



Paediatric Kidney Replacement Therapy

Editor: Tadeja Kokelj Jeršin



"Baby Kidneys" is artwork
by Dr. Mayleen Laico

All rights are reserved by the author and publisher, including the rights of reprinting, reproduction in any form and translation. No part of this book may be reproduced, stored in a retrieval system or transmitted, in any form or by means, electronic, mechanical, photocopying, recording, or otherwise, without the prior written permission of the publisher.

First edition: October 2025

**European Dialysis and Transplant Nurses Association/European Renal Care Association
(EDTNA/ERCA)**

Seestrasse 91, CH 6052 Hergiswil, Switzerland

www.edtnaerca.org

ISBN: 978-618-5955-06-9

Publisher: RAT Advertising LTD

156 I. Gkoura Str

PO: 18452 - Athens, Greece

www.rat.gr



Paediatric Kidney Replacement Therapy

A Guide for Nurses

Editor

Tadeja Kokelj Jeršin, RN, M.A.

Paediatric Dialysis and Transplant Centre,
Department of Paediatric Nephrology, Children's Hospital,
University Medical Centre Ljubljana, Ljubljana, Slovenia.

President of the Nephrology,
Dialysis and Transplant Nurses at Nurses
and Midwives Association of Slovenia.
EDTNA/ERCA Paediatric Nephrology Consultant

Authors

Konstantinos Petsios, RN, MHSc, MHMn, PhD

Assistant Professor in Paediatric Nursing
Nursing Department,
National & Kapodistrian University of Athens

Mattia Parolin, MD

Paediatric Nephrology Dialysis and Transplant Unit,
University Hospital of Padova

Serife Cetin, RN, PhD

Assistant Professor
Department of Dialysis,
Department of Medical Services and Techniques,
Incesu Vocational School of Health Services,
Kayseri University, Kayseri, Turkey.

Inmaculada Moreno González, RN

Nursing supervisor of The Paediatric Nephrology Department
Hospital Regional Universitario De Málaga
SEDEN Paediatrics and Hospitalisation Board Member, Spain.

Tadeja Kokelj Jeršin, RN, M.A

Paediatric Dialysis and Transplant Centre,
Department of Paediatric Nephrology,
Children's Hospital,
University Medical Centre Ljubljana, Slovenia.
President of the Nephrology,
Dialysis and Transplant Nurses Section
at Nurses and Midwives Association of Slovenia.
EDTNA/ERCA Paediatric Nephrology Consultant

Sanja Kostić Smuk, RN

Paediatric Dialysis and Transplant Centre,
Department of Paediatric Nephrology,
Children's Hospital,
University Medical Centre Ljubljana,
Ljubljana, Slovenia.

Ksenija Valentak, RN

University Hospital Centre Zagreb, Croatia

Senka Besedić, RN

University Hospital Centre Zagreb, Croatia

Suzana Belajević, RN

University Hospital Centre Zagreb, Croatia

Drago Baković, MD

Croatian Institute of Public Health Department of Epidemiology,
Croatia.

Despoina Koumpagioti, RN, MSc, PhD

Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Eirini Tzepapadaki, RN, MSc

Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Eirini Patta, RN

Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Pagona Anastasiou, RN MSc
Head Nurse, Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Panagiota Vouzi, RN
Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Maria Stravakou, RN, MSc
Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Aggelos Karalis, RN, MSc
Haemodialysis Unit,
Children's Hospital "P. & A. Kyriakou", Athens

Lynsey Stronach, BSc, MSc
Advanced Nurse Practitioner for Haemodialysis,
Eagle Haemodialysis Unit,
Great Ormond Street Hospital, London.

Kathryn Waters, BSc, MSc
Advanced Nurse Practitioner for Haemodialysis,
Eagle Haemodialysis Unit,
Great Ormond Street Hospital, London.

Germana Longo, MD
Paediatric Nephrology Unit,
Department of Woman's and Child's Health,
University Hospital of Padova, Padua, Italy.

Jose Maria Igeno San Miguel, RN
Paediatric Nephrology Unit,
Department of Woman's and Child's Health,
University Hospital of Padova, Padua, Italy.

Julia Thumfart, RN
Charité Universitätsmedizin Berlin,
Section Leader Paediatric Nephrology

Kalliopi Anna Poulia, RD, MmedSci, PhD
Assistant Professor in Clinical Dietetics
Laboratory of Dietetics and Quality of Life
Department of Food Science and Human Nutrition
School of Food and Nutritional Sciences
Agricultural University of Athens, Greece

Alison Mc Hugh-Larkin, MIACP, BA Hons, MSc
Clinical Accredited Psychotherapist
Health Psychology, Beaumont Hospital,
Dublin, Ireland.

Hanne Agerskov, RN, PhD,
Professor
Odense university Hospital and
University of Southern Denmark

Christina Egmosen Frandsen, RN, PhD,
Assistant Professor
Odense university Hospital and
University of Southern Denmark

English Proofreading

Susan Rogers, RGN,
EDTNA/ERCA English Proofreading Coordinator
Coordinator, Dialysis Nurse, The Netherlands

Claire Carswell, RMN, PhD Post-Doctoral Research Fellow,
School of Nursing and Midwifery,
Queen's University Belfast, UK.
EDTNA/ERCA Scientific Board Member

Deepa Kariyawasam, RD
Specialist Renal Dietitian/
Multi-professional Clinical Lead of the London Kidney Network
Department of Dietetics King's College Hospital NHS Foundation Trust,
London, UK

Grace Muray, RN, Pg. Dip. Renal Nursing,
MSc. (c) Renal Nursing,
School of Nursing and Midwifery,
Trinity College Dublin, Ireland.

Acknowledgments

This publication is an initiative of EDTNA/ERCA, reflecting our commitment to providing up-to-date, evidence-based information on *Paediatric Kidney Replacement Therapy – A Guide for Nurses*. It is intended as a comprehensive resource for nephrology nurses and other healthcare professionals involved in the care of children with advanced kidney disease.

We would like to express our sincere gratitude to **Tadeja Kokelj Jeršin** the editor of this book, for her dedication, expertise, and tireless efforts in authoring and coordinating the development of this important work.

Our heartfelt thanks also go to **Dr. Mayleen Laico**, who created the artwork for the front cover of this book. Her contribution to the visual design is deeply appreciated.

Last but not least, we extend our sincere appreciation to our native English-speaking colleagues who contributed to the English proofreading of the text: **Susan Rogers, Claire Carswell, Deepa Kariyawasam, and Grace Murray**. Their careful review and linguistic support have significantly enhanced the clarity and readability of the final publication.

On behalf of the EDTNA/ERCA Executive Committee
Anastasia Liossatou
EDTNA/ERCA Executive Committee member
Publications Coordinator

Table of contents

Chapter 1.

The history of paediatric kidney replacement therapy <i>Konstantinos Petsios</i>	13
---	----

Chapter 2.

Acute kidney injury in paediatric population <i>Mattia Parolin</i>	34
---	----

Chapter 3.

Chronic kidney disease in paediatric population <i>Şerife Çetin</i>	44
--	----

Chapter 4.

Indications and goals for kidney replacement therapy <i>Inmaculada Moreno González</i>	60
---	----

Chapter 5.

Modalities of kidney replacement therapy <i>Tadeja Kokelj Jeršin, Sanja Kostić Smuk</i>	68
--	----

5.1. Peritoneal dialysis

5.1.1. Continuous ambulatory peritoneal dialysis and automated peritoneal dialysis	72
5.1.2. Peritoneal membrane function	73
5.1.3. Peritoneal dialysis catheter	75
5.1.4. Peritoneal dialysis components <i>Ksenija Valentak, Senka Besedić, Suzana Belajević, Drago Baković</i>	77
5.1.5. Management of most common complications in peritoneal dialysis	79

5.2. Haemodialysis

<i>Lynsey Stronach, Kathryn Waters</i>	85
5.2.1. Paediatric haemodialysis	
<i>Despoina Koumpagioti, Eirini Tzepapadaki,</i> <i>Eirini Patta, Pagona Anastasiou</i>	89
5.2.2. Dialysis machine, required equipment and water quality	
<i>Despoina Koumpagioti, Eirini Tzepapadaki,</i> <i>Eirini Patta, Pagona Anastasiou</i>	92
5.2.3. Vascular access and extracorporeal blood circulation	
<i>Lynsey Stronach, Kathryn Waters</i>	95
5.2.4. Anticoagulation in the extracorporeal circuit	
<i>Lynsey Stronach, Kathryn Waters</i>	98
5.2.5. Life threatening complications on haemodialysis	
<i>Lynsey Stronach, Kathryn Waters</i>	102
5.3. Kidney Transplantation	107
5.3.1. Preparing children with end stage kidney disease for kidney transplantation	107
5.3.2. Types of Kidney Transplantation (living donor / deceased donor)	110
5.3.3. Surgery and recovering after kidney transplantation	113
5.3.4. Post kidney transplantation medical management	
<i>Germana Longo, Jose Maria Igeno San Miguel</i>	115

Chapter 6.

Advantages and disadvantages of kidney replacement therapy modalities	
<i>Julia Thumfart</i>	120

Chapter 7.

Special nutritional requirements for infants and children
 with chronic kidney disease on haemodialysis

Kalliopi Anna Poulia 129

Chapter 8.

Impact on quality of life of children on long-term
 kidney replacement therapy

Konstantinos Petsios 139

Chapter 9.

Psychological care approach to children with
 chronic kidney disease

Alison Mc Hugh-Larkin 165

Chapter 10.

Impact on the lives of families with a child on kidney
 replacement therapy and their need for family support

Hanne Agerskov 170

Chapter 11.

Challenges nephrology nurses face while caring for children
 with acute kidney injury or chronic kidney disease,

Jose Maria Igeno San Miguel 180

Chapter 1

The history of paediatric kidney replacement therapy

Learning objectives

- To acknowledge the evolving landscape of kidney replacement therapy (KRT) in paediatric patients.
- To recall the major milestones in the development of dialysis and transplantation in paediatric patients.
- To understand the role of technological and procedural innovations in the evolution of paediatric kidney dialysis and transplantation.
- To illustrate how historical innovations have shaped modern clinical practice.
- To acknowledge the limitations of early KRT approaches in children and how they were addressed over time.
- To recognize the major contributions of key individuals, institutions, and countries in advancing paediatric kidney replacement therapy.
- To assess the current state of KRT in children and identify emerging trends.

Introduction

Kidney replacement therapy (KRT) for paediatric kidney disease is steadily evolving since its introduction in late 50s. Kidney disease in children is a multifaceted and multidimensional clinical condition that requires effective management of long term KRT, and it stands as a challenge for both healthcare professionals, paediatric patients and their families. The occurrence of kidney disease was initially studied in adult patients and research was gradually extended to children.¹

Historically, initial treatment approaches were centred on adults, but gradually attention was turned towards children. Paediatric kidney disease is a chronic condition that impacts not only the affected child but also the functioning of the whole family. The development of therapeutic approaches in children was initially delayed due to peculiarities related to the great variation in the frequency of disease occurrence in children, with different aetiology and pathophysiology in childhood, as well as the special developmental and growth needs and limitations in therapeutic approaches, mainly due to technological

limitations. Consequently, children with kidney disease that need KRT, are a particularly vulnerable patient population requiring highly specialized care.^{2,3}

Even currently, the incidence of CKD in children varies worldwide based on recent registry-based studies. Many national and international registries have been developed over the years. The three biggest registries are the ERA–EDTA registry, the United States Renal Data System registry and, the Australia and New Zealand Dialysis and Transplant Registry. The results from these studies are expected to continue to change daily clinical practices and lead to new improvements in chronic paediatric kidney care.⁴

The progress from a point in time after 1960 has been impressive. Even today, despite developments in therapeutic approaches, significant differences appear in the paediatric population related to a series of clinical, family and social determinants.⁵ Over time, a higher number of children on KRT manage to survive, graft survival is improving and the duration of dialysis is steadily decreasing. Moreover, use of KRT in infants and neonates is increasing.^{6,7}

The history of paediatric KRT is not simply a reference to the most important historical milestones of the treatment. It also conceals how the combination of clinical expertise, evidence-based practice, targeted research combined with innovation, observation and the development of biotechnology, radically changed the treatment itself. KRT in paediatrics has evolved in parallel with advances in adults care, challenged due to somatometric limitations and growth and physiology determinants. It is by the late 1950's that the first references to paediatric cases appear.^{8,9}

Unquestionably, the history of KRT in children is closely linked to the development of paediatric nephrology as a specialty. Before 1950, scientists in paediatrics focused on fluid and electrolyte balance. It was just after World War II that KRT began and was characterized by significant innovations and improvements. These included the use of ACTH and glucocorticoid treatment for nephrotic syndrome, and understanding immunology's role in glomerular injury. Furthermore, the advent of dialysis with peritoneal dialysis (PD) & haemodialysis (HD), and successful kidney transplantation for end-stage kidney disease in children further developed paediatric nephrology. In addition, the recognition that kidney disease is the main cause of childhood hypertension (up to 80%)⁶ had major implications.

This chapter provides an historical description of KRT evolution in children. It captures the evolution of these therapies from their earliest conceptualizations to contemporary practices, based on the unique challenges encountered in paediatric care, the scientific discoveries and technological innovations and developments that changed the clinical implementations of the therapy, and the major ethical considerations that have shaped the field. A chronological overview of the most critical milestones regarding KRT is presented in Table 1.

Table 1. Key Milestones in Kidney Replacement Therapy in Children.

Year	Milestone
1943	Kolff's first dialysis machine (rotating drum haemodialyzer)
1959	First successful identical twin kidney paediatric transplant (Murray J.)
1959	Discovery of drug-based immune suppression
1960s	First chronic dialysis and transplants in children, Paediatric nephrology coalesced as a discipline
1964	First US paediatric kidney transplant
1966	The first International Study of Kidney Disease in Children
1968	First use of maintenance paediatric HD (Fine et al.)
1970s	CAPD developed, home dialysis more feasible
1974	Founding of the International Paediatric Nephrology Association (IPNA)
1977	First computer-based organ matching system (UNOS predecessor)
1980s	Cyclosporine improves transplant survival (Borel J.)
1990s–2000s	Focus on growth, development, and improved transplant techniques
1997	Quality goals in dialysis established
1998	The Kidney Project launched
2000	Home PD, neonatal CRRT, better NICU protocols
2000s	Exploration of new immunosuppressive drug classes
2010s	CARPEDIEM, NIDUS, infant-specific machines developed
2010s–present	Personalized KRT, wearable tech, bioengineered solutions, neonatal dialysis, precision medicine, and better long-term outcomes

The foundations KRT

The base for the KRT application was the scientific work of Thomas Graham the "Father of Dialysis." The basics regarding osmosis and diffusion formed the fundamental principles for blood filtration. As early as 1913 Abel, Rowntree and Turner were using acellular semipermeable membranes to perform external blood purification on animals. Haas (1924) and Kolff (1943) used early dialysis equipment for humans, and Kolff achieved the first successful treatment of a patient with acute kidney disease in 1945. The first clinical application of PD was performed by Ganter (1923), involving the instillation of a sterile physiological solution into the peritoneum of a woman with post-partum kidney disease. In these early stages dialysis failures were attributed to technical limitations and lack of immunology understanding leading to rejection, causing a greater delay of KRT in children. Medawar's experiments in the 1940s were instrumental in identifying the immunologic basis of organ rejection, a discovery that was fundamental for developing strategies to prevent transplant rejection.¹⁰

The first successful live donor human kidney transplant was performed by Dr J. Murray and his colleagues (1954) between identical twin brothers that did not require immunosuppressive medication due to genetic compatibility, and then on non-identical twins and finally, using a cadaveric donor. The advancement of kidney transplantation was done on the groundwork laid in the 1950's and 1960's.¹¹

Regional societies of paediatric nephrology such as the European Society of Paediatric Nephrology (1967) and American Society of Paediatric Nephrology (1969) formed the scientific basis to the application of KRT in children. Peritoneal Dialysis (PD) was the first modality to gain traction in paediatric settings. Its application for acute kidney injury (AKI) became institutionalized in many children's hospitals beginning in the 1950's. This earlier adoption of PD for acute paediatric needs, compared to chronic HD, suggests that the immediate life-saving urgency of acute kidney failure in children prompted the use of PD, which was simpler and less invasive than early HD. In this era, technical limitations related to access, fluid constituents and infections limited its implementation.¹²

The first documented use of maintenance paediatric HD for chronic kidney failure was reported in 1968 by Fine et al.¹³ The adaptation of adult machinery and procedures for children began pioneering

efforts in the 1950's to customize chronic paediatric dialysis. This chronological difference highlights that the early limitations of KRT for children meant that only the most severe, acute cases were considered treatable, and long-term survival was not the primary or even feasible goal. Paediatric KRT management differs from that in adults with respect to their small body weight and the inherent challenges in establishing and maintaining vascular access, along with the lower margin of safety that needs to be balanced with treatment efficacy. Consequently, the development of paediatric-specific chronic solutions lagged significantly behind adult innovations, as the immediate focus was on survival from acute episodes.¹⁴

The use of smaller dialysis machine (e.g. Milton-Roy Model A -1964) and dialyzers (e.g. Kiil Dialyzer-1960) with reduced blood volume offered the technological base for the KRT in children. The Scribner shunt (1960) was an advancement for chronic HD providing a long-term access to the blood vessel that, were later replaced with a double lumen.¹⁵

Significant therapeutic and technological developments during the 1980's and 1990's led in a new age of safety and effectiveness for paediatric kidney replacement therapy. The inherent risks and limits of adapting adult technologies prompted the development of specialist paediatric equipment, which greatly increased access to KRT and enhanced child safety. Equipment innovations for paediatric dialysis were crucial. HD double lumen subcutaneously tunnelled catheters were developed in the early 1980's. And the silicone-based, soft, subcutaneously tunnelled cuffed PD catheters made chronic PD a feasible alternative for PD by 1980.¹⁶ Additional developments included the creation of miniature dialyzers and tubing especially made for children and infants, which allowed for the precise blood volume control necessary for paediatric patients, and the packaging of parenteral fluids in soft plastic bags rather than stiff glass bottles. Volumetric ultrafiltration control, continuous blood volume monitoring, the widespread use of buffered bicarbonate solutions (instead of acetate), and the creation of more biocompatible synthetic membranes were among the broader technological advancements that made dialysis safer and more efficient. Moreover, the use of specialized software in contemporary dialysis machines enabled accurate therapeutic parameter adjustment within paediatric ranges, such as smaller dialyzers and decreased extracorporeal blood

volume with paediatric-specific blood lines. Consequently, paediatric KRT started to forge its own unique identity and technological trajectory. It evolved from a simplified form of adult care to the creation of specialized instruments and methods that radically changed the long-term viability, safety, and feasibility of treating paediatric kidney disease.¹⁷

In addition, transplant results were significantly enhanced by the immunosuppressive revolution, especially the development and effects of calcineurin inhibitors (CNIs). By successfully preventing organ rejection, cyclosporine's introduction in the 1980s brought about a considerable improvement in graft survival rates, bringing about a radical change in transplantation.¹⁸ In paediatric kidney replacement therapy, the 21st century has seen a significant change from focusing only on graft survival to holistically maximizing patient health and quality of life for the long term. The ongoing improvement of immunosuppressives, sophisticated surgical methods, and the growing emphasis on overall patient outcomes are all examples of this progression. Advanced surgical techniques continue to evolve for complex paediatric cases and are expected to further enhance allograft survival, particularly in very young children.¹⁹

The remarkable improvements in patient survival rates have fundamentally shifted the primary challenges in paediatric KRT from acute mortality to managing chronic morbidity and the complexities of lifelong care. Since the first paediatric transplant in 1959, both patient and graft survival rates have dramatically improved, transforming the prognosis for children with ESKD. The 1-year patient survival rate, which was 70% in 1970, has risen to an impressive 97% today. The 5-year patient survival rate improved from 91% before 1990 to 98% after 2010, primarily attributed to a significant decline in infection-related mortality. Consequently, this success means that children with ESKD are now living significantly longer, transforming a previously fatal disease into a chronic condition.²⁰

These days, paediatric patients with kidney pathology are treated with a range of dialysis techniques, including PD, HD, continuous kidney replacement therapy (CKRT), and paediatric technologies like sustained low-efficiency dialysis (SLED). In addition, a specialized device called the Cardio-Renal Paediatric Dialysis Emergency Machine (CARPEDIEM), was created in 2012 and marked the beginning of the "fitted era" for paediatric CKRT.¹⁴ Even though

CKRT stands as a main therapeutic choice for acute kidney failure in critically ill children, limited published data guides the everyday clinical practice regarding optimal initiation, delivered dose, anticoagulation strategy, quality monitoring, and fluid removal.²¹ Increased fluid removal with fewer negative effects has been made possible by modifications to flow parameters in ultrafiltration as well as novel biocompatible solutions. In critically ill children, hybrid methods such as persistent low-efficiency daily haemodiafiltration reduce the requirement for anticoagulants by clearing both small and larger solutes.²²

