CHAPTER 10
Rehabilitation

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Introduction

Kidney transplantation in childhood and adolescence is the only renal replacement therapy that can enable a largely normal life. To achieve this, these patients require specialised long-term aftercare. Structured rehabilitation programmes play a key role in this. While good outpatient aftercare focuses on managing physical problems, it often falls short in addressing the full range of follow-up needs. In addition to the side effects of immunosuppressive therapy, patients may face complications such as arterial hypertension, hyperlipoproteinemia, cardiovascular disease, obesity, diabetes mellitus, bacterial and viral infections and neoplasia, all of which can affect long-term graft survival and limit participation in social life. There is also a risk of gradual loss of organ function, which may eventually require dialysis again.

The mental stability of the transplanted child can be negatively affected by difficulties in accepting the new organ, inadequate coping with the illness and the demands of ongoing medical treatment, and fears and worries about the future. These factors can also affect the function of the transplant. This also applies to the child's social integration into the natural living environment, acceptance by peer groups, self-confidence and overall quality of life [1]. Non-adherence to medication plays an important role in the survival of the transplanted organ, especially in adolescents. Up to 1/3 of the adolescents do not take their immunosuppressive medication regularly in this phase of life. The risk of organ loss is particularly high during the transition period between the ages of 17 and 24 years [2].

Children with complex congenital syndromes, who previously had no treatment options, now have a better chance of survival. An increasing number of these children are treated with peritoneal dialysis from infancy and receive a

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transplant (often a live donation from a parent) by the age of 2–3 years. In many cases, these children have additional extrarenal symptoms such as physical and mental disabilities associated with significant developmental delays in motor, cognitive, language, social and emotional areas. This places increasing demands on parents in terms of care and expertise.

A child's chronic illness causes a variety of emotional stresses, not only for the child's parents but also for the child's siblings. Because one or both parents are very involved with the sick child, siblings and the other parent may feel neglected. This can lead to family dysfunction. This highlights the importance of early rehabilitation: parent coaching should go hand in hand with efforts to stabilise the child's physical and emotional well-being.

Approximately 30% of children and adolescents in Germany receive a living kidney donation. The donor must learn to protect the remaining single kidney (e.g. through annual follow-up examinations) [3]. Donors may not always regain their previous physical, mental and work capacity. They may also feel a strong sense of responsibility for the transplanted child, especially at a time when young people are seeking independence from their parents. This can lead to additional stress, making rehabilitation important for donors as well [4].

Aims of rehabilitation

The main aim of rehabilitation is to improve participation in family, school, social life and eventually work life and to improve life quality. This includes:

- Strengthening the patient's ability to manage their illness, improving coping mechanisms and organ acceptance
- Improving and stabilising medication adherence
- Preventing or reducing the impact of secondary complications
- Improving physical and mental performance
- Improving psychosocial well-being
- Addressing the special relationship between the donor and the recipient in the case of living donation
- Promote age-appropriate autonomy
- Stabilise and optimise nutritional status
- Provide education for patients and parents, tailored to the type of rehabilitation, transition

Ideally, rehabilitation should lead to a comprehensive and significant stabilisation of the patient's health status, with a focus on preventing rapid deterioration of the transplant function or even organ loss.

Implementing rehabilitation

In paediatrics, it is important to consider the wider context of the child. In the case of inpatient rehabilitation, the primary caregiver is admitted to the hospital as a "co-therapist". However, the aim should be to involve all family members in the rehabilitation programme.

During the course of congenital kidney disease and subsequent transplantation several stages of rehabilitation are beneficial: during infancy, school age and adolescence. Final rehabilitation should take place between the ages of 15 and 18 years, depending on the individual's developmental stage, and should include a transition programme that fully prepares the young person for adulthood and a long life with the transplanted organ.

Older adolescents and young adults with developmental delays or who are still in school or in vocational training can continue to receive paediatric rehabilitation until the age of 27 years.

Rehabilitation for children from 1 to 14 years of age (or longer in special cases, e.g. developmental delay, physical and mental disability) should be carried out as "Family Oriented Rehabilitation (FOR)", involving as many family members as possible. With the increasing number of young children undergoing transplantation (e.g. early nursery school age), the additional offer of family-oriented infant rehabilitation is very useful. All FORs should aim for groups of families to be admitted to the rehabilitation clinic at the same time and then generally attend rehabilitation together for 4 weeks. Longer periods of rehabilitation are also possible (e.g. 6 weeks).

