Review Article

Cardiological rehabilitation, prehabilitation, and cardiovascular prevention in adults with congenital heart defects: tasks and services of the German Pension Insurance—part 2: cardiological rehabilitation

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Abstract: Congenital heart defects (CHD) represent the most common inborn organ anomaly, with more than a million newborns affected annually. Advances in diagnostics and treatment have led to significantly improved survival rates, resulting in a growing population of an estimated 50 million adults with congenital heart defects (ACHD) worldwide. As these individuals age, they often face a high burden of morbidity and complex long-term health challenges that require specialized, lifelong care. In this context, cardiological rehabilitation (CR) becomes increasingly important, not only to reduce morbidity but also to enhance patients' quality of life and support their social and occupational integration. While CR has been extensively studied and implemented for acquired heart diseases, structured rehabilitation programs tailored to the specific needs of ACHD remain limited in clinical practice and in the scientific literature. Globally, both the availability of CR and the presence of structured concepts vary widely. CR is predominantly offered in high-income countries, with Western Europe providing the most extensive services. In many low- and middle-income countries, access to CR remains limited or is sometimes not available at all. However, even in high-income settings, targeted ACHD programs are scarce, meaning that many ACHD are treated in general CR programs that do not adequately address the complexity of CHD. The present article outlines the core components of CR, provides recommendations on how these are implemented in current practice, identifies existing limitations, and discusses how services could be better aligned with the complex medical and psychosocial needs of ACHD. It also describes the role of the German Pension Insurance in funding and

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providing rehabilitation services in Germany. Tailored rehabilitation programs, greater integration of ACHD expertise, and targeted research are essential to improve long-term outcomes and establish patient-centered care structures for the growing ACHD population. In this way, the present paper is intended to support the development of rehabilitation programs for countries where such structures currently do not exist.

Keywords: Cardiological rehabilitation (CR); adults with congenital heart defects (ACHD); German Pension Insurance; prevention

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Introduction

Each year, approximately 1.35 million children are born worldwide with congenital heart defects (CHD), making it the most common congenital defect (1,2). Due to significant advances in diagnosis and treatment, survival rates for these patients have dramatically improved, allowing many to live into adulthood (1). However, while mortality decreases, morbidity remains high. As patients with CHD continue to age, the demand for specialized care is expected to grow, as they face long-term health challenges that require ongoing medical attention and intervention (3,4). In this context, cardiac prevention, prehabilitation, and rehabilitation programs gain importance, not only for reducing morbidity but also for improving quality of life and ensuring long-term social integration (5-7).

In Part I of this research, the importance of cardiological prevention and prehabilitation for adults with congenital heart disease (ACHD) was discussed, with an emphasis on how the German Pension Insurance can support patients in these areas. Now, in Part II, the focus is on cardiological rehabilitation (CR), examining the current offerings of the German Pension Insurance and the potential for developing specialized programs to support ACHD better.

CR for ACHD

Despite the globally increasing number of ACHD, estimated at approximately 50 million (8), there are only a few scientific studies on medical rehabilitation measures for this specific patient group (9). Until just a few decades ago, the clinical relevance of the heterogeneous and complex group of CHD patients was underestimated (10).

While rehabilitation programs for acquired heart diseases have been extensively studied, there is only limited national and international data on ACHD from uncontrolled, retrospective studies, which usually involve small patient numbers with various forms of CHD (9,11). The scarcity of research on ACHD rehabilitation is reflected in the limited data on the availability of ACHD-specific rehabilitation programs. As such programs are generally rare, many ACHD are instead referred to standard CR (12). However, worldwide, the availability of CR is also limited and predominantly found in high-income countries (13). Globally, Europe offers the most CR programs (14), with availability notably greater in Western Europe compared to Eastern Europe. The median number of patients served annually is highest in Western European countries and, overall, exceeds that of other high-income nations such as the United States, Canada, Australia, and New Zealand. Furthermore, in Europe, the Southern and Western regions provide more extensive CR in terms of total hours, with Portugal offering the longest programs and Bosnia and Herzegovina the shortest. Additionally, European CR services feature a higher staff-to-patient ratio compared to those in other high-income countries (15). After Europe, CR availability is highest in the Americas, followed by countries in South-East Asia, the Eastern Mediterranean Region, and the Western Pacific. Worldwide, Africa has the lowest CR availability, with services present in only some countries, such as South Africa or Kenya (14). Across countries, the structure of CR can vary significantly with respect to its core components, the number and specific professions of healthcare providers involved, and the mode of delivery (15).

