regional pension insurance funds of the states of Saxony-Anhalt and Mecklenburg-Vorpommern participate either as part of the organizational network structure, or through collaboration in projects.

The projects mainly focus on rehabilitation research topics associated with cardiovascular diseases, chronic back-pain, rheumatic diseases and neurological diseases. Simultaneously, each project contributes to the recognition and solution of organizational interface problems in rehabilitation. These “Interfaces” in health care arise from the compartmentalisation of administration and treatment stemming from the complex and diverse structure of the German health and rehabilitation system. They can lead to difficulties for both patients and rehabilitation professionals. At the same time, interfaces can be viewed as the result of specialisation in specific areas of treatment or research, which can be exploited to provide a greater variety of treatment options. One goal of this network is to help develop a basic concept for the analysis of interfaces within the rehabilitation system.

The network includes a centre for scientific methods which advises projects in all aspects of study design, choice of statistical samples, instruments, and data analysis. Furthermore, it is preparing an overview of research methods for the analysis and solution of interface problems.

Structure of the research network

Planning and Managing Board
Prof. Dr. W. Slesina
Prof. Dr. B.-P. Robra
Dr. H. Schneider

Central Office
University of Halle-Wittenberg
Prof. Dr. W. Slesina

Supporting Society
“Regional Rehabilitation Research in Mecklenburg-Vorpommern and Saxony-Anhalt e.V.”

Method Centre

Method Counselling
Institute for Medical Epidemiology, Biometrics and Informatics, University of Halle-Wittenberg
Cross Section Project on Methods
Quality insurance and methodical basis of interface analysis in rehabilitation system

Research Areas

Structures of supply, capacity and utilisation of medical and vocational rehabilitation
Optimisation of patient referral to rehabilitation centres and therapies
Ways to a successful and efficient re-habilitation

Project Areas

Organizational Aspects of Demand for Rehabilitation, and the Financing and Practice of Rehabilitation in the State of Saxony-Anhalt

To achieve seamless and comprehensive provision of rehabilitation, basic information has to be gathered on the availability of professional and non-professional rehabilitation institutions and initiatives in the region. Which forms of treatment are currently available in Saxony-Anhalt? Which groups of the population or diseases might not be receiving sufficient care? The projects associated with this area aim to provide answers to such questions.

Optimal Strategies of Patient Referral to Rehabilitation Institutions

The form of rehabilitation (ranging from completely in-patient care, partly out-patient care to completely out-patient care) prescribed to a patient, and the individual rehabilitation programme he is admitted to are important factors in patient rehabilitation care. The projects as associated with this area aim to provide answers to such questions.

Optimal strategies of patient referral to rehabilitation clinics, hospitals and initiatives in Saxony-Anhalt aim at the early referral of patients, the improvement of care and the provision of comprehensive and efficient rehabilitation.

Activities of the Network

Meetings on actual rehabilitation issues like networking, integration, early rehabilitation, and after-care are regularly held.

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Aims

The central theme of the network “rehab building blocks” refers to the different phases of rehabilitation treatment and the interdisciplinary interfaces involved. It is planned to evaluate the methods and efficacy of specific clinical treatments used in cardiovascular, neurological and vocational rehabilitation as well as in the area of musculo-skeletal disease.

Organization and Structure

The network is arranged around the research institute for rehabilitation medicine at the university of Ulm, where the central administrative and coordinating office of the network is situated. Departments of the university of Ulm and several rehabilitation hospitals with different rehabilitative specializations are also involved.

Project Areas

"Reha-Net" – the Common Data Base

The network’s common data base “Reha-Net” has accumulated an extensive collection of rehabilitation data collected from records of patients participating both in the projects and ordinary treatments. Access to data associated with a specific project, or with any combination of projects is possible. The regional pension insurance institute of Wuerttemberg plays an important role in the anonymization of patient data and in appending further relevant information, for instance the granting of a pension due to loss of working capacity.

Project Area Neurological Rehabilitation

Projects in this area are mainly concerned with assessing the efficiency of rehabilitative treatments of stroke patients suffering from depression or from a loss of organizational and functional capabilities.

Project Area Rehabilitation of Patients with Chronic Back-Pain

Diseases of the musculo-skeletal system constitute another central topic. A randomised study evaluates whether intensive psychological care with a non-standard stress management programme can lead to a better result of rehabilitation compared with conventional therapy. In addition, the extra effects and costs of the intensified psychological therapy in comparison with the basic therapy is evaluated from an eco-sociological point of view.

A theoretical and practical management concept for patients with chronic spine problems is being developed on the basis of results from this research.

Project Area Cardiovascular Rehabilitation

One project is concerned with the question of whether intensified aftercare and patient schooling on issues such as risk factors, stress management, and diet can improve the long term prospects following hospital rehabilitation? Another project is an epidemiological study of the extent to which short term successes of hospital rehabilitation (e.g. weight loss, nicotine abstinence, normal cholesterol) correspond with results in the longer term.

Activities

Progress and results of the Ulm networks projects are presented annually at a scientific symposium. Furthermore, the service department for computer science provides a continuous opportunity to participate in information and training seminars about the network. A regular newsletter is issued by the central office containing information and announcements of meetings connected with both the Ulm research network, as well as with other networks in the nationwide research programme “Rehabilitation Sciences”.

Information about the research network Ulm and its individual projects are available on the homepage: http://www.uni-ulm.de/reha-net.

Epidemiological considerations and health economics play a major role in these studies. Emphasis is put on questions of efficiency – in a purely medical sense as well as from the point of view of costs.

One characteristic of the Research Network Ulm is the association of university and medical rehabilitation institutes, each having access to the joint research data base “Reha-Net”. Furthermore, the network cooperates with the regional pension insurance institute of Wuerttemberg. Individual research projects are supported by a central office advising on methods for the planning, execution and evaluation of studies.

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