Adolescents aged 15–18 years and young adults should receive rehabilitation unaccompanied in larger groups specifically designed for this age group, depending on their developmental age and comorbidity. If parents have their own rehabilitation needs, such as in the case of living donors, they should be admitted to the same clinic at the same time if a rehabilitation measure is approved by the funder.

Based on preliminary findings, the rehabilitation clinic develops a personalised treatment plan that includes medical, psychological, educational, physiotherapeutic, occupational and sports therapy services as required. In addition,

the children and young people and their siblings receive a qualified education in core subjects in consultation with their home school. Rehabilitation is therefore not dependent on school holidays.

Motivation for rehabilitation

The motivation of children and adolescents to participate in rehabilitation depends not only on their age, but also on the motivation of their caregivers, who are actively involved in the child's care as co-therapists. The willingness to accept all therapy offers (which are always mandatory) is essential for the overall success of rehabilitation. Providing patients and families with sufficient information about the goals of rehabilitation, the course of rehabilitation and the conditions and possibilities of the rehabilitation clinic is an important motivational aid.

The rehabilitation team

The interdisciplinary rehabilitation team includes professionals from the fields of nursing, psychology, physiotherapy, occupational therapy, speech therapy, dietetics, education and social work as well as medical specialists. Sports instructors and specialist teachers should also be part of the team.

The medical management of a rehabilitation facility requires many years of competent and constantly updated specialist knowledge, oriented towards the specifics of congenital and acquired nephrological diseases, dialysis treatment and kidney transplantation. Close cooperation between the rehabilitation clinic and the referring physician or centre is necessary.

Diagnostic and therapeutic services

Medical care:

- Continuous medical care by nurses and doctors throughout rehabilitation is essential. Where appropriate, staff should be experienced in dialysis therapy (particularly peritoneal dialysis and, where possible, haemodialysis), which should also be available during rehabilitation.
- Short-term blood tests for serum sodium and potassium, blood gas analysis, prompt determination of essential serum parameters and level checks

(immunosuppressive drugs), urinalysis, 24-hour blood pressure measurement, sonography, ECG.
- Lectures and training on nephrological diseases, organ functions, immune system, immunosuppressive drugs, concomitant medication after transplantation, post-transplant infections, transition training

Educational services:
- Individual patient care based on clinical picture and co-morbidities
- Individual and group care for parents and siblings
- Learning support for school-age children
- Active leisure activities
- Occupational therapy to improve functioning in daily activities
- Encouraging and supporting interaction between all patients and families, both with and independently of the rehabilitation team

Psychological services:
- Psychosocial assessment, including standardised and validated tests
- Behavioural assessment, family interaction
- Assessment of adherence, disease acceptance, self-confidence, self-responsibility
- Individual and group psychological interventions, crisis management.

Physiotherapy and sports therapy:
- Psychomotor skills, activation of muscle activity during sport and play, also as part of leisure activities
- Improving physical performance, coordination and balance
- Stabilisation of body awareness
- Relaxation programmes

Nutrition therapy and advice including tube feeding
- Ensuring an individualized and healthy diet
- Practical training in a teaching kitchen

Legal regulations

In Germany, the rehabilitation for children and young people is a social service covered by the statutory health insurance or the German Pension Insurance. The necessary legal basis for this is formulated in the German Social Code (SGB IX: Rehabilitation and Participation of People with Disabilities) and in the respective social codes of the individual rehabilitation providers.

These regulations are intended to take account of the special needs of children with disabilities, including emotional disabilities.

The Flexible Pensions Act, which came into force in December 2016, established legal regulations for the rehabilitation of children and adolescents. Children's rehabilitation is defined as a compulsory benefit if the child's chronic illness affects his or her participation in school and vocational training and thus also has affects his or her ability to earn a living in the future. Children are entitled to be accompanied if this is necessary for the implementation or success of the child's rehabilitation. This also applies to the admission of family members if their involvement in the rehabilitation process is necessary. Inpatient services are generally provided for four weeks. The four-year period between two rehabilitation measures, which applies to adults, does not apply to children.

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