Given the variation in CR delivery across countries, only a few nations have developed guidelines to define structured strategies specifically aimed at improving long-term outcomes for ACHD. According to the guidelines for

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Table 1 Core components of CR according to the AHA and AACVPR, adapted from Brown *et al.* [2024] (16)[†]

Core components
• Aerobic exercise training
• Strength training
• Physical activity counseling
• Psychosocial management
• Weight management and body composition
• Nutritional counseling
• Cardiovascular disease and risk factor management, with
○ Tobacco cessation
○ Diabetes management
○ Dyslipidemia management
○ Hypertension management

[†], modified and reformatted by the authors. AACVPR, American Association of Cardiovascular and Pulmonary Rehabilitation; AHA, American Heart Association; CR, cardiological rehabilitation.

CR in Germany, Austria, and Switzerland (LLKardReha-D-A-CH), it is recommended that ACHD participate in specialized rehabilitation programs, particularly after cardiac surgery or interventional procedures, or in the event of complications. These programs should take place in centers specialized in the treatment of ACHD and be integrated into a medical network that ensures proper and continuous ACHD care. The goal of rehabilitation is to provide interdisciplinary care for health challenges in ACHD, assess risks individually, and promote physical and psychosocial quality of life through tailored training programs (6).

The American Heart Association (AHA) and the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) have summarized the core components of CR (*Table 1*) (16).

Additionally, topics such as disability, pregnancy, as well as career planning and reorientation, should be considered to provide the best possible support to these patients (17).

In this context, it must always be considered that ACHD is a heterogeneous group (6). Physical endurance varies depending on the type and complexity of the heart defect, which in turn influences the type and intensity of the recommended physical activity. Anatomical and physiological differences make it difficult to integrate ACHD into regular exercise groups for heart patients in traditional rehabilitation settings and emphasize the importance of ACHD-specific rehabilitation programs (17). For instance, unlike acquired heart diseases, ventricular dysfunction in ACHD often involves the right or systemic right ventricle or an univentricular heart. Standard diagnostic thresholds, such as those for echocardiography or cardiac magnetic resonance imaging (MRI), may not apply due to variations in CHD anatomy, making complications like heart failure more difficult to detect (11). Similarly, while standard cardiac drugs are commonly used in the management of ACHD, therapy must respect the individual's specific cardiac anomaly. Patients with complex defects, including Fontan circulation, atrial switch operations, or systemic right ventricle in congenitally corrected transposition, often require alternative therapeutic strategies. Certain medications, like systemic vasodilators, can, for example, worsen existing right-left shunts and exacerbate cyanosis (11,18). Postoperative cardiac arrhythmias must be detected early during rehabilitation. Even supraventricular tachycardias can be poorly tolerated and may lead to serious complications, particularly in cyanotic or palliated conditions such as after Fontan operation or in Eisenmenger's syndrome (11,19). As ACHD age, managing acquired comorbidities like hypertension, renal or hepatic failure, diabetes mellitus, and metabolic disorders also takes on greater importance in rehabilitation (11,16).