History of PD in children

The use of PD in children has increased dramatically over the past few decades.²³ Its origins in paediatric care relate to the use of the peritoneal cavity to treat dehydration in infants. It took almost fifty years after the first clinical application of PD in an adult by G. Ganter to implement it in everyday paediatric clinical practice. In the meantime, several case studies referring to treatments by peritoneal irrigation were published.²⁴ During the 1950's and 1960's, technological advancements and innovations with the use of modern catheters and a variety of dialysis solutions, transformed PD techniques, and provided the solution of intermittent forms of PD. Compared to HD at this early stage of KRT development, the use of PD appeared more suitable for use in paediatric patients since it was a practical, safe, and easily adapted technique that could be implemented in patients of all ages independently of their somatometric characteristics. However, early PD techniques had poor outcomes to children with end-stage kidney disease.²⁵

A major milestone for PD dialysis was the introduction of a permanent peritoneal catheter that made feasible long-term PD for paediatric patients. In addition, the discovery of Continuous Ambulatory Peritoneal Dialysis (CAPD) in 1976 by Moncrief, Popovich, and their associates was also an important landmark that transformed PD from an intermittent hospital-based procedure to a continuous, home-based therapy. CAPD created a solution for paediatric patients of all ages to undergo dialysis at home, which enabled a more normal childhood. Prior to this, haemodialysis was often the only option for children with end-stage kidney disease (ESKD), but it posed significant challenges, particularly regarding vascular access

and the impact on a child's quality of life. Subsequently, this led to the development of large CAPD centres throughout the world and increased the demand for the multidisciplinary paediatric kidney specialists.^{10,26,27}

During the 1980's, Automated Peritoneal Dialysis (APD) was introduced, further enhancing convenience for families by allowing exchanges to be performed overnight by a machine, reducing the burden on caregivers during the day.²⁸ Today, APD is the predominant mode of PD in children. In parallel, technical innovations regarding catheter design and materials, development of biocompatible dialysate solutions with neutral pH, lower glucose degradation products, and alternative osmotic agents, along with improvements in surgical implantation techniques, led to significantly lower rates of complications and adverse events and better patient outcomes.^{26,27}

The creation of national and international paediatric dialysis registries has been crucial in collecting data, understanding trends, identifying complications, and developing evidence-based guidelines for paediatric PD care. The success of PD in children relies heavily on a comprehensive multidisciplinary team, including paediatric nephrologists, surgeons, nurses, dietitians, social workers, and child life specialists, who provide holistic care and extensive training to families. The registries provide essential clinical data of paediatric patients on PD (nutrition, growth, systemic disorders, symptoms, complications and comorbidities), providing the ability to compare practices and outcomes between national and international kidney centers.²⁹

Today, PD remains the modality of choice for many children with ESKD globally. It offers numerous advantages, allowing children to be treated at home, maintaining a more normal lifestyle, and serving as an excellent bridge to kidney transplantation, which is often the ultimate goal. While challenges like peritonitis and other complications persist, continuous research and advancements in technology and clinical practice aim to optimize PD outcomes for children further. For example, the use of remote patient monitoring for automated PD is proposed as a tool to improve clinical outcomes and research data supports it, since it is associated with fewer and shorter unplanned hospitalizations, improved fluid management and favourable adherence to PD.³⁰

History of HD and continuous kidney replacement therapy in children

The historical evolution of HD and continuous kidney replacement therapy in children followed the development of KRT in adults, with a slight delay due to the specific challenges of treating paediatric patients, particularly due to the pathophysiological and somatometric differences, especially in neonates, infants and small children. HD was performed on children in the late 1960's for the management of severe uraemia, acute kidney disease and overhydration in children. We should acknowledge that at this initial stage, there was limited laboratory testing available, and dialysis management decisions mainly relied on clinical judgment.³¹⁻³³

The innovative use of Teflon arteriovenous shunts decreased the barriers associated with vascular access and enhanced the use of HD as a maintenance therapy for end-stage kidney disease since it gave clinicians the choice of a reusable vascular access.³⁴ Important technological advances led to efficient improvements in dialysis techniques especially in children, particularly in response to several challenges. These include vascular access, the size of the catheters, the minimisation of extracorporeal volumes and the availability of paediatric pumpless systems, dialyzer circuits with low priming volumes and special dialysis membranes that tolerated softer ultrafiltration rates (1–3 ml/min), and the construction of arteriovenous shunts or fistulas in tiny vessels. The first large paediatric chronic HD programs were established in a variety of settings, mainly in the USA (Seattle, San Francisco, Los Angeles, Minneapolis) & Europe (London, Paris).¹⁴ The project of specialized paediatric dialysis centres was introduced in Europe using the multidisciplinary experience and expertise as a basis.³⁵

Another important milestone in the evolution of paediatric HD was the development of Continuous Kidney Replacement Therapy (CRRT). Continuous arteriovenous haemofiltration was developed as an alternative to intermittent HD, especially for critically ill patients and the application in paediatrics began cautiously due to technical challenges such as the need for smaller blood volumes, the need for precise fluid balance and anticoagulation and the need for equipment designed for neonates, infants and small children.^{14,35,36}

The clinical protocols that were developed in order to implement paediatric CRRT, led to its expansion and optimization. After the start of this century, CRRT became the gold standard in paediatric intensive care units (PICUs) for managing acute kidney injury (AKI) and several clinical protocols and innovations were engaged in clinical practice, such as blood priming strategies for neonates and infants, heparin anticoagulation, and the management of fluid overload.^{37,38}

Recent innovations include the use of dialysis machines designed for neonates (e.g.: CARPEDIEM (Cardio-Renal Paediatric Dialysis Emergency Machine), and NIDUS (Newcastle Infant Dialysis and Ultrafiltration System)).³⁸⁻⁴⁰ The research interest currently is focused mainly on:³⁸⁻⁴¹

- Precision medicine approaches
- Use of artificial intelligence with advanced machine algorithms
- Nurse specialization and continuous education
- Use of biocompatible membranes that reduce even more the extracorporeal circuit volumes
- Implementation of therapeutic plans that improve clinical stability and safety
- Establishment of regulations for HD practice in children that standardise clinical practice

The use of hybrid modalities (e.g., SCUF, hybrid PD/CRRT), the development of big databases with clinical data, the use of specific measurement (Kt/V, urea reduction ratio), and integration with extracorporeal life support (ECLS/ECMO) in critically ill children are continually under assessment.⁴² The evolution of HD and CRRT in children reflects advances in technology, innovative clinical practice, advanced clinical knowledge, and implementation of multiprofessional care plans. Current paediatric KRT are now highly specialized, supporting even the smallest and most critically ill children and with fewer complications and adverse effects in comparison with the past, as indicated by decreased morbidity and mortality. Nevertheless, despite these advances' PD seems to be preferred in small children.

Paediatric kidney transplantation

Transplantation is widely regarded as the best paediatric therapeutic option for kidney replacement, leading to lower mortality and morbidity, a significantly better quality of life, and improved growth compared to dialysis. The evolution of paediatric kidney transplantation parallels the broader development of organ transplantation related to significant medical, surgical, and immunological advances. In the early 1950's Murray J. et al. (1954) performed the first successful kidney transplantation between two identical twins.⁴⁵

The field of paediatric kidney transplantation has continued to evolve ever since and in the current era the outcomes are equal to adults, with a current 1-year patient survival of 97% and 5-year graft survival of 89%. Therefore, kidney transplantation is considered the best choice of treatment for children suffering from end stage kidney disease. Globally it is estimated that 1300 kidney transplantations are performed per year.²⁰ Almost a decade later the first immunosuppressive drugs like azathioprine and steroids became available, making transplants between non-identical individuals a reality. Innovations such as microsurgical vascular anastomosis, laparoscopic donor nephrectomy, and en-bloc transplantation of infant kidneys have expanded surgical options.⁴⁶

However, transplantation in children was still rare due to several technical challenges and a lack of paediatric nephrology expertise. For example, the recipients had significantly smaller vessels and anatomy in comparison to the transplanting of adult-sized kidneys and consequently an increased risk of thrombosis of the anastomosed area, graft hypoperfusion and delayed graft function.⁴⁷

The wide use of cyclosporine (70s) rapidly increased the transplant success rates since it was effective in the prevention of rejection. That was also supported with the latter use of mycophenolate mofetil and tacrolimus. MMF was approved for preventing acute rejection following kidney transplantation and often used in combination with cyclosporine and steroids. As a consequence, the survival rates improved significantly and the kidney transplantation era began.⁴⁸

After the start of the millennium, the focus was on better outcomes and individualized care with emphasis on the reduction of immunosuppression toxicity, enhancement of adherence to chronic kidney treatment and a smooth transition to adult care.

Patient selection criteria for paediatric kidney transplantation has evolved significantly, moving towards a more individualized and comprehensive assessment. The Kidney Donor Profile Index (KDPI) is used widely in the adult population to score deceased donor kidneys based on age, health, and cause of death, with lower scores indicating an expected longer function. This Profile Index is not always accurate in predicting graft survival in children and alternative indices may be more effective in this population.⁴⁹

The antibody-based induction therapies, and genomic tools for rejection prediction and personalised medicine were reported with improved outcomes.^{50,51} Currently, pre-emptive kidney transplantation, performed before dialysis begins, is widely recognized as the optimal treatment for end-stage kidney disease in children since it is associated with a lower risk of rejection, longer life expectancy, better quality of life, and lower treatment costs, while avoiding the dietary restrictions and health complications associated with dialysis.⁵²

Nowadays, the survival rates in children are excellent, with many livings into adulthood with their first graft. Despite the remarkable progress, paediatric kidney transplantation is performed globally, but unevenly, with significant disparities in access and outcomes. Long-term issues such as cardiovascular risk, infections, and secondary malignancies remain key concerns. Furthermore, research currently focuses on immune tolerance induction, xenotransplantation and regenerative medicine. In clinical practice, the focus has shifted towards individualized and holistic care with the adoption of steroid-sparing regimens, the implementation and continuous evolution of immunosuppressive protocols and the development of advanced diagnostic and monitoring tools such as non-invasive biomarkers.⁵³

History of KRT in infants

Infants, especially neonates, pose significant clinical challenges due to their small size, immature organ systems, and vulnerability to complications. Understanding the historical barriers provides insight into the development of safer and more effective therapies. The physical constraints of paediatric patients, particularly in neonates and infants, were the primary and most immediate barriers to early KRT adoption, necessitating specialized technological innovation. HD was rarely used in neonates and infants due to the significant risk

of major complications in very young patients, and due to equipment limitations and blood volume concerns.⁵⁴

The history of KRT in infants' dates back to the late 1950's when PD was first used and still stands as the first choice of KRT in infants and neonates. HD use was at that time rare due to access limitations, hypotension, hypothermia and other symptoms related to the total blood volume needed for dialysis filters to work properly. The Cardio-Renal Paediatric Dialysis Emergency Machine (Carpediem - 2012) and the Newcastle Infant Dialysis and Ultrafiltration System (NIDUS-2014) were developed to manage this barrier, designed specifically for the delivery of KRT to infants, by using smaller extracorporeal volumes and improved precision. During the same time period, the use of haemofiltration in small infants started using ultrafiltration devices with a very small extracorporeal volume, in a continuous veno-venous haemofiltration mode (Aquadex machine - 2013).^{55,56}

The introduction of smaller dialysis machines and improved catheter designs, as well as better understanding of fluid management and nutrition in infants with kidney disease, have improved survival rates and outcomes for infants requiring KRT, although challenges such as vascular access and haemodynamic instability persist. The field continues to evolve with ongoing research, development of new technologies, improved standardization of care protocols in neonatal and paediatric intensive care units, and well-coordinated multidisciplinary teams to optimize care for infants requiring KRT.⁵⁷

Transplantation in infants is restricted by size and weight limitations, and many infants require prolonged dialysis while awaiting eligibility, increasing the risk of complications. Advances in dialysis techniques and nutrition have improved pre-transplant outcomes.^{58,59} In addition the complex care of infants and neonates may require a combination of KRT approaches with combined peritoneal and extracorporeal KRT. A continuous approach is preferred in critically ill, haemodynamically unstable patients, while stable patients may do better with intermittent or prolonged intermittent duration.^{60,61}

Despite the present advances, opportunities to enhance our current technology must continue. These include circuits designed to function for multiple days, better vascular access solutions, fluid removal strategies, extended clearance rates, options for programs/clinicians for an approach to setting ultrafiltration rates, and in-line monitoring systems.^{61,62}

Other advancements will come from clinical studies and observations that can guide evidence-based practice. Ongoing research in bioengineered kidneys and regenerative medicine as well as advances in genetics guiding diagnosis and treatment of congenital kidney disorders are on the way. Moreover, optimization of patient selection, strategies to provide better care of all aspects of the KRT prescription, improved anticoagulation strategies, and successful management of the challenges that are unique to infants (ie, nutrition, growth, development), are expected that will improve outcomes in the near future. Ongoing improvements in miniaturization, transplantation, and interdisciplinary care continue to advance the field.^{60,61}

Historical milestones regarding ethical and societal dimensions of KRT in children

The history of KRT in children is not just a narrative of medical scientific progress but is enriched with several complex ethical and societal transitions that shaped its evolution. In its origins, KRT in children was limited not only due to technical or clinical restrictions but due to scarcity and high cost, as well as perceived social worth. The shift in its implementation in children started in the USA with the Public Law 92-603 in 1972 that established the U.S. End-Stage Renal Disease (ESKD) program, mandating Medicare coverage for dialysis patients regardless of age or ability to pay, effectively ending rationing based on such discriminatory criteria. This act ensured that the availability of this life-saving therapy was no longer determined by arbitrary social criteria or economic status, but by medical need, representing a significant societal commitment to healthcare access.¹⁰

Despite the advancements, the provision of chronic dialysis to children sparked ethical debates and scepticism regarding the balance between prolongation of life vs the significant pain, suffering, and developmental challenges. This perspective highlighted the tension between preserving life at all costs and ensuring a quality of life deemed acceptable. As outcomes improved, with advancements in medical and surgical techniques and increased experience in specialized centres, the ethical landscape evolved. The question shifted from whether to treat, to how to make treatment decisions in complex, ambiguous situations.^{10,14,62}

Moreover, the management of paediatric kidney disease in low-resource settings poses multiple challenges such as late diagnosis, access barriers, and unavailability of transplantation as a therapy.⁶³ The quality of life for children undergoing KRT remains a significant ethical and practical concern. Children on long-term dialysis often report a poor quality of life for both children and caregivers. This can often negatively affect the family's functioning and parental anxiety levels, and frequently leads to exhaustion, depression, and high levels of stress, which in turn can negatively impact the child's health outcomes.⁶⁴

In 1984 the National Organ Transplant Act in the USA established the Organ Procurement and Transplantation Network (OPTN), setting policy on equitable organ allocation. It was a major shift toward equity in organ allocation and recognition of paediatric-specific needs in transplant candidacy and prioritization. A wide variance regarding the access and guidelines in national and international level exist. Therefore, it is estimated that only 21% of low- and low-middle income countries are able to provide kidney transplantation services to paediatric patients.⁶⁵

Furthermore, it increased public awareness and raised public sympathy for paediatric KRT units. It was during the early 1990's that hospitals began forming paediatric ethics consult services to handle complex cases, such as withdrawing dialysis in severely disabled children. Ethical concerns arise around transitioning adolescent patients from paediatric to adult care, involving autonomy, continuity of care, and mental health. Consequently, disparities in access to KRT in children persist, raising integrity concerns. Studies indicate a strong association between the incidence of paediatric KRT and social deprivation.⁶⁶

Conclusion

A series of major clinical, scientific, technical developments, and innovations have characterized the history of KRT in children. It has been a difficult journey with a series of clinical, technical, ethical and societal barriers that shaped KRT evolution that led to the sophisticated, patient-centred approaches of today. Continuous improvements in HD and PD equipment have allowed their application even to infants and newborns, with more individualised settings.

More specifically, developments are continually emerging in therapeutic approaches and advances in the efficiency of biocompatible membranes, dialysis solutions, and vascular access. The development of national and international data registries and the introduction of paediatric data analysis continue to move paediatric KRT forward. The use of modern devices with precise control of ultrafiltration by volumetric blood monitoring, and the availability of small-size dialyzers and tubes for infants and small children, represent just some of the main developments in the history of paediatric KRT.

Ethical considerations have played a pivotal role throughout this history. Consequently, regulations, ethical compliance, and caregiver support are also important parameters of individualised kidney care nowadays. During this evolution, children with end-stage or acute kidney disease, show decreased morbidity and mortality. What was once a fatal condition is now a chronic one, shifting the focus from acute mortality to managing lifelong morbidity and the complexities of chronic care. Despite progress, significant challenges remain today, such as the lack of organs for transplantation in children, the management of long-term complications of KRT and the improvement of the quality of life of children who remain on dialysis for a long time.

Today, the emphasis has shifted not only to survival but also to the quality of life, development, psychosocial adaptation and integration of children with kidney disease. Gradually, from fragmented local efforts, we were led to the creation of specialized paediatric nephrology units that offer comprehensive care, including nutritional support, psychological support and preparation for transplantation. All these improvements in paediatric KRT have a direct impact on the quality of life, nutritional status, growth and development for those children who receive any form of KRT therapy.

In summary, the history of KRT in children is a story of triumph of medical science, from the despair of the early decades to an era where end-stage kidney disease in children can be effectively treated, offering hope and a promising future.

References

1. Cirillo L, De Chiara L, Innocenti S, Errichiello C, Romagnani P, Becherucci F. Chronic kidney disease in children: an update. *Clin Kidney J.* 2023;16(10):1600-1611. Published 2023 Apr 24. doi:10.1093/ckj/sfad097.
2. Bonthuis M, Harambat J, Jager KJ, Vidal E. Growth in children on kidney replacement therapy: a review of data from patient registries. *Pediatr Nephrol.* 2021;36(8):2563-2574. doi:10.1007/s00467-021-05099-4.
3. Todisco T, Ubertini GM, Bizzarri C, Loche S, Cappa M. Chronic Kidney Disease and Growth Failure in Children. *Children (Basel).* 2024;11(7):808. Published 2024 Jul 1. doi:10.3390/children11070808
4. Harada R, Hamasaki Y, Okuda Y, Hamada R, Ishikura K. Epidemiology of Paediatric chronic kidney disease/kidney failure: learning from registries and cohort studies. *Pediatr Nephrol.* 2022;37(6):1215-1229. doi:10.1007/s00467-021-05145-1
5. Driollet B, Bayer F, Kwon T, et al. Social Deprivation Is Associated With Lower Access to Pre-emptive Kidney Transplantation and More Urgent-Start Dialysis in the Paediatric Population. *Kidney Int Rep.* 2021;7(4):741-751. Published 2021 Dec 14. doi: 10.1016/j.ekir.2021.12.015
6. Chesney RW. The development of paediatric nephrology. *Pediatr Res.* 2002;52(5):770-778. doi:10.1203/00006450-200211000-00026
7. Maurer E, Neuhaus TJ, Weitz M, Kuehni CE, Laube GF. Paediatric end-stage renal disease and renal replacement therapy in Switzerland: survival and treatment trends over four decades. *Swiss Med Wkly.* 2020;150: w20300. Published 2020 Jul 27. doi:10.4414/smw.2020.20300
8. Carter FH Jr, Aoyama S, Mercer RD, Kolff WJ. Haemodialysis in children; report of five cases. *J Pediatr.* 1957;51(2):125-136. doi:10.1016/s0022-3476(57)80169-3.
9. Cho H. Paediatric Haemodialysis. *Child Kidney Dis* 2020;24:69-74. DOI: <https://doi.org/10.3339/jkspn.2020.24.2.69> ISSN 2384-0242
10. J. S. Cameron (ed.) A history of the treatment of renal failure by dialysis. 1st Edition. Oxford University Press, 2002.
11. Tan SY, Merchant J. Joseph Murray (1919-2012): First transplant surgeon. *Singapore Med J.* 2019;60(4):162-163. doi:10.11622/smedj.2019032
12. Cullis B. Peritoneal dialysis for acute kidney injury: back on the front-line. *Clin Kidney J.* 2022;16(2):210-217. Published 2022 Sep 11. doi:10.1093/ckj/sfac201
13. Fine RN, De Palma JR, Lieberman E, Donnell GN, Gordon A, Maxwell MH. Extended Haemodialysis in children with chronic renal failure. *J Pediatr.* 1968;73(5):706-713. doi:10.1016/s0022-3476(68)80176-3.
14. Garzotto F, Zanella M, Ronco C. The evolution of paediatric continuous renal replacement therapy. *Nephron Clin Pract.* 2014;127(1-4):172-175. doi:10.1159/000363204

