

CHAPTER 11

Child development in the context of renal replacement therapy

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Development describes a change in human experience and behaviour that builds up over time. It should be noted that the permanent decline in abilities, such as occurs in neurodegenerative diseases, is also considered as development. In the context of chronic kidney disease and renal replacement therapy, a number of factors can exert an influence on the course of development. These can be divided into three categories. In general, the earlier and more extensively the disease affects the developing organism, the greater the difficulties and abnormalities that can be observed.

1. General effects of impaired kidney function, such as

- systemic inflammation,
- consequences of acidaemia and uraemia,
- sympathetic overactivity,
- hypertension and vascular changes.

While some of these factors can be alleviated by transplantation, others persist post-transplantation and continue to exert an influence. Immunosuppressive therapy, which almost always includes a potentially neurotoxic calcineurin inhibitor and corticosteroids, may introduce additional influencing factors.

2. Extra-renal manifestations of kidney disease, such as

- syndromic diseases without structural brain changes (e.g. Alport syndrome, HUS),
- syndromic diseases with structural brain changes (e.g. Joubert syndrome),
- metabolic diseases (e.g. cystinosis, oxalosis),
- systemic diseases with kidney involvement (e.g. vasculitis, SLE)

It is important to note that individuals with congenital nephrotic syndrome may have severe developmental problems even in the absence of kidney dysfunction. The significant loss of protein can result in a deficiency of essential nutrients required for normal physiological development.

3. Environmental factors such as

- Reduced play and learning opportunities due to hospitalisation
- Traumatic experiences
- Changed parental behaviour
- Physical stigmatisation
- Difficult social contacts

Possible impacts on different areas of development are listed in Table 1.

The above risks and impairments have been shown to increase the likelihood that people with childhood-onset ESRD will

- have lower grades and educational attainment
- lack school-leaving qualifications
- become unemployed
- live on benefits
- have a delayed transition to independent living
- live in a partnership [2, 3, 4].

In the light of these findings, it is imperative to prioritise the early identification of developmental disorders and delays at an early stage and to address them through targeted interventions. This can be achieved by:

1. Regular paediatric developmental screening to detect abnormalities
2. In-depth developmental psychology and/or neuropaediatric assessment to differentiate abnormalities, initiate differential diagnosis and develop support plans
3. Connection to multi-professional diagnostics and treatment in a socio-paediatric centre (SPC)

The support measures can be summarised as follows:

Table 1 Possible developmental abnormalities associated with renal replacement therapy

Area of development	Possible abnormalities
Sensors	<ul style="list-style-type: none"> • Hearing impairment (e.g. Alport) • Visual impairment (e.g. cystinosis) • Dizziness • Pain • Tactile-kinaesthetic abnormalities • Proprioceptive-vestibular abnormalities (positional sensitivity)
Motor skills	<ul style="list-style-type: none"> • Orofacial weakness with sucking and swallowing difficulties and articulation problems • Muscular hypotonia with trunk instability • Disproportionately short stature with impaired development of movement sequences • Organic brain movement disorders (e.g. Joubert syndrome)
Language	<ul style="list-style-type: none"> • Delayed speech development with a reduced understanding of cause and effect • Interaction problems • Phonetic disorders
Cognition	<ul style="list-style-type: none"> • Global intellectual disability • Memory problems • Concentration disorders • Reduced processing speed • Executive dysfunction
Social-emotional development	<ul style="list-style-type: none"> • Attachment disorders (e.g. in the case of prolonged intensive care after birth) • Repeated trauma and trauma-related disorders • Isolation, hospitalisation, (anxiety including fear of the future) • Depression • Behavioural problems (e.g. obsessive-compulsive or oppositional behaviour)

Special educational early intervention

- Applicable in the first 3 years of life or before the start of KiTa (note: differences between districts)
- Early start important
- Direct developmental support and training of parents
- Integration of appropriate facilities in case of visual or hearing impairment
- Funded in Germany through “Eingliederungshilfe”/integration assistance (social benefit according to SGB IX § 46),
- Requires a certification of need by treating paediatrician

Therapeutic measures

- Physiotherapy (e.g. strengthening, tone regulation, training of physiological movement patterns)
- Occupational therapy (e.g. sensory integration, body awareness, stimulus regulation)
- Speech therapy (e.g. tube weaning, swallowing training, articulation support)
- Psychotherapy (e.g. for trauma, depression, interactional disorders)

All of these therapies require a doctor’s prescription and regular reviews of their usefulness and success.

Psychological and educational interventions

- Inconsistent research on cognitive outcome after transplantation.
- Cognitive decline after transplantation has also been described [5].
- Heterogeneous developmental profiles with circumscribed cognitive problems despite normal intelligence (e.g. concentration, attention or processing speed) are common.
- Early neuropsychological diagnostics and analysis of performance profiles are needed to initiate targeted support and compensate for disadvantages.
- Use of hospital schooling and home schooling for extended periods of absence (e.g. following transplantation)
- Involvement of specialist staff from relevant special educational needs schools to determine compensation for disadvantages at school (also applies to children without certified special educational needs).

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