For ACHD, aerobic exercises such as walking, cycling, or swimming, combined with resistance training using weight machines, body weight, or elastic bands, are commonly recommended (16,20). Patients with cyanotic CHD may use supplemental oxygen to enhance exercise performance (21). As tolerated, exercise intensity should be gradually adapted while avoiding hemodynamic instability or any exacerbation of symptoms. Asymptomatic patients without limitations can participate in individually tailored exercise programs. However, patients with complex heart defects or significant residual conditions should train under professional supervision with low dynamic and static intensity, provided their health condition permits. This includes, among others, patients after palliative procedures, after Fontan surgery, or those with a systemic right ventricle in transposition of the great arteries (22). If necessary, the focus of the training should be on the lower extremities, as increasing peripheral muscle mass can reduce respiratory dependence for cardiac filling (22,23). Inspiratory muscle training can be used as a supplementary measure, especially in patients with weakened respiratory muscles (22).

The positive effects of CR are reflected in the results

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of several studies. Buckley *et al.* found that exercise-based CR in individuals with CHD, compared to patients who did not receive CR, led to a lower rate of major adverse cardiovascular events within 12 months, including overall mortality, acute coronary syndrome, and ischemic strokes (24). Sheng *et al.* reported that ACHD who fully participated in a 36-session program based on exercise therapy, nutritional counseling, and psychosocial support showed statistically significant improvements in physical performance, measured by metabolic equivalents, exercise time, and maximal oxygen uptake. These results highlight the effectiveness of CR in enhancing the fitness and quality of life of those affected (25).

However, it should be noted that rehabilitation spots specifically for ACHD are generally scarce, as only a few follow-up clinics are specialized in guideline-compliant CR for this patient group. This situation results in long waiting times for patients and often a lack of urgently needed ACHD expertise and certification in rehabilitation centers (17).

Distinctive aspects of medical rehabilitation in Germany

In order to better understand the role of the German Pension Insurance and its rehabilitation programs, it is important to recognize that different countries have varying approaches to rehabilitation.

Medical rehabilitation in Germany differs from that in other countries due to several characteristics that have historically been shaped by social legislation during the German Empire (Kaiserreich) and the tradition of balneology (therapeutic baths) (26).

A central feature is the predominance of rehabilitation in inpatient facilities led by specifically trained medical experts, while in countries such as Belgium or Denmark, rehabilitation is usually conducted on an outpatient basis. In several other countries, it also takes place in non-specialized centers primarily focused on physiotherapy (26).

The duration of rehabilitation in Germany is often standardized to three weeks, whereas in Europe, it varies between 2 and 24 weeks (26,27).

In Germany, insured individuals are required to submit their own application. An exception is the post-operative rehabilitation process following major surgeries or severe illnesses, which is initiated by the hospital. In many other countries, including Switzerland and the Netherlands, access to medical rehabilitation is facilitated through a doctor, usually the attending physician or an occupational health doctor (26).

Moreover, rehabilitation centers in Germany are often specialized in specific medical conditions, such as neurological or cardiovascular diseases, offering tailored programs. The close interdisciplinary collaboration ensures individual and comprehensive care (26).

Another feature of the German system is the clear division of responsibilities between the various service providers. While in countries like France, health insurance alone covers the costs, in Germany, the responsibility is divided among different institutions: accident insurance (after accidents), pension insurance (particularly for working individuals, focusing on work disability prevention), and health insurance (especially for pensioners, focusing on disability and long-term care prevention). Each covers the costs depending on the cause of the rehabilitation (26,28).

The role of the German Pension Insurance in cardiac rehabilitation and the relevant legal framework in Germany

If a patient's health is already severely impaired or at risk, and preventive measures alone are insufficient to prevent further health deterioration, the German Pension Insurance offers specialized rehabilitation programs. These focus particularly on restoring employability and quality of life after a health incident or procedure (29,30).

The regulations in Sections 5 and 6 of Volume IX of the Social Insurance Code ensure that the German Pension Insurance, as the main provider of participation benefits, is responsible for vocational rehabilitation, with the goal of maintaining or restoring employability and facilitating (re) integration into working life and society. At the same time, the provisions in Sections 13, 15, 17, and 25 of Volume IX of the Social Insurance Code ensure coordinated and uniform rehabilitation care, which is particularly crucial in complex conditions such as cardiovascular diseases. Through close cooperation with other providers, the German Pension Insurance ensures that preventive and rehabilitation measures are effectively implemented to maintain the insured's ability to work in the long term and promote their participation in working life. This legally anchored collaboration makes the German Pension Insurance an important player in coordinating measures that rely on cross-provider support to ensure seamless and effective care (29,31).