15. Besarab A, Frinak S, Margassery S, Wish JB. Haemodialysis Vascular Access: A Historical Perspective on Access Promotion, Barriers, and Lessons for the Future. *Kidney Med.* 2024;6(9):100871. Published 2024 Jul 15. doi: 10.1016/j.xkme.2024.100871
16. Esson ML, Quinn MJ, Hudson EL, Teitelbaum I. Subcutaneously tunneled peritoneal dialysis catheters with delayed externalization: long-term follow-up. *Adv Perit Dial.* 2000; 16:123-128.
17. Parolin M, Ceschia G, Vidal E. New perspectives in Paediatric dialysis technologies: the case for neonates and infants with acute kidney injury. *Pediatr Nephrol.* 2024;39(1):115-123. doi:10.1007/s00467-023-05933-x
18. Azzi JR, Sayegh MH, Mallat SG. Calcineurin inhibitors: 40 years later, can't live without... *J Immunol.* 2013;191(12):5785-5791. doi:10.4049/jimmunol.1390055
19. Kaijansinkko H, Bonthuis M, Jahnukainen K, et al. Clinical outcomes of Paediatric kidney replacement therapy after childhood cancer-An ESPN/ERA Registry study. *Am J Transplant.* 2025;25(4):767-779. doi: 10.1016/j.ajt.2024.11.002
20. Oomen L, Bootsma-Robroeks C, Cornelissen E, de Wall L, Feitz W. Pearls and Pitfalls in Paediatric Kidney Transplantation After 5 Decades. *Front Pediatr.* 2022; 10:856630. Published 2022 Apr 8. doi:10.3389/fped.2022.856630
21. Fuhrman DY, Gist KM, Akcan-Arikan A. Current practices in paediatric continuous kidney replacement therapy: a systematic review-guided multinational modified Delphi consensus study. *Pediatr Nephrol.* 2023;38(8):2817-2826. doi:10.1007/s00467-022-05864-z
22. Raina R, Sethi SK, Nair N, Yap HK. Editorial: Kidney replacement therapy advances in children. *Front Pediatr.* 2022; 10:970884. Published 2022 Jul 19. doi:10.3389/fped.2022.970884.
23. Fraser N, Hussain FK, Connell R, Shenoy MU. Chronic peritoneal dialysis in children. *Int J Nephrol Renovasc Dis.* 2015; 8:125-137. Published 2015 Oct 7. doi:10.2147/IJNRD.S82419
24. Mehrotra R, Devuyst O, Davies SJ, Johnson DW. The Current State of Peritoneal Dialysis. *J Am Soc Nephrol.* 2016;27(11):3238-3252. doi:10.1681/ASN.2016010112
25. Warady BA, Schaefer F & Alexander AR (ed.) *Paediatric Dialysis*. Second Edition. New York Dordrecht Heidelberg London. Springer; 2012.
26. Domenici A, Giuliani A. Automated Peritoneal Dialysis: Patient Perspectives and Outcomes. *Int J Nephrol Renovasc Dis.* 2021; 14:385-392. Published 2021 Oct 7. doi:10.2147/IJNRD.S236553
27. LaPlant MB, Saltzman DA, Segura BJ, Acton RD, Feltis BA, Hess DJ. Peritoneal dialysis catheter placement, outcomes and complications. *Pediatr Surg Int.* 2018;34(11):1239-1244. doi:10.1007/s00383-018-4342-1
28. Struijk DG. Peritoneal Dialysis in Western Countries. *Kidney Dis (Basel).* 2015;1(3):157-164. doi:10.1159/000437286

29. Borzych-Dużałka D, Schaefer F, Warady BA. Targeting optimal PD management in children: what have we learned from the IPPN registry?. *Pediatr Nephrol.* 2021;36(5):1053-1063. doi:10.1007/s00467-020-04598-0
30. Chan EY, Liu MS, Or PC, Ma AL. Outcomes and perception of cloud-based remote patient monitoring in children receiving automated peritoneal dialysis: a prospective study. *Pediatr Nephrol.* 2023;38(7):2171-2178. doi:10.1007/s00467-022-05828-3
31. Mateer FM, Greenman L, Danowski TS. Haemodialysis of the uremic child. *AMA Am J Dis Child.* 1955;89(6):645-655. doi:10.1001/archpedi.1955.02050110785001.
32. Carter FH Jr, Aoyama S, Merver RD, Kolff WJ. Haemodialysis in children; report of five cases. *J Pediatr.* 1957;51(2):125-136. doi:10.1016/s0022-3476(57)80169-3.
33. Walker JG, Garsenstein M, Higgs B, Lawson TR, Shaldon S. The use of haemodialysis in acute renal failure and overhydration in children. *Arch Dis Child.* 1962;37(196):578-583. doi:10.1136/adc.37.196.578
34. Featherstone PJ, Ball CM. A brief history of haemodialysis and continuous renal replacement therapy. *Anaesth Intensive Care.* 2019;47(3):220-222. doi:10.1177/0310057X19853391
35. Ehrich J, Tasic V, Edvardsson VO, et al. Achievements, priorities and strategies in Paediatric nephrology in Europe: need for unifying approaches or acceptance of differences?. *Front Pediatr.* 2024; 12:1458003. Published 2024 Dec 20. doi:10.3389/fped.2024.1458003
36. Ronco C, Ricci Z. Paediatric continuous renal replacement: 20 years later. *Intensive Care Med.* 2015 Jun;41(6):985-93. doi: 10.1007/s00134-015-3807-0. Epub 2015 Apr 17. PMID: 25894625.
37. Cortina G, Daverio M, Demirkol D, Chanchlani R, Deep A. Continuous renal replacement therapy in neonates and children: what does the Paediatrician need to know? An overview from the Critical Care Nephrology Section of the European Society of Paediatric and Neonatal Intensive Care (ESPNIC). *Eur J Pediatr.* 2024;183(2):529-541. doi:10.1007/s00431-023-05318-0
38. Sanderson KR, Harshman LA. Renal replacement therapies for infants and children in the ICU. *Curr Opin Pediatr.* 2020;32(3):360-366. doi:10.1097/MOP.0000000000000894
39. Coulthard MG, Crosier J, Griffiths C, et al. Haemodialysing babies weighing <8 kg with the Newcastle infant dialysis and ultrafiltration system (Nidus): comparison with peritoneal and conventional haemodialysis. *Pediatr Nephrol.* 2014;29(10):1873-1881. doi:10.1007/s00467-014-2923-3
40. Regiroli G, Loi B, Pezza L, et al. Continuous Venovenous Hemofiltration Performed by Neonatologists With Cardio-Renal Paediatric Dialysis Emergency Machine to Treat Fluid Overload During Multiple Organ Dysfunction Syndrome: A Case Series. *Pediatr Crit Care Med.* 2023;24(4): e196-e201. doi:10.1097/PCC.0000000000003177

41. Thadani S, Wu TC, Wu DTY, et al. Machine Learning-Based Prediction Model for ICU Mortality After Continuous Renal Replacement Therapy Initiation in Children. *Crit Care Explor.* 2024;6(12): e1188. Published 2024 Dec 17. doi:10.1097/CCE.0000000000001188
42. Totapally A, Bridges BC, Selewski DT, Zivick EE. Managing the kidney - The role of continuous renal replacement therapy in neonatal and Paediatric ECMO. *Semin Pediatr Surg.* 2023;32(4):151332. doi: 10.1016/j.sempedsurg.2023.151332
43. Suttles TL, Poe J, Neumayr TM, Said AS. In vivo measurement of Paediatric extracorporeal oxygenator insensible losses; a single center pilot study. *Front Pediatr.* 2024; 12:1346096. Published 2024 Feb 29. doi: 10.3389/fped.2024.1346096
44. Wasik HL, Harvey E, Neu A. Peritoneal dialysis in children, what's different: Your questions answered. *Perit Dial Int.* 2024;44(5):365-373. doi:10.1177/08968608241273633
45. Murray JE, Merrill JP, Harrison JH. Renal homotransplantation in identical twins. *Surg Forum.* 1954;5:432-436.
46. Riella J, Tabbara MM, Abreu P, Gonzalez J, Ciancio G, Figueiro JM. Complex Vascular Reconstruction of an En Bloc Paediatric Kidney Damaged during Organ Procurement. *Case Rep Transplant.* 2022;2022:3242809. Published 2022 Jun 16. doi:10.1155/2022/3242809
47. Cho MH. Paediatric kidney transplantation is different from adult kidney transplantation [published correction appears in *Korean J Pediatr.* 2018;61(8):264. doi: 10.3345/kjp.2018.61.8.264.]. *Korean J Pediatr.* 2018;61(7):205-209. doi:10.3345/kjp.2018.61.7.205
48. Fine RN. Evolution of Paediatric renal transplantation: A 20-year experience. *Transplant Proc.* 1983;15(1 Pt 2):1380-1382.
49. Kizilbash SJ, Evans MD, Chinnakotla S, Chavers BM. Use of expanded-criteria donors and > 85 KDPI kidneys for Paediatric kidney transplantation in the United States. *Am J Transplant.* 2021;21(3):1160-1170. doi:10.1111/ajt.16162
50. Dharnidharka VR, Fiorina P, Harmon WE. Kidney transplantation in children. *N Engl J Med.* 2014;371(6):549-558. doi:10.1056/NEJMra1314376
51. Smith JM, Martz KL, Blydt-Hansen TD. Paediatric kidney transplantation: 2020 Clinical Trials and Challenges. *Am J Transplant.* 2020;20(5):1205-1212. doi:10.1111/ajt.15739
52. Prezelin-Reydit M, Madden I, Macher MA, et al. Preemptive Kidney Transplantation Is Associated With Transplantation Outcomes in Children: Results From the French Kidney Replacement Therapy Registry. *Transplantation.* 2022;106(2):401-411. doi:10.1097/TP.0000000000003757
53. Weiss DA, Tullius SG. Paediatric kidney transplantation: an overview and update. *Nat Rev Nephrol.* 2020;16(10):573-585. doi:10.1038/s41581-020-0301-z

54. Pollack S, Eisenstein I, Tarabeih M, Shasha-Lavski H, Magen D, Zelikovic I. Long-term Haemodialysis therapy in neonates and infants with end-stage renal disease: a 16-year experience and outcome. *Pediatr Nephrol.* 2016;31(2):305-313. doi:10.1007/s00467-015-3214-3
55. Ronco C, Garzotto F, Brendolan A, et al. Continuous renal replacement therapy in neonates and small infants: development and first-in-human use of a miniaturized machine (CARPEDIEM). *Lancet.* 2014;383(9931):1807-1813. doi:10.1016/S0140-6736(14)60799-9
56. Coulthard MG, Crosier J, Griffiths C, et al. A new dialysis and ultrafiltration system for infants weighing under 8 kg: safety and efficacy. *Kidney Int.* 2014;86(5):1011-1017. doi:10.1038/ki.2014.162
57. Ariceta G, Bakkaloglu SA, Fraga M, et al. The evolving role of Paediatric nephrology. *Pediatr Nephrol.* 2020;35(9):1575-1588. doi:10.1007/s00467-020-04557-9
58. Vondrak K, Krmar RT, Klaus G, et al. Paediatric kidney transplantation in Europe: need for a harmonized approach. *Front Pediatr.* 2024;12:1432027. doi:10.3389/fped.2024.1432027.
59. Sgambat K, Moudgil A. Long-term outcomes of Paediatric kidney transplantation. *Clin J Am Soc Nephrol.* 2021;16(6):869-877. doi:10.2215/CJN.13631020
60. Askenazi D, Goldstein SL, Devarajan P, et al. Survey of continuous kidney replacement therapy practices in Paediatric intensive care units: the CARPEDIEM international study. *JAMA Netw Open.* 2023;6(1): e2253252. doi:10.1001/jamanetworkopen.2022.53252.
61. Slagle C, Askenazi D, Starr M. Recent Advances in Kidney Replacement Therapy in Infants: A Review. *Am J Kidney Dis.* 2024;83(4):519-530. doi: 10.1053/j.ajkd.2023.10.012
62. Alexander, S.R., Cochat, P. (2021). Notes on the History of Dialysis Therapy in Children. In: Warady, B.A., Alexander, S.R., Schaefer, F. (eds) *Paediatric Dialysis*. Springer, Cham. https://doi.org/10.1007/978-3-030-66861-7_1.
63. McCulloch M, Luyckx VA, Cullis B, et al. Challenges of access to kidney care for children in low-resource settings. *Nat Rev Nephrol.* 2021;17(1):33-45. doi:10.1038/s41581-020-00338-7
64. Wightman A. Caregiver burden in Paediatric dialysis. *Pediatr Nephrol.* 2020;35(9):1575-1583. doi:10.1007/s00467-019-04332-5
65. Iyengar A, McCulloch MI. Paediatric kidney transplantation in under-resourced regions-a panoramic view. *Pediatr Nephrol.* 2022;37(4):745-755. doi:10.1007/s00467-021-05070-3
66. Linder E, Burguet A, Nobili F, Vieux R. Neonatal renal replacement therapy: An ethical reflection for a crucial decision. *Arch Pediatr.* 2018;25(6):371-377. doi: 10.1016/j.arcped.2018.06.002

Chapter 2

Acute kidney injury in the paediatric population

Learning objectives

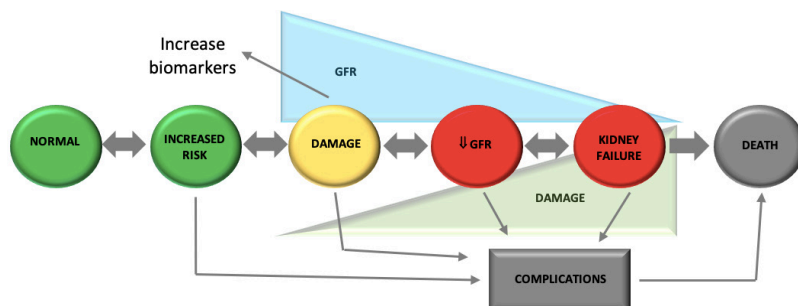
- To define acute kidney injury and explain its pathophysiological mechanisms in the paediatric population.
- To recognize the clinical significance and potential long-term consequences of acute kidney injury in children, particularly in critical care settings.
- To identify the importance of early diagnosis and appropriate management strategies to prevent progression to chronic kidney disease in paediatric patients with AKI.

Introduction

The term acute kidney injury (AKI) refers to the loss of kidney function, which results in a reduction of the glomerular filtration rate, retention of urea or other waste products, and/or dysregulation of the extracellular volume and electrolytes. This term, introduced several years ago to replace the more generic concept of acute kidney failure (ARF), aims to emphasize how kidney damage precedes the simple decline in GFR, and thus represents only one stage of AKI, particularly one of the more advanced stages (Fig. 1).¹

The increasing recognition of AKI as an early form of kidney injury that can be reversible if managed promptly is essential. The impact of AKI is profound, especially in critical care settings, where it is a likely common and life-threatening complication. Early diagnosis and management are crucial for improving patient outcomes and reducing long-term sequelae, such as the progression to chronic kidney disease (CKD).² The ability to identify AKI early, differentiate between its causes, and intervene effectively can be the difference between recovery and more severe, irreversible kidney damage.

Figure 1. AKI timeline.



Definition of AKI

Historically, AKI lacked a standardized definition, which led to confusion and difficulties in comparing study results. In the years before the 2000s, different studies used various criteria to define AKI, such as absolute creatinine thresholds, changes in urine output, or the need for dialysis.³ However, these thresholds were not universally agreed upon, making it challenging to draw consistent conclusions from the literature. In the early 2000s, more structured definitions of AKI were proposed. The first of these was the pRIFLE criteria, introduced for the paediatric population, which categorized AKI based on severity (Risk, Injury, Failure) and its potential for progression to CKD.⁴ This was followed by the Acute Kidney Injury Network (AKIN) criteria, introduced in 2005.⁵ These definitions sought to standardize the diagnosis and staging of AKI. In 2012, the Kidney Disease Improving Global Outcomes (KDIGO) guidelines harmonized these criteria, providing a uniform system for diagnosing and staging AKI.²

AKI is now defined based on two main factors: the change in serum creatinine relative to the baseline and the duration of oliguria (low urine output).⁶ According to KDIGO, an increase in creatinine of at least 0.3 mg/dL within 48 hours, or an increase in creatinine to 1.5 times the baseline value, defines the condition. Oliguria is defined as urine output of less than 0.5 mL/kg per hour for at least six hours. (Table 1)

Table 1. KDIGO Definition and Criteria for Staging AKI in Children.

Stage	Serum Creatinine Increase (SCr)	Diuresis
I	1.5-1.9 times baseline or increase ≥ 0.3 mg/dL (≥ 26 μ mol/L)	<0.5 mL/kg/h for 6-12 hours
II	2.0-2.9 times baseline	<0.5 mL/kg/h for 12-24 hours
III	≥ 3.0 times baseline or increase ≥ 4 mg/dL (≥ 354 μ mol/L) or Creatinine clearance <35 mL/min/1.73m ²	<0.5 mL/kg/h for >24 hours or <0.3 mL/kg/h for >12 hours

Creatinine and urine output are thus, to date, the only two validated parameters for the definition and staging of AKI. However, creatinine has several limitations as a marker of kidney injury, yet remains the only one, alongside diuresis, for defining AKI. This is because it is a long-established, widely used marker, with which healthcare personnel are familiar, inexpensive, and available almost everywhere. These aspects make creatinine an indispensable marker, but it presents several limitations, the most significant being that it is a late marker, registering a change only after damage has occurred. In fact, creatinine can take 48-72 hours to increase after a kidney insult.⁷ Additionally, it is influenced by various conditions such as age, sex, ethnicity, muscle mass, nutritional status, and any concomitant diseases or drug therapies. Furthermore, paediatric patients have a high functional reserve, meaning that the increase in creatinine occurs with a greater loss of nephron mass than in adults and is typically greater than 50%, i.e., when more than half of the kidney functional units show dysfunction.⁸

As discussed, the definition of AKI, based on creatinine and diuresis, has inherent limitations, especially since many patients do not have a baseline creatinine measurement before hospitalization. Furthermore, the normal reference values for creatinine are measured in a steady-state situation, which is very different from, for example, the condition of a patient hospitalized in an intensive care unit. Creatinine and diuresis are therefore limited parameters for AKI, as they describe functional and not structural damage at the kidney level.

In light of this variability, new kidney injury biomarkers have been studied and are currently under validation to assess their precise role in clinical practice. These biomarkers are molecules produced

by the kidney in the event of tissue damage, which rise and return to baseline more rapidly than creatinine, potentially revealing the ability to identify AKI earlier. Among these molecules, the most frequently studied to date is NGAL (neutrophil gelatinase-associated lipocalin), a 25 kDa protein that is abundant in kidney tubular cells and produced in greater amounts under stress or injury conditions. Other kidney injury biomarkers currently explored in clinical research include KIM-1 (Kidney Injury Molecule 1), TIMP-2 (Tissue inhibitor of metalloproteinase 2), IGFBP7 (insulin-like growth factor binding protein 7), and CCL14 (Urinary C-C motif chemokine ligand 14).⁹ Among these, NGAL is certainly the most studied and used and could potentially allow for serial monitoring of kidney injury. Early use in critically ill patients at risk of AKI is particularly promising.¹⁰

Epidemiology

AKI is a significant concern in paediatric patients, particularly those in paediatric intensive care units (PICU). Studies have shown that approximately 30% of children admitted to PICU develop AKI during their hospital stay. This rate is more than five times higher than in children admitted to general wards.^{6,11} The development of AKI in critically ill patients is associated with a higher risk of morbidity, increased need for intensive care, and a significantly higher mortality rate. AKI has been identified as an independent risk factor for increased mortality in critically ill children.¹²

In the context of PICU, the epidemiology of AKI is particularly concerning because the condition is often associated with other severe complications. Children in PICU who develop AKI typically require more intensive monitoring and interventions, increasing the burden on healthcare resources. Moreover, these children have a higher risk of developing long-term complications, such as CKD and cardiovascular issues.¹³

The prevalence of AKI in critically ill paediatric patients highlights the importance of early recognition and intervention. Clinicians must remain vigilant in identifying at-risk patients and promptly addressing the underlying causes to prevent the progression of kidney dysfunction and mitigate the associated risks.

Pathophysiology and classification

From a pathophysiological standpoint, AKI can be classified into three types: prerenal (functional), intrinsic renal, and postrenal, depending on the level at which the insult occurs.