Insured individuals can access rehabilitation services

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from the German Pension Insurance if their ability to work is at risk or impaired. A minimum insurance period of 5–15 years is usually required. However, in some cases, it is sufficient to have paid mandatory contributions for at least six calendar months in the two years preceding the application. Additionally, it is important to note that these services are not available if exclusion criteria, such as civil service status, apply. Moreover, unless there is a compelling medical reason requiring urgent rehabilitation, a previous rehabilitation must have taken place at least four years prior (32).

The German Pension Insurance offers medical rehabilitation services on an outpatient or inpatient basis, both in its own rehabilitation centers and in contracted clinics. In total, the pension insurance providers in Germany operate approximately 90 own rehabilitation facilities, supplemented by hundreds of contracted clinics (30,32).

The costs for medical rehabilitation measures, including accommodation, meals, medical care, therapeutic services, and medical treatments, are covered by the German Pension Insurance. However, while in a rehabilitation clinic, patients must pay a co-payment of up to ten euros per day for up to 42 days per year. Previously utilized rehabilitation services, including those provided by health insurance, are taken into account. The exact amount of the co-payment is determined on an individual basis, as patients can often be partially or fully exempted from the payment depending on their income situation (32).

It is important to emphasize, however, that the rehabilitative services offered by the German Pension Insurance are not specifically designed for ACHD but rather are general offerings for all insured individuals with health impairments. Many rehabilitation facilities are often not adequately prepared for the specific needs of ACHD. Nevertheless, ACHD can utilize general medical rehabilitation services that are tailored to their individual needs and preferences (12,32). For example, clinics specializing in cardiovascular diseases, such as the Roderbirken Clinic of the German Pension Insurance Rhineland, can be selected for these patients (33). For successful rehabilitation, these facilities should either have a specialized cardiologist on staff or maintain close cooperation with specialized regional or nationwide centers to ensure optimal care (12).

Rehabilitation programs of the German Pension Insurance for patients with CHD

The rehabilitation clinics of the German Pension Insurance, which also treat patients with CHD, generally offer comprehensive prevention and rehabilitation programs (34).

Rehabilitation programs typically consist of a combination of physical therapies, such as sports and exercise therapy, physiotherapy, and physical therapy, to enhance fitness and recovery, along with psychological therapies, including individual and group psychotherapy, to support mental well-being. Health lectures and smoking cessation programs round off the program, aiming to improve the overall well-being of ACHD and prepare them for life after rehabilitation (35,36). The German Pension Insurance also offers comprehensive measures for occupational rehabilitation to support individuals with health impairments in returning to work. The services include individual consultations for reintegration and workplace adjustments tailored to the specific needs of the patients. Through close cooperation with various partners, it is ensured that the affected individuals receive the necessary support to improve their participation in working life. These measures are crucial for enabling successful integration into the labor market (36,37).

To continue supporting patients after rehabilitation, the German Pension Insurance offers digital follow-up services. These include, for example, multimodal rehabilitation follow-up (IRENA), therapeutic rehabilitation follow-up (T-RENA), and psychosomatic rehabilitation follow-up (Psy-RENA), all of which can be conducted online. Insured individuals can utilize these digital follow-up services regardless of the facility where the rehabilitation took place, provided they have access to a computer or mobile device and an internet connection (36,38).

With over one million medical and vocational rehabilitation services provided annually, the German Pension Insurance is the largest rehabilitation provider in Germany and thus bears special responsibility for the quality of care (39). The quality assurance in medical rehabilitation, initiated by the German Pension Insurance, includes clear requirements for structural, process, and outcome quality. Structural standards are tailored to specific building, technical, and staffing requirements based on the indication. Process quality is ensured through detailed documentation

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of therapy contents using their own classification system for therapeutic services and through rehabilitative therapy standards (36). For selected medical conditions, there are evidence-based minimum requirements, known as evidence-based therapy modules, such as sports and exercise therapy or vocational integration. A peer-review process, where specialists review discharge documents and therapy plans, contributes to quality assurance. Additionally, approximately 60,000 rehabilitation patients are surveyed annually about their subjective assessment of their health status and work capacity (36).

Evaluation and challenges of the German Pension Insurance services

A study conducted by the University of Potsdam at twelve German rehabilitation facilities in 2017 and 2018 analyzed the effectiveness of rehabilitation programs. Among the 1,262 participants under 65 years of age, significant improvements were observed after six months: health-related quality of life increased on average by 7% compared to the start of rehabilitation, and both endurance capacity and physical and mental well-being showed marked improvements. Furthermore, 69% of participants successfully returned to work (40).

In its strategy paper on the further development of prevention and rehabilitation services, the German Pension Insurance presents key insights and guidelines that are crucial for optimizing healthcare services. A person-centered approach and the consideration of individual needs are essential for the effectiveness of rehabilitation and prevention services. The German Pension Insurance promotes active collaboration with its insured individuals to increase their satisfaction and improve the utilization of its services. This approach ensures that the specific requirements and needs of patients are central to the healthcare offerings (36,41).

The German Pension Insurance faces several challenges in providing rehabilitative services. In particular, the application process is often perceived as complicated and time-consuming, leading to underutilization of the services (41). This is especially true for socially disadvantaged groups, such as individuals with a migration background or lower social status (41,42). Furthermore, there are bottlenecks in outpatient care, which hinder access to the necessary services (41). To continue providing optimal care for patients in the future, the German Pension Insurance has a clear vision for the development and adaptation of its rehabilitative services. Central to this vision is access to digital services, which should be designed to be simple, accessible, and non-discriminatory (41).

Conclusions

For ACHD, the German Pension Insurance holds a crucial role in providing ongoing healthcare and supporting their long-term well-being. However, the general rehabilitation services are often not specifically tailored to the complex anatomical, physiological, and psychosocial demands of ACHD. Certified expertise is lacking in many facilities, and specialized care is available only in a few institutions, leading to long waiting times and regional disparities in access.

To further enhance care, it is essential that the German Pension Insurance develops and finances more targeted programs for ACHD. These specific programs should focus on physical and psychological rehabilitation, as well as the promotion of occupational reintegration to facilitate patients' (re)entry into the workforce. Tailored occupational rehabilitation programs, including retraining, further education, and workplace adjustments, are necessary to meet the specific needs of a growing population of ACHD reaching working age. To achieve this, partnerships with supra-regional ACHD centers have to be strengthened, and ACHD certification should be expanded to rehabilitation clinics. Administrative barriers should further be reduced, as these often limit access for patients from socioeconomically disadvantaged groups, including the quite new group of individuals with a migration background.

As part of this effort, further research is needed to better understand the specific rehabilitation goals for ACHD. Studies should explore the most effective ways to design and implement personalized rehabilitation programs and should investigate the optimal intensity, duration, and type of interventions, including both physical and psychological components. In this context, developing evidence-based recommendations for various types of CHD is crucial, as standardized rehabilitation guidelines are currently lacking. Furthermore, barriers to participation, such as limited access to specialized centers, socio-economic factors, and patient awareness, should be investigated. Additionally, long-term outcomes, including the impact of rehabilitation on ACHD physical recovery, mental well-being, return to work, and overall quality of life, should be assessed to refine and sustain these programs effectively. Comparative analyses of international rehabilitation models could further

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help identify transferable approaches and support targeted improvements within the German system. By addressing these challenges through focused research, rehabilitation programs can be improved to ensure better long-term outcomes for ACHD.

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