Prerenal AKI is a dysfunction caused by reduced kidney perfusion secondary to hypotension or hypovolemia without permanent structural changes in the kidney parenchyma, at least in the early stages, which may lead to a reduction in oxygen and nutrient delivery to the kidney. Kidney flow autoregulation tends to preserve the glomerular filtration rate by increasing kidney sympathetic tone, activating the renin-angiotensin-aldosterone system, and other hormones like vasopressin that enhance sodium and water reabsorption in the proximal tubule, thereby decreasing sodium and water loss and maintaining intravascular volume and blood pressure.¹⁴ Interventions to increase intravascular volume, such as fluid administration, can be effective in resolving the issue. However, if prerenal AKI is unrecognized or not resolved, it progresses to acute tubular necrosis (ATN), which can be considered a form of intrinsic renal AKI. This occurs when the tubular epithelial cells undergo necrosis, shedding and obstructing the lumen, resulting in urinary stasis, increased pressure at this level, which then affects the glomerular function, leading to structural damage at the cortical level.¹⁵

Prerenal AKI is the most common type in PICU, accounting for 30-60% of AKI episodes. Risk factors for the development of this type of AKI include reduced intravascular volume, impaired cardiac function, or peripheral vasodilation. Reduced intravascular volume may result from dehydration, hemorrhage, burns, shock, or nephrotic syndrome, while peripheral vasodilation is associated with the need for vasoactive drugs, sepsis, or anaphylaxis.

Intrinsic renal AKI occurs when there is damage to the parenchyma, either as ATN or as glomerular, vascular, or interstitial disease, such as infection or drug-induced damage. Intrinsic renal AKI accounts for approximately 20-40% of AKI cases.¹⁶ Finally, postrenal AKI is caused by urinary flow obstruction, with causes including renal stones, tumors, and congenital anomalies like posterior urethral valves. Functional obstructions, such as those from neurogenic bladder, can also occur. Postrenal AKI is a less common occurrence, representing 1-10% of AKI causes in paediatric patients.¹⁷

Risk factors for AKI

Several factors increase the risk of developing AKI, especially in critically ill patients. These risk factors can be classified into patient-related factors and clinical factors. Patient-related factors include underlying medical conditions such as congenital heart disease, prematurity, CKD, and organ transplantation. Clinical factors include infections or sepsis, mechanical ventilation, and the use of nephrotoxic drugs. Additionally, patients receiving extracorporeal treatments such as cardiopulmonary bypass or undergoing major surgeries are at increased risk for AKI.¹⁸

It is essential to identify high-risk patients early to minimize the chances of AKI developing and to implement preventive measures. For example, nephrotoxic drugs, such as aminoglycosides, nonsteroidal anti-inflammatory drugs (NSAIDs), and certain antibiotics, should be carefully monitored in critically ill patients to prevent kidney damage.

Management of AKI

Currently, there is no effective and specific treatment for AKI, so management of this syndrome is based on a fundamental principle: identifying and promptly correcting the triggering cause to prevent the progression of kidney damage and reduce systemic complications. Since AKI is a syndrome rather than a single disease, management requires a multifactorial and often multidisciplinary approach involving nephrologists, intensivists, and other specialists.

The primary objective is to remove or treat the etiological factor, when possible. In prerenal AKI, it is crucial to restore renal perfusion by correcting volume status (e.g., administering crystalloids) and improving hemodynamics, often using vasoactive drugs in critically ill patients. In postrenal AKI, quick intervention is required to remove the obstruction, such as with bladder catheterization, ureteral stents, or nephrostomy placement. In renal AKI, it may be necessary to treat underlying infections or inflammations, discontinue nephrotoxic drugs, or in some cases, perform a renal biopsy to identify glomerular or interstitial lesions.¹⁹

A key aspect remains careful monitoring of the fluid balance, as most AKI cases are functional. In some stages of AKI, oliguria or anuria are present, and fluid accumulation can cause pulmonary edema, worsening the outcome. In other cases, particularly during the recovery

phase, polyuria may occur with excessive sodium, potassium, and fluid loss, requiring reintegration. Therefore, it is essential to monitor and correct any electrolyte imbalances, particularly hyperkalemia, hypo- or hypernatremia, and hypocalcemia, along with careful evaluation of acid-base metabolism.²⁰

Another important aspect is to suspend or reduce potentially nephrotoxic drugs, such as non-steroidal anti-inflammatory drugs, aminoglycosides, iodinated contrast agents (when possible), and renin-angiotensin system inhibitors in selected cases. Furthermore, the dosage of drugs should be adjusted based on the remaining renal function to avoid accumulation and systemic toxicity.

In severe cases, KRT through dialysis techniques may be required.²¹

Outcomes

The prognosis of AKI varies significantly based on factors such as the underlying cause, the severity of the damage, and the pre-existing clinical conditions of the patient. Hospital mortality associated with AKI in critically ill patients can reach 23%. However, the increasing number of cases has led to a rise in the total number of deaths related to AKI.²²

A crucial aspect is the risk of progression to CKD. Patients who have experienced an episode of AKI have a 2.15 times greater risk of developing CKD over five years compared to those without a history of AKI.²³ Furthermore, the incidence of AKI requiring renal replacement therapy is increasing. In the United States, the cases have risen, with a 10% annual increase. Despite a slight reduction in in-hospital mortality rates in these patients, the absolute number of deaths has more than doubled in recent years.²⁴

Among the most common acute complications of AKI is hyperkalemia, increasing the risk of potentially fatal arrhythmias.

Finally, AKI represents, even in paediatric patients, a significant risk factor for major cardiovascular events. Patients with a history of AKI have an increased risk of developing conditions such as myocardial infarction, heart failure, and stroke in the months and years following the acute episode.²³

Given the severity of potential complications, it is essential to implement long-term monitoring of patients who have suffered from AKI. This includes regular checks on kidney function and timely interventions to prevent or slow the progression toward CKD or other associated conditions.

Conclusion

AKI remains a significant challenge in critically ill paediatric patients, particularly those in intensive care settings. The multifactorial nature of AKI, with its varied causes, clinical presentations, and potential for severe long-term consequences, necessitates a vigilant approach to early detection and management. Prompt recognition of AKI is crucial, as it allows for timely intervention that can prevent further kidney damage, mitigate systemic complications, and improve overall outcomes. While creatinine and diuresis remain essential markers in defining and staging AKI, emerging biomarkers hold great promise in identifying kidney injury at earlier stages, before significant damage occurs. Early recognition not only aids in addressing the underlying causes—whether prerenal, intrinsic, or postrenal—but also enhances the potential for recovery and reduces the risk of progression to CKD. Given the high morbidity, mortality, and long-term implications associated with AKI in paediatric patients, a proactive, multidisciplinary approach to monitoring kidney function is essential. Ultimately, early detection and intervention are key to improving the prognosis of paediatric patients affected by AKI, underscoring the importance of continued research and clinical vigilance in this field.

References

1. Kidney Disease: Improving Global Outcomes (KDIGO). (2012). Clinical practice guideline for acute kidney injury. *Kidney International*, 2(4), 1-138.
2. Lakhmir S Chawla, Paul W Eggers, Robert A Star, Paul L Kimmel. Acute kidney injury and chronic kidney disease as interconnected syndromes. *N Engl J Med* 2014 Jul 3;371(1):58-66
3. Ravindra L Mehta, John A Kellum, Sudhir V Shah, Bruce A Molitoris, Claudio Ronco, David G Warnock et al. Acute Kidney Injury Network: report of an initiative to improve outcomes in acute kidney injury. *Crit Care* 2007;11(2):R31
4. Yadira A Soler, Mariely Nieves-Plaza, Mónica Prieto, Ricardo García-De Jesús, Marta Suárez-Rivera. pRIFLE (Paediatric Risk, Injury, Failure, Loss, End Stage Renal Disease) score identifies Acute Kidney Injury and predicts mortality in critically ill children: a prospective study. *Pediatr Crit Care Med*. 2013 May;14(4):e189–e195
5. José António Lopes, Sofia Jorge. The RIFLE and AKIN classifications for acute kidney injury: a critical and comprehensive review. *Clin Kidney J*. 2012 Jan 1;6(1):8–14
6. Ahmad Kaddourah, Rajit K Basu, Sean M Bagshaw, Stuart L Goldstein. Epidemiology of acute kidney injury in critically ill children and young adults. *N Engl J Med*. 2017 Jan 5;376(1):11-20.
7. Edward D Siew, Michael E Matheny. Choice of Reference Serum Creatinine in Defining Acute Kidney Injury. *Nephron* 2015;131(2):107-12
8. Dixon Thomas, Seeba Zachariah, Abdelgadir Elamin Eltom Elamin, Ahmed Luay Osman Hashim. Limitations of serum creatinine as a marker of renal function. *Sch. Acad. J. Pharm.*, 2017; 6(5): 168-170.
9. Marlies Ostermann, Matthieu Legrand, Melanie Meersch, Nattachai Srisawat, Alexander Zarbock, John A. Kellum. Biomarkers in acute kidney injury. *Annals of Intensive Care* 14, Article number:145 (2024)
10. Stuart L Goldstein, Kelli A Krallman, Alexandra Schmerge, Lynn Dill, Bradley Gerhardt, Praneeta Chodaparavu et al. Urinary neutrophil gelatinase-associated lipocalin rules out nephrotoxic acute kidney injury in children. *Pediatr Nephrol*. 2021 Jul;36(7):1915-1921
11. Lillian Mauroner, John A Kellum, Andrew S Levey, Cassandra Formeck, Dana Y Fuhrman. The Incidence and Outcomes of Acute Kidney Disease in Critically Ill Children. *Kidney360*. 2025 Jan 10
12. Jitendra Meena, Georgie Mathew, Jogender Kumar, Rahul Chanchlani. Incidence of Acute Kidney Injury in Hospitalized Children: A Meta-analysis. *Paediatric s* 2023 Feb 1;151(2)
13. Cal H Robinson, Nivethika Jeyakumar, Bin Luo, Ron Wald, Amit X Garg, Danielle M Nash et al. Long-Term Kidney Outcomes Following Dialysis-Treated Childhood Acute Kidney Injury: A Population-Based Cohort Study. *J Am Soc Nephrol* 2021 Aug;32(8):2005-2019
14. Marlies Ostermann, Kathleen Liu. Pathophysiology of AKI. *Best Pract Res Clin Anaesthesiol* 2017 Sep;31(3):305-314

15. Rinaldo Bellomo, Claudio Ronco, Ravindra L. Mehta, Pierre Asfar, Julie Boisramé-Elms, Michael Darmon, Jean-Luc Diehl et al. Acute kidney injury in the ICU: from injury to recovery: reports from the 5th Paris International Conference. *Annals of Intensive Care* 7, Article number: 49 (2017)
16. Simon Lines A, Andrew Lewington. Acute kidney injury. *Clinical Medicine* Volume 9, Issue 3 June 2009, Pages 273-277
17. Jonathan S Chávez-Iñiguez, Goretty J Navarro-Gallardo, Ramón Medina-González, Luz Alcantar-Vallín, Guillermo García-García. Acute Kidney Injury Caused by Obstructive Nephropathy. *Int J Nephrol*. 2020 Nov 29;2020:8846622
18. Shweta Naik, Jyoti Sharma, Rameshwor Yengkom, Vijay Kalrao, Atul Mulay. Acute kidney injury in critically ill children: Risk factors and outcomes. *Indian J Crit Care Med*. 2014 Mar;18(3):129-133
19. Rupesh Raina, Abigail M. Chauvin, Timothy Bunchman, David Askenazi, Akash Deep, Michael J. Ensley et al. Treatment of AKI in developing and developed countries: An international survey of paediatric dialysis modalities. *PLoS ONE* 12(5): e0178233
20. Raghavan Murugan, John A. Kellum. Fluid balance and outcome in acute kidney injury: is fluid really the best medicine? *Crit Care Med*. 2012 June ; 40(6): 1970-1972
21. Sidharth K. Sethi, Timothy Bunchman, Ronith Chakraborty, Rupesh Raina. Paediatric acute kidney injury: new advances in the last decade. *Kidney Res Clin Pract* 2021;40(1):40-51
22. Eric A J Hoste, Sean M Bagshaw, Rinaldo Bellomo, Cynthia M Cely, Roos Colman, Dinna N Cruz, et al. Epidemiology of acute kidney injury in critically ill patients: the multinational AKI-EPI study. *Intensive Care Med* 2015 Aug;41(8):1411-23
23. John A. Kellum, Paola Romagnani, Gloria Ashuntantang, Claudio Ronco, Alexander Zarbock, Hans-Joachim Anders. Acute kidney injury. *Nature Reviews Disease Primers*, Article number:52 (2021)
24. Oleksa Rewa, Sean M. Bagshaw. Acute kidney injury—epidemiology, outcomes and economics. *Nature Reviews Nephrology* 10,193-207 (2014)

Chapter 3

Chronic kidney disease in the paediatric population

Learning objectives

- To explain chronic kidney disease and its epidemiology in the paediatric population.
- To relate chronic kidney disease to its aetiology and pathophysiology.
- To evaluate the child with chronic kidney disease.
- To relate chronic kidney disease to its signs and symptoms.

Introduction

Chronic Kidney Disease (CKD) in the paediatric population is a significant public health concern, characterised by a gradual decline in kidney function over time. The prevalence of CKD among children is estimated to range from 15 to 74.7 per million.¹ An increasing number of premature and low-birth-weight infants, presumed to have a lower nephron quantity, along with a rising prevalence of obesity in children, is predicted to further increase the number of children with CKD.^{2,3} However, with advancements in the healthcare field, improvements in treatment and survival rates can be achieved.¹

Chronic kidney disease in the paediatric population

Description and Grading

CKD is defined in children as the presence of functional kidney damage, including proteinuria, albuminuria, renal tubular abnormalities, histological abnormalities, or pathological abnormalities detected through imaging, in the kidneys for more than three months, or a GFR of less than 60 mL/min/1.73m² for more than three months, regardless of the presence of functional kidney damage.⁴ When the GFR is less than 90 mL/min/1.73 m², it may be considered 'low' in children and adolescents over the age of two.^{4,5} GFR is the sum of the filtration rates of all functioning nephrons in the kidneys. It represents the volume of blood filtered, measured in millilitres per 1.73 square metres per minute. The serum creatinine level is an endogenous marker of kidney function; however, it is influenced by factors such as muscle mass, age, and sex.^{5,6} In children under the age of two, GFR values are below the levels considered physiologically normal.

Additionally, the definition of CKD differs for newborns and infants under three months due to the timeframe specified in the current classification.⁴

The normal glomerular filtration rate limits at different ages are indicated in Table 1.⁷

For this reason, other methods are used instead of GFR in children under the age of two. The most commonly used method is the Schwartz formula. In addition, creatinine clearance measured in a correctly and appropriately collected 24-hour urine sample is another frequently used method for calculating GFR.^{2,3,6} When measuring GFR in children with low muscle mass, a cystatin C-based formula is recommended.^{2,5}

Grading is necessary to determine the progression and complications of CKD. It is a crucial aspect of managing both the patient and the disease. In this context, the KDIGO Evaluation and Management of CKD guideline classifies CKD into five stages (Table 2).^{4,8}

Table 1. Normal glomerular filtration rate limit at different ages.⁷

Age	Sex	Normal GFR
1 week	Males and females	41 ± 15 mL/min/1.73 m ²
2-8 week	Males and females	66 ± 25 mL/min/1.73 m ²
>8 week	Males and females	96 ± 22 mL/min/1.73 m ²
2-12 year	Males and females	133 ± 27 mL/min/1.73 m ²
13-21 year	Males	140 ± 30 mL/min/1.73 m ²
13-21 year	Females	126 ± 22 mL/min/1.73 m ²

Table 2. Grading in CKD.⁴

GFR categories	Description	GFR range
Grade 1	Normal or high	≥90
Grade 2	Mildly decreased	60–89
Grade 3a	Mildly to moderately decreased	45–59
Grade 3b	Moderately to severely decreased	30–44
Grade 4	Severely decreased	15–29
Grade 5	Kidney disease (KRT is required)	<15

GFR, glomerular filtration rate.

Epidemiology of CKD in the Paediatric Population

The prevalence of CKD in children is relatively low compared to adults, yet it remains a critical issue due to its long-term implications. The precise incidence varies by region, though estimates suggest that 1–2 per 1,000,000 children progress to end-stage kidney disease (ESKD) each year in developed countries.^{9,10} Some studies report figures as high as 9 per million in certain developed countries. This incidence is influenced by various factors, including age and underlying health conditions. In general, the incidence of CKD among children under the age of 16 has been reported to range from 5 to 10 per million.^{11,12} These numbers are concerning, particularly in developing countries where access to healthcare and early diagnosis may be limited.

Aetiology of CKD in the Paediatric Population

The aetiology of CKD in the paediatric population is multifaceted, involving genetic predispositions, congenital anomalies, and a range of aetiological processes that contribute to kidney damage and systemic complications.⁴

Congenital Anomalies and Genetic Factors

Epidemiological studies indicate that congenital anomalies of the kidneys and urinary tract (CAKUT) are the leading cause of CKD in children.^{2,4,11,12} This can disrupt normal kidney development and function, leading to impaired GFR and subsequent kidney damage.² And it accounts for approximately 50% of cases in the paediatric population.^{11,13,14}

The pathophysiology of CAKUT is complex and multifactorial, involving genetic, epigenetic, and environmental factors that disrupt normal kidney and urinary tract development.

Approximately 30% of paediatric CKD cases are attributed to genetic kidney diseases, which often lead to rapid progression to ESKD.^{11,15} Mutations in various genes have been implicated in these anomalies, including those affecting nephron development and urinary tract formation.^{2,13} For instance, mutations in genes associated with syndromic conditions, such as VACTERL association, have been implicated in the development of kidney anomalies.¹⁴ Additionally, mutations in the *PBX1* gene have been associated with syndromic forms of CAKUT, leading to bilateral kidney agenesis and other

kidney developmental defects.¹⁶ Studies have identified missense variants in *GFRA1* and *NPNT* that correlate with kidney agenesis, highlighting the genetic underpinnings of these conditions.¹⁷ Other genetic conditions, such as steroid-resistant nephrotic syndrome, Alport syndrome, and kidney cystic diseases, contribute to the burden of CKD in children.^{11,13} Prenatal exposures, such as maternal diabetes, obesity, and low birth weight, have been linked to an increased incidence of these CAKUT-related anomalies.¹⁸

Acquired Causes of CKD

Acquired causes of CKD in children include a range of conditions, such as glomerulonephritis, urinary tract infections, and complications arising from systemic diseases. Glomerulonephritis, particularly post-infectious and autoimmune forms, is a significant contributor to CKD in the paediatric population.^{2,11}

Systemic lupus erythematosus is another critical condition, with kidney involvement occurring in approximately 75% of paediatric cases, leading to significant morbidity.¹⁹

Moreover, children who undergo haematopoietic stem cell transplantation (HSCT) are at an increased risk of developing CKD due to factors such as total body irradiation and the use of nephrotoxic immunosuppressive agents.^{20,21}

The underlying reasons include inflammation, oxidative stress, and haemodynamic changes. Chronic inflammation contributes to kidney injury and fibrosis.²²

Additionally, oxidative stress has been implicated in the progression of kidney failure, as it can lead to cellular damage and exacerbate kidney injury.²²

Type 1 diabetes and type 2 diabetes, which have become more prevalent with the rise in juvenile obesity in recent years, pose a risk for CKD.⁷ Microalbuminuria is tested for the prediction and detection of diabetic nephropathy in paediatric diabetes. It has been shown that the prevalence of microalbuminuria is significantly higher (three times) in patients with type 2 diabetes (68%) compared to those with type 1 diabetes (24%).²³ In patients with diabetic kidney disease, there are significant alterations in the tubules, as well as in the interstitium and glomerulus.⁷ These findings indicate that diabetic nephropathy has progressed to kidney failure.

Table 3 summarises the common causes of CKD in childhood.^{3,11,24}

Table 3. Common Causes of CKD in childhood.^{3,11,24}

• Congenital Anomalies of the Kidneys and Urinary Tract (CAKUT) - Aplasia, hypoplasia, and dysplasia - Obstructive uropathy - Reflux nephropathy - Prune belly syndrome
• Focal segmental glomerulosclerosis
• Polycystic kidney disease
• Chronic glomerulonephritis
• Medullary cystic kidney disease
• Haemolytic uraemic syndrome
• Congenital nephrotic syndrome
• Familial nephritis/Alport syndrome
• Cystinosis
• Chronic interstitial nephritis

Pathophysiology of CKD in the paediatric population

The pathophysiological mechanisms of paediatric CKD are multifaceted, involving congenital anomalies, acquired diseases, systemic infections, and haemodynamic changes. Regardless of the aetiology of CKD, certain mechanisms are believed to play a role in its pathophysiology. When glomerular damage begins, there is an increase in glomerular blood flow rate in healthy nephrons. Kidney function is temporarily preserved through compensatory hyperfiltration. However, the increase in hydrostatic pressure and the filtration of toxic substances lead to damage in healthy nephrons. In addition, proteinuria, which occurs during the course of the disease, exacerbates glomerulosclerosis and tubulointerstitial fibrosis through its toxic effects on the glomeruli and tubules. If hypertension, which may develop secondary to proteinuria, is not controlled, it further damages the nephrons through the hyperfiltration mechanism. Metabolic conditions that arise as a result of kidney damage further exacerbate the deterioration. Hyperphosphataemia leads to calcium phosphate accumulation in the interstitial region and endothelium. Hyperlipidaemia causes oxidant-mediated damage to the endothelium, resulting in a reduction in glomerular velocity.

In this vicious cycle, CKD inevitably progresses, with a continuous decline in the glomerular filtration rate, ultimately leading to ESKD.²⁵

Clinical symptoms of CKD in the paediatric population

The clinical presentation of CKD in paediatric patients can vary widely, often depending on the stage of the disease and the underlying aetiology. Oedema, haematuria, hypertension, and proteinuria may be detected in patients with CKD secondary to chronic glomerulonephritis.²⁶ Frequent urinary tract infections, polyuria, dehydration, and growth retardation, especially in infancy, may be observed in patients with CKD secondary to CAKUT.²⁷ In hereditary kidney diseases, such as familial juvenile nephronophthisis, patients may present with non-specific symptoms such as headache, fatigue, anorexia, and growth retardation.²⁸

One of the earliest and most common signs of CKD in children is growth retardation. This condition is frequently associated with malnutrition, which is prevalent among children with CKD due to protein-energy wasting and micronutrient deficiencies.^{2,11}

As CKD progresses, clinical findings related to disease complications become apparent. Uraemia, a condition resulting from kidney failure, manifests through various systemic symptoms, including dermatological (itching, etc.), neurological (reduced concentration, etc.), gastrointestinal, and haematological complications. Patients often exhibit a characteristic pale skin appearance due to the accumulation of uraemic toxins. Additionally, pericarditis and pleuritis due to uraemia may be observed in the advanced stages of the disease.²⁴ Children may exhibit symptoms such as fatigue, lethargy, and reduced physical activity levels, which can be attributed to anaemia, a common complication of CKD due to reduced erythropoietin production.^{11,24} Along with proteinuria, children may experience oedema, especially in the lower extremities, as a result of fluid retention. Changes in urination patterns, such as nocturia or reduced urine output, may also occur.^{11,24}

As CKD progresses, children may experience more pronounced symptoms, including hypertension, which is often observed due to fluid overload and increased vascular resistance.^{11,24} Hypertension can further complicate the clinical picture, leading to cardiovascular issues, such as left ventricular hypertrophy, which are notably prevalent in children with CKD.^{11,24} In uraemia exceeding a

certain level, neurological symptoms such as fatigue, memory loss and difficulty concentrating, headache, dizziness, peripheral neuropathy, and lethargy may occur.²⁴ Children with CKD are at risk of developmental delay, learning and behavioural issues, sleep disturbances, adjustment disorder, and depression.²⁴

Gastrointestinal symptoms include nausea, vomiting, abdominal pain, constipation, diarrhoea, and dyspepsia.^{24,29} Haematological findings of CKD may include increased blood urea nitrogen and serum creatinine, hyperkalaemia, hyponatraemia, hypernatraemia, hypocalcaemia, hyperphosphataemia, hyperuricaemia, hypoalbuminaemia, hypertriglyceridaemia, and hypercholesterolaemia. A complete blood count may show normochromic normocytic anaemia, thrombocytopenia, and granulocytopenia.^{11,24,30} Children with CKD are at risk of metabolic bone disease (MBD), which can lead to skeletal deformities and fractures due to disturbances in calcium and phosphate metabolism.^{11,24} Hypocalcaemia and hyperphosphataemia are triggers that lead to increased parathyroid hormone levels. Elevated parathyroid hormone results in increased bone resorption and an overall decrease in bone deposition. Patients with CKD often have concomitant 25-hydroxy vitamin D deficiency, which contributes to worsening bone disease.^{11,24}

Patients develop metabolic acidosis as a result of decreased ammonia synthesis, impaired bicarbonate reabsorption, and reduced acid excretion.²⁴ Metabolic acidosis contributes to growth failure and bone disease. In addition, children with CKD are at an increased risk for infections secondary to an impaired immune response.²⁴

Management CKD in the paediatric population

The main goals are to slow the progression to ESKD, replace decreased kidney function, manage complications that arise during this process, and improve quality of life.

General Kidney Protective Measures

Educational initiatives targeting parents and caregivers of children about risk factors and early signs of kidney disease can increase awareness, ensuring timely and effective treatment and care.³¹ General kidney protective measures that should be implemented in all children with CKD include avoiding potential nephrotoxic agents, managing high blood pressure, and avoiding excessive protein

supplementation.^{2,24} Lifestyle modification is an important factor in delaying the progression of CKD to ESKD. In this context, the KDIGO *Evaluation and Management of Chronic Kidney Disease* guideline (2024) provides recommendations on a healthy diet, physical activity, smoking cessation, and weight control. It also emphasises that managing risk factors, disease-related symptoms, and complications plays a role in slowing disease progression.^{4,5}

Kidney replacement therapy in children

KRT generally becomes necessary in children when the GFR falls below 15 mL/min/1.73 m². As the child approaches ESKD (stage 4 CKD), it is important to prepare both the child and their family for KRT. In this regard, the preferred treatment method should be determined by the paediatric nephrologist. Decisions should be made collaboratively with the patient and their family, considering both medical and social factors. Clinically available KRT include PD, haemodialysis, and kidney transplantation.^{3,4,24}

Complications

Complications begin to appear from Stage two CKD onwards. The main complications include fluid-electrolyte and acid-base balance disorders, bone-mineral disorders, nutritional disorders and growth retardation, anaemia, cardiovascular diseases, and infections.^{4,5,23,24,32}

Nutritional Disorders

Children with CKD should be specifically assessed for their dietary requirements. They should receive an estimated energy requirement for their age, based on body mass index, physical activity status, gender, and weight gain or loss response. Children with advanced CKD, especially infants, often experience growth and developmental delays. Compared to healthy children, an energy intake of at least 100–120% of the recommended daily intake (RDI) is required. In addition, dietary protein intake of 100–140% and 100–120% of the RDI is recommended in CKD and ESKD, respectively. The greatest risk for malnutrition is during infancy. These children may also have poor oral-motor skills and may be unable to breastfeed or bottle-feed to meet their nutritional needs. For these reasons, supplemental tube feeding, often via a gastrostomy tube and under the guidance of a paediatric kidney dietitian, is necessary.^{3-5,24,32}

Growth Retardation

Intervention is recommended in children with CKD if their short stature is 2 standard deviations below the normal height for age. Adequate calorie intake should be ensured, and if anaemia, metabolic acidosis, or bone-mineral disorders are present, they should be corrected. Recombinant growth hormone therapy is recommended for children whose height remains 2 standard deviations below normal despite optimal medical support. Growth hormone therapy is discontinued once the patient reaches their target height or if kidney transplantation is performed.^{3-5,24}

Anaemia

Anaemia remains a common and challenging complication of CKD in children. Its aetiology is multifactorial, with the primary contributing factors being endogenous erythropoietin deficiency and iron deficiency. Untreated anaemia increases the risk of hospitalisation, left ventricular hypertrophy, and overall paediatric CKD morbidity.^{3,24} Treatment of anaemia in patients with CKD mainly consists of iron supplementation and erythropoiesis-stimulating drugs. Iron treatment is recommended in cases of iron deficiency and in addition to erythropoiesis-stimulating drugs to prevent the development of iron deficiency. The most commonly used erythropoiesis-stimulating drugs in the clinic are recombinant human erythropoietin (epoetin alfa) and darbepoetin alfa. Both preparations are administered parenterally.^{3,24,33} The optimal target haemoglobin level for children with CKD is debated, but a widely accepted range is 10 to 12 g/dL.^{24,33} If anaemia does not improve despite treatment, the underlying causes should be investigated. For example, vitamin B12 deficiency, folate deficiency, liver disorders, thyroid disorders, infections, inflammation, aluminium toxicity, and others.³³

Bone-Mineral Disorders

In this regard, MBD worsens morbidity in children with CKD. It is important to assess and protect bone health in children with CKD stages 2–5 and those on dialysis. Children have higher calcium requirements than adults because of accelerated skeletal growth. However, the presence of hyperphosphataemia, which is often seen with moderate to severe CKD, and high dietary calcium intake, can lead to vascular calcification. Phosphorus retention results in

increased levels of fibroblast growth factor and parathyroid hormone, both of which are phosphaturic. The ability to excrete phosphorus in the urine is reduced. Due to these changes, secondary hyperparathyroidism and related bone disease begin to occur in stage two CKD. Therefore, dietary phosphorus should be restricted to 100% of the RDI in children with mild CKD and to 80% of the RDI in children with advanced CKD, usually accompanied by the use of a phosphorus binder to achieve normal age-based serum phosphorus levels. It is essential to educate families and children about the phosphate content of foods (e.g., dairy products, beans, lentils, nuts), as well as certain medications. Attention to the possibility of vitamin D 25OH deficiency is also important due to its contribution to impaired enteral calcium absorption, the development of secondary hyperparathyroidism, and the subsequent increased risk of renal osteodystrophy and pathological fractures. Cholecalciferol or ergocalciferol therapy is indicated when 25(OH)D levels are < 30 ng/ml. Active vitamin D therapy (e.g., calcitriol) is recommended for patients with persistently elevated parathyroid hormone despite good control of serum phosphorus and normal 25OH(D) levels.^{2,3,5,24,32,33}

Cardiovascular Complications

Cardiovascular disease is the leading cause of death in children with CKD.²⁴ Left ventricular hypertrophy, increased arterial stiffness, and increased carotid intima-media thickness are the most prevalent cardiovascular complications.³ Identifying and controlling obesity, dyslipidaemia, and hypertension, and promoting a healthy diet and physical activity are among the strategies to reduce cardiovascular risk in children with CKD.^{3,24} Statin therapy is recommended for older children with severe hypercholesterolaemia that cannot be corrected by lifestyle modification. Pharmacological treatment of hypertension varies according to the primary cause of CKD, the level of proteinuria, and the level of blood pressure. Drugs that block the renin-angiotensin system are the first choice, as they reduce proteinuria. Diuretic treatment can be given to patients with hypertension and oedema. Patients with oedema and hypertension that do not regress despite diuretic treatment, or in whom diuretic treatment is contraindicated, should be placed on dialysis. Absolute control of blood pressure, avoidance of anaemia, and prevention of volume overload are necessary to reduce the risk of left ventricular hypertrophy.^{3,5,24,33}

Fluid-Electrolyte and Acid-Base Balance Imbalances

One of the primary consequences of CKD is the inability of the kidneys to excrete excess electrolytes, particularly potassium and phosphate, leading to hyperkalaemia and hyperphosphataemia. These imbalances can result in serious cardiovascular complications, secondary hyperparathyroidism, and renal osteodystrophy.^{4,5,24,30,32} The first step in the approach to hyperkalaemia is dietary potassium restriction.^{4,24} However, the dietary management of potassium can pose unique challenges, as the provision of adequate energy, protein, and micronutrients for growth cannot be compromised, and specialised low-potassium nutritional formulas may not be widely available or palatable.^{2,4} If dietary restriction does not provide sufficient reduction, potassium-binding drugs (e.g., sodium polystyrene sulfonate) are added to the treatment. Other treatments for hyperkalaemia management include salt restriction, diuretic therapy, treatment of metabolic acidosis (oral sodium bicarbonate), and emergency dialysis in cases of life-threatening hyperkalaemia (e.g., cardiac arrhythmia).^{4,5,24,32}

Treatment of hyperphosphataemia includes restriction of dietary phosphorus intake and phosphorus-binding drugs. The first choice for phosphorus-binding drugs is calcium-based preparations (calcium acetate, calcium carbonate, calcium gluconate).^{4,5,24,32}

Hypocalcaemia is more common in secondary hyperparathyroidism. If symptomatic, it is treated with intravenous calcium. Asymptomatic hypocalcaemia is prevented by adequate dietary intake, management of hyperphosphataemia, and vitamin D deficiency. In the event of hypercalcaemia, sevelamer, a phosphate-binding drug, should be preferred, and vitamin D treatment should be discontinued until the calcium level reaches the normal range.^{4,5,24,32}

Additionally, fluid, calcium, and sodium imbalances may develop.^{4,24} In patients with hypertension and oedema due to volume overload from oliguria, it is recommended to restrict water and sodium, and, if necessary, use diuretics in treatment.^{4,5,24}

Metabolic acidosis is prevalent in CKD due to the kidneys' diminished capacity to excrete hydrogen ions and regenerate bicarbonate, which can exacerbate bone disease and growth failure in children.^{4,5,24,32} Data from the observational CKiD study revealed that prepubertal children with acidosis who were treated with alkali showed improved growth.

The recommended use of pharmacological treatment (bicarbonate), with or without dietary intervention, is aimed at preventing the development of acidosis with potential clinical implications.^{4,5,24}

Infection

Children with CKD are at increased risk of infections secondary to an impaired immune response and have specific vaccine requirements. Children with CKD should receive the influenza vaccine yearly and may have additional specific pneumococcal, meningococcal, hepatitis B, and COVID-19 vaccine requirements based on the underlying cause and stage of their CKD.²⁴

The quality of life

The psychosocial aspects of living with CKD cannot be overlooked. Quality of life assessments reveal that children with CKD often face emotional and social challenges that can affect their overall well-being. Research indicates that children undergoing dialysis report different quality of life outcomes compared to those in the earlier stages of CKD, suggesting that the stage of the disease significantly influences their emotional health and family dynamics.^{34,35} Addressing these psychosocial factors is crucial for comprehensive care, as they can impact treatment adherence and overall health outcomes.^{34,35}

Delivery of care and patient education

Paediatric healthcare providers interact not only with the person with CKD but also with their caregivers and siblings. Age-appropriate care and education are required for both the child and the caregivers.⁴ Effective patient education strategies must be tailored to the specific needs of children with CKD and their families.³⁶

The needs and abilities of the family unit must be considered holistically. Interactions with patients and families gradually change throughout childhood. They should be entirely caregiver-centered for infants and include the whole family unit during childhood. The transition to adult-centered care should begin in adolescence and continue beyond.⁴

Adolescence and emerging adulthood bring individuation and the exploration of sexuality and adult behaviours, and kidney disease care must recognise and adapt to these changes.⁴

It is suggested that educational materials avoid technical jargon and instead use clear, accessible language to describe CKD and its implications.³⁷ Furthermore, the incorporation of self-management interventions, such as health information dissemination and telephone-based support, has been identified as crucial for empowering families to manage CKD effectively.³⁸

Educational initiatives should focus not only on imparting knowledge about CKD but also on fostering a sense of agency among patients and their families, encouraging them to actively participate in their care.³⁷

Effective patient education provided by nurses for children with CKD should encompass clear communication, parental involvement, and the use of innovative educational tools. It should promote self-management by addressing information deficits.

The primary goal of paediatric CKD care is to optimise neurodevelopmental outcomes. CKD can impact development, cognition, school attendance, occupational outcomes, and future employment. Reducing these deficits through effective, personalised care is essential to giving children with CKD the best possible future.⁴

Conclusion

CKD in the paediatric population is a complex condition that requires a comprehensive, multidisciplinary approach to management. Understanding the unique challenges faced by children with CKD, including the psychosocial implications and the need for tailored management strategies, is essential to improving outcomes. As research continues to evolve, it is imperative that healthcare providers remain vigilant in their efforts to support these vulnerable patients and their families.

References

1. Kim JY, Lee Y, Kang HG, Ha IS, Cheong HI, Choi HJ, et al. Left-ventricular diastolic dysfunction in Korean children with chronic kidney disease: data from the KNOW-Ped CKD study. *BMC Nephrol.* 2020;21(1). <https://doi.org/10.1186/s12882-020-02152-6>
2. Cirillo L, De Chiara L, Innocenti S, Errichiello C, Romagnani P, Becherucci F. Chronic kidney disease in children: an update. *Clin Kidney J.* 2023;16(10):1600-1611. <https://doi.org/10.1093/ckj/sfad097>
3. VanSickle JS, Warady BA. Chronic kidney disease in children. *Pediatr Clin North Am.* 2022;69(6):1239-1254. <https://doi.org/10.1016/j.pcl.2022.07.010>
4. Kidney Disease: Improving Global Outcomes (KDIGO). Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease [Internet]. 2024 [cited 2025 Feb 7]. Available from: <https://kdigo.org/wp-content/uploads/2024/03/KDIGO-2024-CKD-Guideline.pdf>
5. Francis A, Shroff R, Earley A, Foster BJ. KDIGO 2024 guidelines—key points for Paediatric ians. *JAMA Pediatr.* 2025;179(2):114-116. <https://doi.org/10.1001/jamaPaediatric.s.2024.5274>
6. Mian AN, Schwartz GJ. Measurement and estimation of glomerular filtration rate in children. *Adv Chronic Kidney Dis.* 2017;24(6):348-356. <https://doi.org/10.1053/j.ackd.2017.09.011>
7. Muntean C, Starcea IM, Banescu C. Diabetic kidney disease in Paediatric patients: a current review. *World J Diabetes.* 2022;13(8):587-599. <https://doi.org/10.4239/wjd.v13.i8.587>
8. Levin A. Executive summary of the KDIGO 2024 clinical practice guideline for the evaluation and management of chronic kidney disease: known knowns and known unknowns. *Kidney Int.* 2024;105(4):684-701. <https://doi.org/10.1016/j.kint.2023.10.016>
9. Milenia V, Siregar R, Hamdi T, Malisie R. Knowledge and attitude of Medan Selayang citizens toward kidney diseases in children. *J Endocrinol Trop Med Infect Dis (Jetromi).* 2022;4(1):1-10. <https://doi.org/10.32734/jetromi.v4i1.7819>
10. Galiyeva D, Jackson C, Burns S, Hughes D, Traynor J, Metcalfe W, et al. Long-term all-cause mortality and cardiovascular outcomes in Scottish children after initiation of renal replacement therapy: a national cohort study. *Pediatr Nephrol.* 2019;35(4):677-685. <https://doi.org/10.1007/s00467-019-04430-4>
11. Becherucci F, Roperto R, Materassi M, Romagnani P. Chronic kidney disease in children. *Clin Kidney J.* 2016;9(4):583-591. <https://doi.org/10.1093/ckj/sfw047>
12. Song R, Yosypiv I. Genetics of congenital anomalies of the kidney and urinary tract. *Pediatr Nephrol.* 2010;26(3):353-364. <https://doi.org/10.1007/s00467-010-1629-4>
13. Vivante A, Hildebrandt F. Exploring the genetic basis of early-onset chronic kidney disease. *Nat Rev Nephrol.* 2016;12(3):133-146. <https://doi.org/10.1038/nrneph.2015.205>

14. Saisawat P, Kohl S, Hilger A, Hwang D, Gee H, Dworschak G, et al. Whole-exome resequencing reveals recessive mutations in TRAP1 in individuals with CAKUT and VACTERL association. *Kidney Int.* 2014;85(6):1310-1317. <https://doi.org/10.1038/ki.2013.417>
15. Lu Y, Song Y, Sun S, Zhang L, Chen Y. Gene therapy for Paediatric genetic kidney diseases. *Pediatr Discov.* 2023;1(1). <https://doi.org/10.1002/pdi3.16>
16. Li Y, Xiao T, Zhang B, Zhao J, Hou W. A pathogenic variant of PBX1 identified by whole exome sequencing in a Chinese CAKUTED case. *Nephron.* 2022;147(5):311-316. <https://doi.org/10.1159/000526847>
17. Al-Hamed M, Sayer J, Alsaah N, Edwards N, Ali W, Tulbah M, et al. Missense variants in GFRA1 and NPNT are associated with congenital anomalies of the kidney and urinary tract. *Genes (Basel).* 2022;13(10):1687. <https://doi.org/10.3390/genes13101687>
18. Atic N. Cardiac evaluation of children with congenital anomalies of the kidneys and urinary tract. *Paediatr Today.* 2016;12(2):169-175. <https://doi.org/10.5457/p2005-114.153>
19. Sánchez C, Rebolledo A, Gahona J, Rojas M, Jiménez R, Bojórquez A. Post-transplant immune complex nephritis in a patient with systemic lupus erythematosus associated with ANCA vasculitis. *Pediatr Transplant.* 2017;21(3). <https://doi.org/10.1111/petr.12895>
20. Goodwin J, Palmer M, Pashankar F, Tufro A, Moeckel G. A 7-year-old boy with renal insufficiency and proteinuria after stem cell transplant for T-cell acute lymphoblastic leukemia. *Clin Nephrol.* 2013. <https://doi.org/10.5414/cn107767>
21. Koh K, Sunkara A, Kang G, Sooter A, Mulrooney D, Onder A, et al. Acute kidney injury in Paediatric patients receiving allogeneic hematopoietic cell transplantation: incidence, risk factors, and outcomes. *Biol Blood Marrow Transplant.* 2018;24(4):758-764. <https://doi.org/10.1016/j.bbmt.2017.11.021>
22. Yarıbeygi H, Farrokhi F, Rezaee R, Sahebkar A. Oxidative stress induces renal failure: a review of possible molecular pathways. *J Cell Biochem.* 2018;119(4):2990-2998. <https://doi.org/10.1002/jcb.26450>
23. Zabeen B, Nahar J, Islam N, Azad K, Donaghue K. Risk factors associated with microalbuminuria in children and adolescents with diabetes in Bangladesh. *Indian J Endocrinol Metab.* 2018;22:85-88. https://doi.org/10.4103/ijem.IJEM_269_17
24. Panzarino V, Lesser J, Cassani FA. Paediatric chronic kidney disease. *Adv Pediatr.* 2022;69(1):123-132. <https://doi.org/10.1016/j.yapd.2022.03.008>
25. Charles C, Ferris AH. Chronic kidney disease. *Prim Care.* 2020;47(4):585-595. <https://doi.org/10.1016/j.pop.2020.08.001>
26. Yuste C, Rubio-Navarro A, Barraca D, Aragoncillo I, Vega A, Abad S, et al. Haematuria increases progression of advanced proteinuric kidney disease. *PLoS One.* 2015;10(5):e0128575. <https://doi.org/10.1371/journal.pone.0128575>
27. Gipson D, Selewski D, Massengill S, Wickman L, Messer K, Herreshoff E, et al. Gaining the PROMIS perspective from children with nephrotic syndrome: a Midwest Paediatric Nephrology Consortium study. *Health Qual Life Outcomes.* 2013;11(1). <https://doi.org/10.1186/1477-7525-11-30>

28. Xiaoyun G. MicroRNA-204 may predict the renal function in patients with chronic kidney disease. *Medicine (Baltimore)*. 2025;104(1):e41202. <https://doi.org/10.1097/md.00000000000041202>
29. Kumar M, Vinod K, Pandit N, Sharma V, Halanaik D, Parameswaran S. Delayed gastric emptying among Indian patients with non-diabetic chronic kidney disease. *Indian J Nephrol*. 2021;31(2):135. https://doi.org/10.4103/ijn.ijn_331_19
30. Zadrazil J, Horák P. Pathophysiology of anemia in chronic kidney diseases: a review. *Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub*. 2015;159(2):197-202. <https://doi.org/10.5507/bp.2013.093>
31. Solarin A, Madise-Wobo A, Awobusoyi O, Umezudike T, Onyido O, Amisu M, et al. Screening for kidney disease in children on World Kidney Day in Lagos State, Nigeria. *Afr J Nephrol*. 2018;21(1). <https://doi.org/10.21804/21-1-2760>
32. Shaw V, Polderman N, Renken-Terhaerd J, et al. Energy and protein requirements for children with CKD stages 2-5 and on dialysis: clinical practice recommendations from the Paediatric Renal Nutrition Taskforce. *Pediatr Nephrol*. 2020;35(3):519-531. <https://doi.org/10.1007/s00467-019-04426-0>
33. Kidney Disease: Improving Global Outcomes (KDIGO). Clinical Practice Guideline for Anemia in Chronic Kidney Disease [Internet]. 2025 [cited 2025 Jan 29]. Available from: https://kdigo.org/wp-content/uploads/2024/11/KDIGO-2025-Anemia-in-CKD-Guideline_Public-Review-Draft_Nov42024.pdf
34. Tavri V, Mihopoulos N, Perdikaris P. Quality of life of children and adolescents with chronic kidney disease: a review of the literature. *World J Adv Res Rev*. 2023;17(2):266-274. <https://doi.org/10.30574/wjarr.2023.17.2.0153>
35. Francis A, Didsbury M, Zwieten A, Chen K, James L, Kim S, et al. Quality of life of children and adolescents with chronic kidney disease: a cross-sectional study. *Arch Dis Child*. 2018;104(2):134-140. <https://doi.org/10.1136/archdischild-2018-314934>
36. Eydivandi Z, Naleshkenani F, Pendar R. Assessment of parental awareness level of children with chronic kidney disease in Ahvaz. *Hormozgan Med J*. 2021;25(2):50-53. <https://doi.org/10.34172/hmj.2021.02>
37. Tuot D, Zhu Y, Velásquez A, Espinoza J, Mendez C, Banerjee T, et al. Variation in patients' awareness of CKD according to how they are asked. *Clin J Am Soc Nephrol*. 2016;11(9):1566-1573. <https://doi.org/10.2215/cjn.00490116>
38. Zimbudzi E, Lo C, Kerr P, Zoungas S. A need-based approach to self-management education for adults with co-morbid diabetes and chronic kidney disease. *BMC Nephrol*. 2019;20(1). <https://doi.org/10.1186/s12882-019-1296-z>

Chapter 4

Indications and goals for kidney replacement therapy

Learning objectives:

- To identify the clinical indications for initiating kidney replacement therapy (KRT) in paediatric patients with acute kidney injury and end-stage kidney disease.
- To recognise key clinical criteria for KRT initiation, including a glomerular filtration rate (GFR) of less than 15 ml/min/1.73 m² and the presence of symptoms associated with advanced kidney failure.
- To describe the benefits and optimal timing of early living donor kidney transplantation as the preferred modality of KRT for children with chronic kidney disease.
- To explain the advantages of PD in infants and young children, particularly its role in supporting normalisation of family life.
- To list the most common causes of acute kidney injury in paediatric populations that may require dialysis.
- To understand the primary goals of KRT in children, including the restoration of kidney function and the enhancement of overall health and quality of life.
- To appreciate the importance of an individualised, multidisciplinary approach to KRT in paediatric patients to achieve optimal clinical outcomes.
- To describe the role of nurses in advanced chronic kidney disease (CKD) clinics, with a focus on supporting families in decision-making around KRT options.

Introduction

Chronic kidney disease (CKD) is a pathology defined by irreversible and progressive kidney damage.^{1,2} Its onset in childhood adds special and particular characteristics given its impact on growth, cognitive development and quality of life, with a strong social and family impact.³⁻⁵ Epidemiological data in the paediatric age group are very scarce.^{1,6} Structural anomalies are the most frequent cause and there is a predominance of boys.^{1,7} Its natural evolution is progressive towards the total loss of kidney function,^{1,6} which would require the initiation of kidney replacement therapy (KRT), transplantation or dialysis in the final stages, whose main objective is to replace the

lost kidney functions and consequently improve the state of health and quality of life of the child and his or her environment.^{1,4}

Early kidney transplantation is the KRT of choice in childhood and should be offered to all children and adolescents who develop stage 5 CKD and have no contraindications.^{2,8} Furthermore, when initiating any dialysis modality in a child with advanced CKD, there should always be the expectation of kidney transplantation.^{2,8}

Unfortunately, early kidney transplantation is not always possible for a variety of reasons: sudden onset end-stage kidney disease, active infection, need for surgical repair of the urinary tract, vaccinations and clinical management of the underlying disease.⁹ In addition, as a general rule, in children under two years of age, kidney transplantation is delayed until the end of the second year in order to reduce vascular surgical risk.^{7,10} In all these situations, although we must always offer both techniques of dialysis, haemodialysis (HD) and peritoneal dialysis (PD), the latter is a valid and effective alternative to maintain the child, in most cases, with proper metabolic and nutritional control until transplantation, as well as a better quality of life and less interference in both their daily life activities and those of their family and environment.^{4,11}

It is of great importance that KRT in children should be an individualised treatment with a comprehensive and multidisciplinary approach in order to achieve the success of the treatment.^{4,8}

Goals of KRT in children with CKD¹²

- Restore fluid and electrolyte balance: This is undertaken to prevent volume overload, metabolic acidosis, and imbalances of electrolytes such as potassium, sodium, and calcium.
- Ensure appropriate growth and development patterns, along with adequate body composition.
- Correct metabolic abnormalities and mitigate toxicities associated with CKD.
- Eliminate toxins: Replacement therapy facilitates the removal of waste products such as urea, creatinine, and other solutes that compromised kidneys are unable to excrete.

- Reduce medium- and long-term mortality and chronic morbidity associated with CKD, particularly in the context of kidney transplantation.
- Provide time for comprehensive evaluation and treatment: Replacement therapy may serve as a temporary measure while long-term treatment options, such as kidney transplantation or chronic dialysis, are assessed.
- Enhance general well-being and quality of life.

Indications for KRT in paediatric patients:¹³

KRT is indicated for children experiencing AKI or ESKD.

AKI is a broad clinical syndrome characterised by an abrupt decline in kidney function. It encompasses a spectrum ranging from subtle disturbances in water and electrolyte balance to severe cases necessitating KRT.

Possible causes of AKI in children include the following:

- **Haemolytic Uremic Syndrome (HUS)**
 1. Caused by certain strains of *Escherichia coli*.
 2. Characterised by haemolytic anaemia, thrombocytopenia, and consequent acute kidney failure.
- **Rapidly Progressive Glomerulonephritis (RPGN)**
 1. A glomerular disease leading to an accelerated decline in kidney function over days to weeks.
 2. Associated with autoimmune conditions such as Anti-Neutrophil cytoplasmic antibodies associated vasculitis (ANCA)-and systemic lupus erythematosus (SLE).
 3. May progress to persistent oliguria and uraemia, necessitating dialysis.
- **Acute Tubular Necrosis (ATN)**
 1. Caused by prolonged kidney ischaemia (e.g. due to shock or nephrotoxicity).
 2. May result in prolonged oliguric kidney failure.
 3. Complications include refractory hyperkalaemia, severe metabolic acidosis, and uncontrolled volume overload.

- **Severe Rhabdomyolysis**

1. Massive destruction of skeletal muscle, leading to the release of myoglobin.
2. May be triggered by trauma, compartment syndrome, viral infections, or metabolic disorders.
3. In cases of severe kidney failure, dialysis is required to eliminate toxins and correct electrolyte imbalances.

- **Hereditary or Metabolic Disorders**

1. Includes inborn errors of metabolism.
2. Dialysis may assist in the removal of toxic metabolites in these conditions.

- **Urinary Obstruction**

1. Causes may include posterior urethral valves or pelvic/retroperitoneal tumours.
2. This condition may result in severe hydronephrosis and subsequent kidney failure.

- **Severe Poisoning or Intoxication**

1. Occurs when toxic substances (e.g. certain drugs or heavy metals) cannot be adequately eliminated by impaired kidney.

Indications for Dialysis in Acute Kidney Injury (AKI) in Paediatrics

Dialysis is indicated in cases of:

- Persistent oliguria/anuria.
- Severe hyperkalaemia.
- Severe metabolic acidosis.
- Refractory volume overload with pulmonary oedema.
- Symptomatic uraemia (e.g. uraemic encephalopathy).
- Drug intoxication.

Advanced CKD: In end-stage kidney disease, KRT is necessary to maintain fluid, electrolyte, and toxin balance when the glomerular filtration rate (GFR) falls below 15 ml/min/1.73 m², accompanied by signs and/or symptoms of advanced kidney failure.

The first-line option for children is early kidney transplantation, preferably from a living donor¹⁴. If this is not possible, a transplant from a deceased donor is considered, due to the following reasons:

- Better long-term outcomes
- Avoidance of the negative effects of dialysis
- Improved growth and neurological development
- Lower long-term costs
- Enhanced quality of life

Peritoneal dialysis (PD) is considered as a secondary option when early kidney transplantation is not possible, or as a temporary measure in the case of underweight children awaiting transplantation¹⁵, for the following reasons:

- Less impact on quality of life
- Can be performed at home
- Offers more flexibility for maintaining school attendance
- Better tolerance in younger children
- Does not require complex vascular accessories
- Reduced risk of cardiovascular complications
- PD maintains better fluid volume balance and reduces cardiac overload

If PD is not feasible, haemodialysis becomes the preferred treatment option for children with advanced CKD.

Some of the most common signs and symptoms that indicate the need to initiate KRT in children include:¹⁶

- **Oliguria or anuria:** A significant reduction in urine output (less than 400 ml/day in young children).
- **Oedema:** Fluid retention in the body, which in children typically manifests most noticeably in the face, legs, and abdomen.

- **Hypertension:** High blood pressure that does not respond adequately to conventional treatments.
- **Electrolyte and acid-base imbalances.**
- **Hyperkalaemia:** Elevated potassium levels, which can lead to severe cardiac arrhythmias.
- **Metabolic acidosis.**
- **Complications of bone-mineral metabolism.**
- **Hypocalcaemia and hyperphosphatemia:** Abnormal calcium and phosphorus levels, which may contribute to the development of rickets, osteomalacia, and vascular calcifications.
- **Toxaemia or other associated complications:**
 - **Nausea and vomiting:** Due to the accumulation of nitrogenous waste products, such as urea and creatinine, in the blood.
 - **Fatigue, weakness, and lethargy:** Related to uraemia or the accumulation of toxins.
 - **Poor growth:** Children with chronic kidney failure often experience stunted growth due to the effects of nutrient and hormone imbalances.
 - **Loss of appetite:** Anorexia and loss of appetite are common in children with end-stage kidney disease.

Conclusion

KRT is indicated for children with acute kidney disease, CKD in its end-stage phase, or when they present signs or symptoms that significantly impair their quality of life.¹⁶

The primary objective of KRT in children with kidney disease is to maintain adequate fluid and electrolyte balance, improve nutritional status, maintain good mental status and increase the quality of life for both the child and their family.¹²

To ensure its success, the treatment must be individualised, comprehensive, and multidisciplinary.

The nurse's role in the consultation for advanced chronic kidney disease (ACKD) will be crucial when the need to initiate KRT in

children is indicated, particularly in assisting with decision-making regarding the different types of KRT.

The order of indication for KRT in children with ACKD should be, first, an anticipated living donor transplant or, if this is not possible, a cadaveric transplant; secondly, peritoneal dialysis, particularly in children under two years of age; and lastly, haemodialysis.¹⁴ These decisions should always be based on the clinical needs of the child and discussed within a multidisciplinary team, including paediatric nephrology, transplant surgery, and other relevant specialists. The child's preferences should take precedence when they have the capacity to make decisions, or when guided by their parents or legal guardians.

References:

1. Cirillo L, De Chiara L, Innocenti S, Errichiello C, Romagnani P, Becherucci F. Chronic kidney disease in children: an update. *Clin Kidney J.* 2023 Apr 24;16(10):1600-1611. doi: 10.1093/ckj/sfad097.
2. Kampmann JD, Heaf JG, Mogensen CB, Mickley H, Wolff DL, Brandt F. Prevalence and incidence of chronic kidney disease stage 3-5 – results from KidDiCo. *BMC Nephrol.* 2023 Jan 19;24(1):17. doi: 10.1186/s12882-023-03056-x.
3. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr Nephrol.* 2012 Mar 27(3):363-73. doi: 10.1007/s00467-011-1939-1.
4. Kari JA, El Desoky SM, Farag YM, Singh AK. Predictors of renal replacement therapy and mortality in children with chronic kidney disease. *Saudi Med J.* 2015 Jan 36(1):32-9. doi: 10.15537/smj.2015.1.9774.
5. Cirillo L, De Chiara L, Innocenti S, Errichiello C, Romagnani P, Becherucci F. Chronic kidney disease in children: an update. *Clin Kidney J.* 2023 Apr 24;16(10):1600-1611. doi: 10.1093/ckj/sfad097.
6. Becherucci F, Roperto RM, Materassi M, Romagnani P. Chronic kidney disease in children. *Clin Kidney J.* 2016 Aug 9(4):583-591. doi: 10.1093/ckj/sfw047.
7. Masalskienė J, Rudaitis Š, Vitkevič R, Čerkauskienė R, Dobilienė D, Jankauskienė A. Epidemiology of chronic kidney disease in children: a report from Lithuania. *Medicina (Kaunas).* 2021 Jan 26;57(2):112
8. Bonthius M, Cuperus L, Chesnaye NC, Akman S, Melgar AA, Baikou S, et al. Results in the ESPN/ERA-EDTA Registry suggest disparities in access to kidney transplantation but little variation in graft survival of children across Europe. *Kidney Int.* 2020 Aug;98(2):464-475. Doi: 10.1016/j.kint.2020.03.029.

9. Oomen L, Bootsma-Robroeks C, Cornelissen E, de Wall L, Feitz W. Pearls and pitfalls in Paediatric kidney transplantation after 5 decades. *Front Pediatr*. 2022 Apr 8;10:856630. doi: 10.3389/fped.2022.856630.
10. Winterberg PD, Garro R. Long-term outcomes of kidney transplantation in children. *Pediatr Clin North Am*. 2019 Feb;66(1):269-280. doi: 10.1016/j.pcl.2018.09.008.
11. Abderraman GM, Niang A, Mohamed T, Mahan JD, Luyckx VA. Understanding similarities and differences in CKD and dialysis care in children and adults. *Semin Nephrol*. 2023 Jul;43(4):151440. doi: 10.1016/j.semnephrol.2023.151440.
12. Medscape. Chronic Kidney Disease in Children: Treatment & Management [Internet]. Updated 2024 [cited 2025 Jun 19]. Available from: <https://emedicine.medscape.com/article/983611-treatment>
13. Kidney Disease: Improving Global Outcomes (KDIGO) Acute Kidney Injury Work Group. KDIGO clinical practice guideline for acute kidney injury and acute kidney disease: 2023 update. *Kidney Int*. 2023;104(5S):S1–S130.
14. Warady BA, Chadha V. Chronic kidney disease in children: the global perspective. *Pediatr Nephrol*. 2007 Dec; 22(12):1999-2009. doi: 10.1007/s00467-006-0410-1.
15. Zaritsky J, Warady BA. Peritoneal dialysis in infants and young children. *Semin Nephrol*. 2011 Mar;31(2):213-24. doi: 10.1016/j.semnephrol.2011.01.009.
16. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr Nephrol*. 2012 Mar;27(3):363-73. doi: 10.1007/s00467-011-1939-1.

Chapter 5

Modalities of kidney replacement therapy

Learning objectives

- To understand kidney replacement therapy in the paediatric population.
- To explain the advantages and disadvantages of the different modalities of kidney replacement in the paediatric population.
- To understand the role of the nurse in knowing the differences between modalities of kidney replacement therapy in the paediatric population.

Introduction

Kidney Disease Improving Global Outcomes (KDIGO) foundation uses guidelines to determine stage of chronic kidney disease (CKD). This is defined by proteinuria and glomerular filtration rate (GFR). When GFR is less than 15ml/min end stage kidney disease (ESKD) is diagnosed, kidney function is no longer sufficient, requiring long-term kidney replacement therapy (KRT) for survival.¹ Three modalities of KRT for ESKD include: peritoneal dialysis (PD), haemodialysis (HD) and kidney transplantation (KT).²

- **Peritoneal dialysis**

PD is a KRT based on infusing a sterile solution into the peritoneal cavity through a catheter and using the peritoneal membrane as a natural semipermeable barrier.³ Solute transport occurs through diffusion, ultrafiltration, and absorption.⁴ PD can be managed at home by the patient or the child's parents, enhancing independence and quality of life (QOL).⁵ There are two main types: continuous ambulatory (CAPD) and automated (APD), with APD offering individually customized therapy based on age, body size, nutritional needs, growth-related metabolic needs and with less burden on child and family.⁶ In the last decade technical innovations in PD have significantly reduced therapy-related complications, allowing patients to be maintained on PD for longer periods.⁷ PD advantages include better preservation of residual kidney function, fewer dietary and fluid restrictions, and a reduced risk of blood borne infections. Residual kidney function is also

maintained for a longer period compared to Haemodialysis (HD). The advantage of the continuous method is the stability of the patient's condition, better initial management of arterial pressure, and better volume control. It also allows better initial blood pressure and volume control and preserves vascular access for potential future HD. However, limitations include increased risk of peritonitis, catheter infections, and potential peritoneal membrane deterioration over time.⁴

- **Haemodialysis**

HD purifies blood using an extracorporeal circuit and a dialyzer. During HD, blood is pumped from the patient's body using a blood pump and is driven through a dialyzer. Solutes move across a semi-permeable membrane by diffusion. During HD, molecules from areas of higher concentration diffuse to areas of lower concentration (e.g., urea, creatinine, and potassium ions diffuse from the blood into the dialysate, while bicarbonate ions diffuse from the dialysate into the blood).⁸ Vascular access - commonly a native arteriovenous fistula - is essential. Alternatives include synthetic grafts or jugular catheters. HD is generally facility-based and may involve more dietary and fluid restrictions than PD. Outcomes are comparable between HD and PD, with treatment decisions often based on patient and provider preference.⁹

- **Kidney transplantation**

The first paediatric KT was in 1954. Since then it has evolved as the preferred long-term treatment of children with ESKD.¹⁰ It has been proven that KT results in superior life expectancy and QOL compared with dialysis treatment for patients with ESKD.⁸

Healthcare professionals play a pivotal role in educating families, managing complications, and supporting the child's adaptation to their chosen therapy. A thorough understanding of each KRT modality ensures safe, personalized, and effective paediatric kidney care. Nurses and healthcare professionals are vital in supporting both child and family - teaching procedures, monitoring health, and helping choose the best therapy. Understanding each KRT method helps healthcare professionals provide compassionate and informed care. The following sections of this chapter will provide a detailed overview of the various modalities of KRT.

References

1. Muhammad F. Hashmi,¹ Onecia Benjamin,² Sarah L. Lappin,³ End-Stage Renal Disease, 2023. Available at: <https://pubmed.ncbi.nlm.nih.gov/29763036/>
2. Noah Wouk, End-Stage Renal Disease: Medical Management, 2021. Available at: <https://pubmed.ncbi.nlm.nih.gov/34783494/>
3. Maria Claudia Cruz Andreoli¹, Claudia Totoli², Peritoneal DIALYSIS, 2020. Available at: <https://pubmed.ncbi.nlm.nih.gov/31939534/>
4. Mohammed Al-Natour,¹ Dustin Thompson,² Peritoneal Dialysis, 2016. Available at: <https://pubmed.ncbi.nlm.nih.gov/27011420/>
5. Rajnish Mehrotra,¹ Olivier Devuyst,² Simon J Davies,³ David W Johnson,⁴ The Current State of Peritoneal Dialysis, 2023. Available at: <https://pubmed.ncbi.nlm.nih.gov/27339663/>
6. Jonathan P Roach,¹ Margret E Bock,² Jens Goebel,³ Paediatric kidney transplantation, 2017. Available at: <https://pubmed.ncbi.nlm.nih.gov/28964479/>
7. Ernest van Heurn,¹ Eva E de Vries², Kidney transplantation and donation in children, 2009. Available at: <https://link.springer.com/article/10.1007/s00383-009-2350-x>
8. Elke Jaibeeh Barah,¹ Jennifer Jackson,² Exploring Haemodialysis Nurses' Perceptions on Kidney Replacement Therapy Modality Education: A Framework Analysis, 2024. Available at: <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jorc.70002>
9. Holmberg Christer,¹ Jalanko Hannu,² Long-term effects of paediatric kidney transplantation, 2016. Available at: <https://www.nature.com/articles/nrneph.2015.197>
10. Amrit Kaur,¹ Andrew Davenport,² Haemodialysis for infants, children, and adolescents, 2014. Available at: <https://doi.org/10.1111/hdi.12163>

5.1 Peritoneal dialysis

Learning objectives

- To understand the basic principles and mechanism of peritoneal dialysis, and distinguish between CAPD and APD.
- To recognise the advantages and limitations of PD compared to HD, particularly in the paediatric population.
- To assess peritoneal membrane function and tailor therapy according to transport characteristics (based on the PET test).
- To identify and manage common PD-related complications (peritonitis, catheter infections, ultrafiltration failure, dialysate leak, and hernias).
- To apply practical measures to prevent infections and ensure safe daily care for children on PD.
- To individualise the PD regimen (solution type, fill volume, dwell time) according to the child's clinical status, age, and residual kidney function.

Introduction

Peritoneal dialysis (PD) is a treatment used for kidney failure. This method uses the natural filtration capacity of the peritoneum, the membrane that lines the abdominal cavity. Unlike most forms of HD (e.g. centre-based HD), this form of dialysis is performed at home, which gives patients significantly greater flexibility and independence, and ultimately greater satisfaction. As with HD, PD requires the patient to be prepared for dialysis by surgically inserting a catheter into the abdominal cavity. This catheter primarily serves to deliver dialysate into the abdominal cavity. Dialysate is a specially prepared fluid that contains a mixture of water, salt, and other minerals to achieve the most successful removal of waste products and excess fluid from the blood.

The method itself is based on the permeability of the peritoneal membrane. The dialysate in the abdominal cavity acts as an absorbent, filtering water and harmful substances from the bloodstream into the abdominal cavity. The dialysate remains in the peritoneal cavity for several hours, while the filtration process continues, allowing for the unhindered transport of water and waste products, which ultimately mimics the function of healthy kidneys. After the dialysate has been in the abdominal cavity for several hours,

it must be drained and replaced with fresh dialysate. This procedure is typically repeated 4–5 times daily.¹ Unlike HD, peritoneal dialysis has several advantages:

1. **Flexibility:** PD can be performed at home, work, or while travelling, allowing patients to maintain a more normal lifestyle.
2. **Continuity:** Imitation of healthy kidneys allows for better control of fluid intake and electrolyte levels, ultimately resulting in better overall patient outcomes.
3. **Nutrition:** PD allows for fewer dietary restrictions with salt intake being more liberal, and excess fluid is not retained in the body for several days as with HD.
4. **Needle-free:** Unlike HD, PD does not require regular needle insertions, which can be particularly beneficial for paediatric patients.^{1,2}

Although PD has many advantages over HD, it is not suitable for all patients. Some of the possible contraindications to PD include: previous abdominal surgery (presence of increased number of adhesions), severe obesity (BMI >35), and inability to provide hygienic conditions for dialysis. PD also requires patient commitment, or in the case of paediatric patients, commitment of the caregiver, to maintain continuity and prevent complications.^{3,4}

5.1.1. Continuous ambulatory PD and automated PD

Peritoneal dialysis (PD) can be performed in two different ways: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). Both methods have their advantages and applications in the treatment of children with CKD.

CAPD is a method that is performed manually by the patient and is usually performed 4–5 times a day. The patient or their caregiver infuses fresh dialysate solution through a catheter into the abdominal cavity, where it is retained for several hours before being drained. This process is repeated throughout the day, meaning that the patient would need to dialyse at least once during the evening. CAPD was created as the first alternative to HD and is older than the newer automated version developed several years later.⁵

Conversely, APD uses an automatic cycling device that performs several dialysate exchanges, or cycles, during the night while the

child is sleeping. This method has become extremely popular in the paediatric population because it offers certain advantages over CAPD:

1. **Flexibility:** Although CAPD in itself provides significantly more flexibility compared to HD, APD has proven to be even more flexible for children, primarily because children are free during the day for school and other activities. Eighty-five percent of paediatric patients on APD regularly attend school.
2. **Better ultrafiltration:** Switching from CAPD to APD can result in improved daily ultrafiltration (846 ± 335 ml/day for APD compared to 590 ± 340 ml/day for CAPD).
3. **Reduction of complications:** On APD, patients have significantly fewer complications such as oedema (from 67% to 8%) and reduced need for antihypertensive therapy (from 83% to 38%).
4. **Lower peritonitis rate:** The peritonitis rate improved from one episode every 35 months per patient on CAPD to one episode every 47 months per patient on APD.⁶

Despite the many advantages, the decision to treat with either CAPD or APD must be individualised for each child. Factors considered include peritoneal membrane transport capacity, residual renal function, family lifestyle, and patient preference. The peritoneal equilibration test (PET) plays a key role in selecting the treatment modality. Patients with high and high to average membrane transport are often more suitable for APD, while those with low to average transport may benefit from CAPD. Although APD has certain advantages over CAPD, studies have not shown a significant improvement in quality of life.^{7,8}

5.1.2. Peritoneal membrane function

Small molecular weight waste products (such as urea and creatinine) are removed by diffusion through the concentration gradient, while water is removed by convection (ultrafiltration) driven by osmotic and hydrostatic gradients. Knowledge of the permeability and effective surface area of the peritoneal membrane in an individual child helps to optimise PD—e.g., by adjusting the filling volume and dwell time—while avoiding membrane overload which could lead to compromised function.⁹

Chronic exposure to high concentrations of glucose and other bioincompatible components of the dialysate during long-term PD promotes inflammatory processes and leads to fibrosis and the formation of new blood vessels in the peritoneum. The resulting structural changes, including membrane thickening and capillary proliferation, increase the permeability of the peritoneal membrane. The result is accelerated solute transport and a shortened duration of the effective osmotic gradient, which over time can result in ultrafiltration failure (loss of fluid removal capacity).¹⁰

Clinically, these changes often manifest as a so-called "fast transporter" membrane type, in which glucose from the dialysate is reabsorbed very quickly so that the osmotic gradient for ultrafiltration is short-lived. This necessitates shorter cycles and higher glucose concentrations to maintain fluid balance. Unfortunately, such measures further increase the glycaemic load on the peritoneum, promote further neoangiogenesis, and create a vicious cycle that accelerates membrane degeneration and ultimately leads to ultrafiltration failure.¹¹

Episodes of peritonitis (bacterial infections in the peritoneal cavity) can also permanently impair membrane function. Children with a history of peritonitis have a more permeable peritoneal membrane for creatinine and glucose than their peers without such episodes. Infections caused by Gram-negative bacteria in particular are associated with accelerated transport across the membrane, which may accelerate the loss of ultrafiltration efficiency.¹²

Regular assessment of the peritoneal membrane is essential for optimal management of paediatric PD patients. The basic method is the peritoneal equilibration test (PET), the most widely used procedure for measuring the transport of water and solutes across the peritoneum. A standard PET involves a 4-hour single exchange with a defined volume of dialysate (most often glucose solution), after which the ratio of the concentration of the selected solute in the dialysate to plasma (D/P, e.g. for creatinine) and the decline in the glucose concentration in the dialysate (D/D0) are determined. According to the obtained D/P ratio, membranes are classified from slow to fast transporters, which helps to adapt the dialysis regimen to each child. In the paediatric population, PET should be performed with a dialysate volume adjusted to the body surface area

(~1000–1100 mL/m²); too small a volume may cause faster concentration equilibration and consequently an incorrect assessment of the transport capacity of the membrane.¹³

In addition to the PET test, ultrafiltration and hydration status of the patient are monitored in daily care. Net ultrafiltration (the difference between total output and input volume) is recorded daily because a decline in ultrafiltration with clinical signs of fluid retention indicates a deterioration in membrane function. In this case, it is necessary to adjust the PD regimen – for example, shorten the dialysate dwell time, increase the concentration of the osmotic agent (glucose), or add an icodextrin solution – according to the established transport properties of the membrane. In children with a fast membrane transport, the administration of icodextrin in longer nocturnal cycles can significantly improve fluid removal. Also, periodic repetition of the PET test (e.g. once a year) can detect changes in membrane function over time, which allows timely adjustment of therapy and prolongation of the effective use of PD.^{11–13}

5.1.3. PD catheter

The key to successful PD is to ensure a functional peritoneal catheter with proper care to prevent complications – especially infections, which are the leading cause of PD failure in children. The standard peritoneal catheter is the Tenckhoff catheter – a flexible silicone tube with one or two Dacron cuffs. The catheter tip can be straight or coiled. In paediatrics, double-cuffed catheters with a downward-pointing tunnel are preferred, as this is associated with a lower rate of peritonitis.¹⁴

After catheter insertion, a period of about two weeks is recommended before starting dialysis, so that the tissue around the catheter tunnel can heal. During this period, the exit site is kept dry, covered with sterile gauze, and without manipulation (this reduces the risk of early leakage and infection). Once healed, daily hygiene of the exit site is essential to prevent infections: the skin around the catheter should be cleaned with a sterile antiseptic and covered with dry gauze. The catheter should be secured to the skin with a patch or tape/plaster to prevent movement and trauma, as catheter tugging at the exit site predisposes to infection. A strict aseptic technique (hand washing, sterile gloves, mask) is used when changing bags and flushing the

system. Prophylactic application of antibiotic ointment to the exit site (e.g., mupirocin or gentamicin) is also recommended, which has been shown to reduce the incidence of catheter infections and peritonitis.¹⁵

Mechanical complications include leakage of dialysate around the catheter or through the tunnel, especially if PD is started too early or with too large a volume, and also hernias, commonly umbilical or inguinal, caused by increased intra-abdominal pressure. Less frequent are pleuroperitoneal leakage (dispersion of dialysate into the pleural space) or catheter cuff extrusion. Intestinal perforation during catheter placement (<1% of cases) is extremely rare.¹⁶

The most important infectious complications are catheter exit site infection (ESI) and peritonitis. ESI is manifested by redness, pain, and purulent discharge around the catheter; and is treated with antibiotics, but if left untreated, it can progress to a tunnel infection and even peritonitis. Peritonitis is an infection of the peritoneum, and is manifested by cloudy dialysate, abdominal pain, and often fever. It is the most severe complication of PD that requires urgent administration of intraperitoneal antibiotics. Peritonitis is also the leading cause of PD therapy failure. Cessation of PD and transition to HD occurs in ~30% of cases.^{16,17}

Functional complications refer to disruption of the flow of dialysate through the catheter (malfunction). The most common causes are obstructions within the catheter or peritoneal cavity: e.g., kinking or movement of the catheter outside the pelvis, wrapping of the catheter around the omentum, or blockage of the opening with fibrin. This results in difficulty filling or draining the fluid. Many of these complications are preventable – for example, some centres routinely remove the omentum during catheter insertion to prevent omental obstruction. In case of suspected catheter malfunction, it is important to recognise the problem early: the nurse checks for external causes (kink in the tube, patient position) and informs the physician. Often, catheter flushing, radiological verification of position, or the surgical revision of repositioning or replacement of the catheter, is necessary.^{14,16}

5.1.4. PD components

PD in paediatric patients requires an individualised approach to ensure effective ultrafiltration and waste removal. The three key components of a PD regimen are solution selection, fill volume, and dwell time. Understanding these aspects is essential for optimising therapy and improving patients' quality of life.

PD solutions contain glucose in various concentrations (1.5%, 2.5%, 4.25%); the goal is to use the lowest effective concentration to minimise glucose absorption and peritoneal membrane damage.¹⁸

In addition to glucose solutions, alternative solutions are available:

- **Icodextrin** – a starch polymer that allows long-term ultrafiltration, most often used for the longest dwells, such as overnight in CAPD, or during the day in APD. It is helpful in patients with poor ultrafiltration but should not be used more than once a day.
- **Amino acid solutions** – used to improve nutritional status, but limited to one exchange per day to avoid metabolic burden.¹⁸

When choosing a solution, it is important to consider the composition of electrolytes and buffers:

- **Sodium (132–134 mmol/L):** Young children with intensive ultrafiltration are at risk of hyponatraemia, while anuric adolescents may retain sodium and water.
- **Calcium (1.25 or 1.75 mmol/L):** Higher concentrations are recommended for children in the growth phase or with hypocalcaemia, while lower concentrations are used in those receiving calcium and vitamin D supplements.
- **Buffer (lactate or bicarbonate):** Biocompatible solutions with bicarbonate reduce peritoneal irritation and better correct metabolic acidosis.¹⁸

The volume of dialysate is determined by body surface area (BSA), as too large or too small a volume can affect dialysis efficiency and patient tolerance.

- **Infants (<2 years):** Initial volume is 30–50 mL/kg per exchange but must be adjusted according to tolerability. Signs of intolerance include abdominal distension, vomiting, tachypnoea, or leakage around the catheter.

- **Children >2 years:** Volume is gradually increased to 1200–1400 mL/m², depending on growth and clinical response.

Effect of volume on dialysis: Higher volume allows for better clearance of waste products, but excessive volume may lead to abdominal pressure, herniation, and reduced ultrafiltration.⁹

Retention/dwell time determines how long the dialysis solution remains in the peritoneal cavity before drainage. This parameter depends on the PD modality and patient characteristics.

- **CAPD:** Dwells last 4–6 hours, and icodextrin can be used overnight for longer retention. Too long a dwell time can lead to fluid reabsorption, reducing ultrafiltration.
- **APD:** Involves shorter cycles (30–60 minutes) during the night, with the option of one longer dwell during the day. This modality is often used in children because it reduces the discomfort of a full abdomen and allows for greater flexibility.⁹

Adaptation to PET

PET determines the transport capacity of the peritoneum:

- Fast transporters quickly lose the osmotic gradient and need a shorter dwell time to prevent fluid reabsorption.
- Slow transporters maintain the osmotic gradient longer and may benefit from longer dwell times for better phosphate clearance.

Nurses should monitor the Kt/V of urea, which indicates the adequacy of dialysis (target: ≥ 1.8 per week). If Kt/V is low, adjustment of the dwell time or number of exchanges may be necessary.¹⁹

Specific clinical situations:

- In peritonitis, the membranes become more permeable, so the dwell time is shortened and the number of exchanges is increased to optimise peritoneal lavage.
- If the child has residual renal function, a less intensive regimen can be used, while with loss of renal function, the regimen is adjusted.
- In hyperkalaemia or metabolic acidosis, a shorter dwell time may improve potassium and acid elimination, whereas hyperphosphataemia may require a longer dwell time.⁹

5.1.5. Management of the most common complications in PD

Peritonitis

Peritonitis (infection of the peritoneum) is the most common complication of PD in children. Clinically, it presents with cloudy (turbid) dialysate and abdominal pain, often accompanied by fever, chills, nausea/vomiting, or abdominal distension. Any appearance of cloudy effluent should be considered a suspicion of peritonitis until another cause is excluded. The diagnosis is confirmed by analysis of the dialysate: >100 leukocytes/ μL (with $\geq 50\%$ neutrophils) strongly suggests peritonitis. The sample is sent for microbiological culture (Gram-positive bacteria will often be found; Gram-negative bacteria are also possible, and up to 5% of cases are fungal). Treatment of peritonitis is carried out by intraperitoneal administration of antibiotics, which allows for rapid bactericidal concentration in the peritoneum. Empirically, a combination that covers both Gram-positive and Gram-negative pathogens (e.g., vancomycin or cephalosporin) is often started, and the duration of therapy is at least 14 days (three weeks are recommended for *Staphylococcus aureus*). Clinical improvement and clarification of the dialysate are expected within 2–3 days. If no improvement is observed, a dialysate sample should be repeated to exclude complications such as intra-abdominal abscess or catheter tunnel infection. In the case of fungal peritonitis, catheter removal and antifungal therapy are indicated, with a delay in placing a new catheter for approximately two weeks. Recurrent or refractory peritonitis may also require catheter removal or replacement to prevent permanent peritoneal damage and ensure patient safety.^{20,21}

Catheter infections (exit-site and tunnel infections)

Infections of the catheter exit site (ESI) and subcutaneous tunnel are common in children on chronic PD. The most common causative agents are *Staphylococcus aureus* (often associated with skin/nasal colonisation) and *Pseudomonas aeruginosa*. These local infections significantly increase the risk of developing peritonitis, as bacteria can enter the peritoneum along the catheter. Therefore, it is important to inspect the catheter exit site daily – warning signs include redness of the skin around the catheter and pain or discharge (pus) from the outlet. Mild ESI is treated with local hygiene and targeted antibiotics

(e.g., mupirocin or gentamicin ointment locally for *S. aureus* or *Pseudomonas* infections, with oral antibiotics if necessary). Tunnel infections (spread of infection along the subcutaneous tunnel of the catheter) require a more aggressive approach – systemic antibiotics and, often, catheter removal if the infection does not resolve or is associated with peritonitis. Early recognition and treatment of ESI/TI are essential to prevent more severe complications. Preventive measures include adequate catheter site care using sterile techniques and prophylaxis against *S. aureus* e.g., daily application of mupirocin cream to the site significantly reduces the incidence of *S. aureus* infection and subsequent peritonitis. (Note: Due to the potential for resistance and colonisation by *Pseudomonas*, some units use gentamicin cream as an alternative.) Furthermore, the first dressing change of the exit site is delayed for approximately one week after catheter placement, and dialysis is ideally started 1–2 weeks after implantation to allow for healing and reduce the risk of leakage and infection.²¹

Ultrafiltration failure (UFF): Inadequate fluid removal in PD leads to fluid retention, oedema, and hypertension. UFF is an important complication of long-term PD, especially in children with no residual diuresis, and can result in fluid overload that compromises the heart and lungs. The most common causes are changes in the peritoneal membrane due to chronic exposure to hypertonic solutions and episodes of peritonitis, which lead to increased permeability (so-called high transporter – rapid reabsorption of dialysate) or fibrosis of the peritoneum. UFF is suspected when a child has a persistent positive fluid balance (fluid input > output), weight gain, oedema, and elevated blood pressure despite adequate dialysis. Recognition includes monitoring daily fluid intake and output, measuring the volume of dialysate drained, and performing a peritoneal equilibration test (PET) to assess the transport properties of the membrane. Management involves adjusting dialysis therapy: using solutions with a higher glucose concentration or adding icodextrin for longer dwells (which provides sustained ultrafiltration during longer dialysis intervals), shortening the dwell time in patients with rapid transport, and controlling salt and fluid intake. If peritoneal inflammation is present, treating peritonitis can improve membrane function. In some cases, unfortunately, chronic UFF means that the peritoneal membrane can no longer dialyse effectively, so switching to HD or kidney transplantation should be considered.^{9,22}

Dialysate leak and hernia: Leakage of dialysis fluid outside the peritoneal cavity is a common non-infectious complication of PD. It most commonly occurs around the catheter exit site (pericatheteric leak), especially if larger volumes are started too soon after catheter placement. Signs include fluid discharge around the catheter or swelling of the subcutaneous tissue, scrotum in boys, or labia in girls (with a leak toward the inguinal region). Rarely, dialysate can spread into the chest cavity (pleuroperitoneal leak) and cause hydrothorax – the child may have difficulty breathing and reduced dialysate output. Management of leaks includes reducing the filling volume, temporarily stopping PD, or using a cycler with multiple small exchanges, which reduces intraperitoneal pressure. Larger leaks may require surgical intervention (e.g., applying fibrin glue to the leak site or closing the defect). Abdominal wall hernias are also common due to chronic increased intra-abdominal pressure – they can be inguinal, umbilical, or incisional. The incidence of hernias in children with PD is reported to be over 50%, especially in infants. Any new swelling in the groin or umbilicus that occurs during PD suggests a hernia. Treatment is surgical closure of the hernia, with temporary discontinuation of dialysis (or volume reduction) until fully healed. Prevention includes careful catheter placement (e.g., laparoscopic technique reduces the risk of leakage and hernia) and avoiding excessive volume per cycle, especially in young children.²⁰

Practical guidelines for preventing complications

Sterile technique: Always work under sterile conditions when changing bags (hand washing, wearing masks, using sterile sets) to prevent contamination (the most common cause of so-called “touch contamination” leading to peritonitis).

Catheter outlet care: Inspect and maintain the catheter exit site daily (washing according to protocol, sterile dressings once a week). Use antibiotic ointment at the exit site (e.g., mupirocin or gentamicin) according to local guidelines to prevent bacterial colonisation.

Fluid balance monitoring: Regularly record fluid intake and output. Any decrease in dialysate outflow or negative ultrafiltration should be reported to the physician immediately – early detection of ultrafiltration failure and timely adjustment of therapy will prevent serious hypervolaemia.

Prevention of constipation: Constipation can cause poor flow or catheter blockage. Ensure an adequate diet rich in fibre and, if necessary, use laxatives to maintain regular bowel movements.

Growth and nutrition monitoring: Children on dialysis have increased nutritional needs. Nurses should monitor the child's weight and growth and collaborate with the dietitian to prevent malnutrition or obesity.

Multidisciplinary team collaboration: Optimisation of care is achieved through teamwork – regular contacts between nephrologists, dialysis nurses, surgeons (for catheter issues), dietitians, and social workers help in the early identification of problems and provide holistic care for the child.²¹

References

1. Mehrotra R, Devuyst O, Davies SJ, Johnson DW. The Current State of Peritoneal Dialysis. *Journal of the American Society of Nephrology* [Internet]. 2016 Jun 23 [cited 2020 Feb 9];27(11):3238–52. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5084899/>
2. Akoh JA. Peritoneal dialysis associated infections: An update on diagnosis and management. *World Journal of Nephrology* [Internet]. 2012 [cited 2019 May 15];1(4):106. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3782204/>
3. Huang YH, Chou CM, Huang SY, Chen HC. Paediatric Emergent Peritoneal Dialysis in Intensive Care Units: Indications, Techniques, and Outcomes. *Blood Purification*. 2024;53(8):676–85.
4. Schuh MP, Nehus E, Liu C, Ehlayel A, Clark S, Chishti A, et al. Omentectomy reduces the need for peritoneal dialysis catheter revision in children: a study from the Paediatric Nephrology Research Consortium. *Paediatric nephrology (Berlin, Germany)* [Internet]. 2021 Dec;36(12):3953–9. Available from: <https://pubmed.ncbi.nlm.nih.gov/34128096/>
5. Fennell RS, Orak JK, Garin EH, Iravani A, Richard G, St John M. Continuous ambulatory peritoneal dialysis in a Paediatric population. *American journal of diseases of children (1960)* [Internet]. 1983 Apr;137(4):388–92. Available from: <https://pubmed.ncbi.nlm.nih.gov/6829519/>
6. Fabian Velasco R, Lagunas Muñoz J, Sanchez Saavedra V, Mena Brito Trejo JE, Qureshi AR, García-López E, et al. Automated peritoneal dialysis as the modality of choice: a single-center, 3-year experience with 458 children in Mexico. *Paediatric nephrology (Berlin, Germany)* [Internet]. 2008 Mar;23(3):465–71. Available from: <https://pubmed.ncbi.nlm.nih.gov/18058137/>

7. Lai W, Chiu M, Tse K, Lau S, Tong P. Automated Peritoneal Dialysis: Clinical Experience in 32 Children [Internet]. 2017 [cited 2025 Feb 28]. Available from: <https://www.semanticscholar.org/paper/Automated-Peritoneal-Dialysis%3A-Clinical-Experience-Lai-Chiu/c78a758b73ccda685e8597b14650ea7cb7f976c4>
8. Thavorncharoensap M, Chaikledkaew U, Youngkong S, Assanatham M, Wisanuyotin S, Chaiyapak T, et al. A comparison of health-related quality of life between continuous ambulatory peritoneal dialysis and automated peritoneal dialysis in children with stage 5 chronic kidney disease in Thailand: a randomized controlled trial. *Paediatric nephrology* (Berlin, Germany) [Internet]. 2025;10.1007/s00467-02406632-x. Available from: <https://pubmed.ncbi.nlm.nih.gov/39833615/>
9. Fischbach M, Warady BA. Peritoneal dialysis prescription in children: bedside principles for optimal practice. *Paediatric Nephrology*. 2009 Sep;24(9):1633–42.
10. Saxena R. Pathogenesis and treatment of peritoneal membrane failure. *Paediatric Nephrology*. 2008 May;23(5):695–703.
11. Claus Peter Schmitt, Zaloszc A, Betti S, Fischbach M. Peritoneal Dialysis Tailored to Paediatric Needs. *International Journal of Nephrology* [Internet]. 2011 Jan 1 [cited 2024 Jan 13];2011:1–9. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3132841/>
12. Andreoli SP, Leiser J, Warady BA, Schlichting L, Brewer ED, Watkins SL. Adverse effect of peritonitis on peritoneal membrane function in children on dialysis. *Paediatric nephrology* (Berlin, Germany) [Internet]. 1999 Jan;13(1):1–6. Available from: <https://pubmed.ncbi.nlm.nih.gov/10100281/>
13. Romani RF, Waniewski J, Kruger L, Lindholm B, Nascimento MM. Comparison of three PET methods to assess peritoneal membrane transport. *Brazilian Journal of Medical and Biological Research*. 2019;52(8).
14. David VL, Mussuto E, Stroescu RF, Gafencu M, Boia ES. Peritoneal Dialysis Catheter Placement in Children: Initial Experience with a “2+1”-Port Laparoscopic-Assisted Technique. *Medicina* [Internet]. 2023 May 16 [cited 2024 Jun 27];59(5):961. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10223083/>
15. Warady BA, Bakkaloglu S, Newland J, Cantwell M, Verrina E, Neu A, et al. Consensus Guidelines for the Prevention and Treatment of Catheter-related Infections and Peritonitis in Paediatric Patients Receiving Peritoneal Dialysis: 2012 Update. *Peritoneal Dialysis International*. 2012 Jun 1;32(Supplement 2):S32–86.
16. Peppelenbosch A, van Kuijk WHM, Bouvy ND, van der Sande FM, Tordoir JHM. Peritoneal dialysis catheter placement technique and complications. *Clinical Kidney Journal* [Internet]. 2008 Sep 18 [cited 2020 Sep 11];1(suppl 4):iv23–8. Available from: <https://dx.doi.org/10.1093%2Fndtplus%2Ffsn120>

17. National Institute of Diabetes and Digestive and Kidney Diseases. Peritoneal Dialysis | NIDDK [Internet]. National Institute of Diabetes and Digestive and Kidney Diseases. 2019. Available from: <https://www.niddk.nih.gov/health-information/kidney-disease/kidney-failure/peritoneal-dialysis>
18. Schmitt CP, Bakkaloglu SA, Klaus G, Schröder C, Fischbach M, European Paediatric Dialysis Working Group. Solutions for PD in children: recommendations by the European Paediatric Dialysis Working Group. Paediatric nephrology (Berlin, Germany) [Internet]. 2011 Jul;26(7):1137–47. Available from: <https://pubmed.ncbi.nlm.nih.gov/21448787/>
19. NKF KDOQI Guidelines [Internet]. Cachefly.net. 2025. Available from: https://kidneyfoundation.cachefly.net/professionals/KDOQI/guideline_upHD_PD_VA/pd_rec6.htm
20. Fraser N, Hussain F, Connell R, Shenoy M. Chronic peritoneal dialysis in children. International Journal of Nephrology and Renovascular Disease. 2015 Oct;125.
21. Chadha V, Schaefer FS, Warady BA. Dialysis-associated peritonitis in children. Paediatric Nephrology [Internet]. 2009 Feb 4;25(3):425–40. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2810362/>
22. Krediet RT. Ultrafiltration Failure Is a Reflection of Peritoneal Alterations in Patients Treated With Peritoneal Dialysis. Frontiers in Physiology. 2018 Dec 20;9.

5.2. Haemodialysis

Learning objectives

- To understand the basic principles of haemodialysis in paediatric patients.
- To identify and address the limitations and unique considerations of haemodialysis in paediatric patients.
- To understand the constraints, specific considerations, and the required equipment of a dialysis machine for paediatric patients.
- To recognize the importance of water quality in paediatric haemodialysis and its impact on patient safety.
- To recognize different vascular access types for haemodialysis; to understand handling techniques, to know how to use safely, to identify possible complications and know how to limit it.
- To understand the importance of anticoagulation in the extracorporeal circuit.
- To recognize life threatening complications on haemodialysis and be able to react appropriately.

The prevalence of end-stage kidney disease and the need for kidney replacement therapy in children vary globally.^{1,2,3} While early kidney transplantation is the preferred treatment,⁴ many children require PD or haemodialysis (HD), delivered either in hospital or at home.

Paediatric patients can undergo five extracorporeal types of treatment: HD, haemodiafiltration (HDF), single-needle haemodialysis (SNHD), isolated ultrafiltration (IUF), and home haemodialysis (HHD). When initiating dialysis, treatment begins with an acute prescription, which is refined over time to develop a long-term regimen tailored to the patient's needs.

Haemodialysis (HD) removes toxins and excess fluid from the blood using a semipermeable membrane. It functions through two main processes:

- **Diffusion:** Small solutes, such as urea and electrolytes, move from the blood to the dialysate following a concentration gradient. Factors affecting diffusion include solute concentration, membrane properties, and blood/dialysate flow rates.

- **Ultrafiltration:** The removal of water from the patient's plasma by creating a pressure gradient across the membrane (hydrostatic pressure). This pressure difference moves water across the membrane, dragging solutes (via convection) that are not excluded by pore size.

Haemodiafiltration (HDF) combines diffusion and convection, improving the removal of middle molecules. It is preferred for Chronic Kidney Disease (CKD) due to its benefits in fluid control, toxin clearance, and patient outcomes.^{5,6}

Key Features of HDF:

- **Convective Clearance:** Solutes move with water through the membrane via pressure-driven flow.
- **Replacement Fluid:** Sterile dialysate (substitution fluid) is infused to allow convection and maintain electrolyte and fluid balance. This volume is removed along with UF during the session.
- **Clinical Benefits:** HDF improves haemodynamic stability, blood pressure control, inflammatory markers, anaemia management, growth, nutrition, and parathyroid hormone (PTH) regulation.⁵

Types of HDF:

- **Pre-dilution HDF:** Replacement fluid is added before the blood enters the dialyser, reducing viscosity and allowing higher convection volumes. This is useful for polyuric patients, those with difficult vascular access, or those experiencing circuit clotting. The Fresenius 6008 automatically delivers the recommended 75–100% of blood volume substitution.^{5,6}
- **Post-dilution HDF:** Replacement fluid is added after the dialyser, optimising solute clearance by maintaining a high concentration gradient. The target substitution volume is 23 L/1.73m².^{5,6}

Isolated Ultrafiltration (IUF) removes excess fluid without clearing solutes. Unlike conventional dialysis, it operates without dialysate flow, reducing heat exchange and potentially causing cold sensitivity in patients. However, in HD and HDF, cooler dialysate has been shown to improve haemodynamic stability and reduce intradialytic hypotension (IDH).⁷

Mechanism of IUF:

- Fluid Removal Without Dialysis: Extracts plasma water via transmembrane pressure differences.
- Negative Pressure: The machine applies controlled pressure to move plasma water into the dialysate.
- No Dialysate Flow: Solutes remain in the blood.
- IUF is often used in combination with HD or HDF treatments or can be used as an isolated treatment for fluid overload management.

Single-Needle Haemodialysis (SNHD) is primarily used for infants under 5 kg or patients with limited vascular access. Unlike conventional HD, which requires two lumens, SNHD alternates blood withdrawal and return using a single lumen.

SNHD Process:

1. Blood Withdrawal: The venous line is clamped, allowing blood to fill the bubble trap until a preset pressure is reached.
2. Blood Return: The clamp releases, returning blood to the patient until the lower pressure threshold is met.
3. Cycle Repeats: This results in intermittent rather than continuous flow.

A Y-connector is required, but recirculation can reach 20%, reducing overall toxin clearance compared to conventional double-needle HD.⁷

Home Haemodialysis (HHD) is considered the optimal method of dialysis, as it allows for individualised treatment plans, leading to improved patient outcomes and quality of life.⁸ By offering greater flexibility in dialysis frequency and duration, HHD can help reduce complications, enhance patient well-being, and improve long-term prognosis.

References

1. Rees L, Schaefer F, Schmitt CP, Shroff R, Warady BA. Chronic dialysis in children and adolescents: challenges and outcomes. *Lancet Child Adolesc Health*. 2017 Sep;1(1):68-77. doi: 10.1016/S2352-4642(17)30018-4. Epub 2017 Jul 20. PMID: 30169229.
2. Bertram JF Goldstein SL Pape L et al. Kidney disease in children: latest advances and remaining challenges. *Nat Rev Nephrol*. 2016; 12: 182-191.
3. Schaefer F Borzych-Duzalka D Azocar M et al. Impact of global economic disparities on practices and outcomes of chronic peritoneal dialysis in children: insights from the International Paediatric Peritoneal Dialysis Network Registry. *Perit Dial Int*. 2012; 32: 399-409
4. Matoussevitch, V; Taylan, C; Konner, K; Gawenda, M; Kuhr, K; Hoppe, B; Brunkwall, J (2015) AV Fistula Creation in Paediatric Patients: Outcome is Independent of Demographics and Fistula Type Reducing Usage of Venous Catheters. *Journal of Vascular Access* 16 (5): 382-387
5. Shroff R, Bayazit A, Stefanidis CJ, Askiti V, Azukaitis K, Canpolat N, Agbas A, Anarat A, Aoun B, Bakkaloglu S, Bhowruth D, Borzych-Duzalka D, Bulut IK, Büscher R, Dempster C, Duzova A, Habbig S, Hayes W, Hegde S, Krid S, Licht C, Litwin M, Mayes M, Mir S, Nemec R, Obrycki L, Paglialonga F, Picca S, Ranchin B, Samaille C, Shenoy M, Sinha M, Smith C, Spasojevic B, Vidal E, Vondrák K, Yilmaz A, Zaloszyk A, Fischbach M, Schaefer F, Schmitt CP. Effect of haemodiafiltration vs conventional haemodialysis on growth and cardiovascular outcomes in children - the HDF, heart and height (3H) study. *BMC Nephrol*. 2018 Aug 10;19(1):199. doi: 10.1186/s12882-018-0998-y. PMID: 30097064; PMCID: PMC6086045.
6. Ahlmann C, Stronach L, Waters K, Walker K, Oh J, Schmitt CP, Ranchin B, Shroff R. Hemodiafiltration for children with stage 5 chronic kidney disease: technical aspects and outcomes. *Pediatr Nephrol*. 2024 Sep;39(9):2611-2626. doi: 10.1007/s00467-024-06285-w. Epub 2024 Feb 13. PMID: 38347283; PMCID: PMC11272808.
7. Schaefer, F., Symons, J.M. (2021). Technical Aspects of Haemodialysis in Children. In: Warady, B.A., Alexander, S.R., Schaefer, F. (eds) *Paediatric Dialysis*. Springer, Cham. https://doi.org/10.1007/978-3-030-66861-7_20
8. Hothi, D.K., Schmitt, C.P. (2021). Home Haemodialysis in Children. In: Warady, B.A., Alexander, S.R., Schaefer, F. (eds) *Paediatric Dialysis*. Springer, Cham. https://doi.org/10.1007/978-3-030-66861-7_23

5.2.1. Special features in paediatric haemodialysis

Children with chronic kidney disease (CKD) often progress to kidney failure, requiring dialysis as a temporary measure until transplantation can be performed.¹ Peritoneal dialysis (PD) is the preferred kidney replacement therapy (KRT) for infants with end-stage kidney disease (ESKD), while the proportion of children on haemodialysis (HD) increases with age, therefore HD is rarely used in neonates and infants due to high complication risks. However, there are certain clinical situations where HD is necessary and beneficial for small children, while recent advancements in HD equipment have made it feasible even for children weighing as little as 2 kilograms.²⁻³

5.2.1.1. Haemodialysis prescription

The HD prescription must be customized to meet each child's specific needs.⁴ Conventional HD enables rapid solute clearance through high blood and dialysate flow rates.⁵ A blood flow rate of 3–5 ml/kg/min is generally sufficient to achieve effective solute removal while maintaining haemodynamic stability.⁶ Blood line and dialyzer selection follow the principle that the extracorporeal circuit should not exceed 8%, and at most 10%, of the child's total blood volume, based on an estimated optimal weight of 80 mL/kg.⁷ In infants, exceeding 10% of their total blood volume in the circuit may cause complications. To reduce this risk, the circuit can be primed with red blood cells or 5% albumin.⁶

5.2.1.2. Vascular access

Regarding vascular access, the European Society for Paediatric Nephrology Dialysis Working Group recommends that children requiring chronic HD should ideally start with a functioning arteriovenous fistula (AVF) where appropriate. Cuffed central venous lines (CVLs) should be used in very small children, based on vessel size, surgical expertise, urgent or unplanned HD needs, patient preference, or when only a short period of HD is expected before transplantation. There is insufficient evidence to make specific recommendations regarding using arteriovenous grafts (AVGs) in children.⁸

5.2.1.3. Haemodialysis adequacy

Evaluating dialysis adequacy in children and adolescents involves achieving biochemical targets and incorporating clinical goals such as growth, bone health, cardiac function, and quality of life. The recommended target is a minimum equilibrated Kt/V (eKt/V) of 1.2 for thrice-weekly patients or a standardized Kt/V of 2.2 for those on augmented schedules.⁹

Conclusion

Recent technical innovations have significantly advanced dialysis, including haemodiafiltration (HDF), which combines diffusion and convection using a high-flux membrane and ultrapure dialysate¹⁰⁻¹¹ to clear middle-sized and large molecules.¹⁰ However, no machine has been approved for HDF in children weighing less than 10 kg.¹⁰ Despite these advancements, providing HD in children remains challenging due to various complications, such as hypotension, muscle spasms, dialysis disequilibrium syndrome, catheter-related issues, and long-term complications comprising hypertension, neurocognitive and neurodevelopmental delays, and psychological stress.² To address children's specialized needs and support their physical and psychosocial well-being, the Paediatric interdisciplinary team responsible for planning and coordinating individualized dialysis care should include a paediatric nephrologist, paediatric dialysis nurse, nutritionist, kidney social worker, and psychologist.¹²

References

1. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr Nephrol*. 2012;27(3):363-373. doi:10.1007/s00467-011-1939-1.
2. Cho H. Paediatric Haemodialysis. *Child Kidney Dis*. 2020;24:69-74. doi:10.3339/jkspn.2020.24.2.69.
3. Donckerwolcke RA, Bunchman TE. Haemodialysis in infants and small children. *Pediatr. Nephrol*. 1994;8(1):103-106. doi:10.1007/BF00868283.
4. Fischbach M, Edefonti A, Schröder C, Watson A. European Paediatric Dialysis Working Group. Haemodialysis in children: general practical guidelines. *Pediatr. Nephrol*. 2005 ;20(8):1054-1066. doi:10.1007/s00467-005-1876-y.
5. Raina R, Vijayaraghavan P, Kapur G, Sethi SK, Krishnappa V, Kumar D, et al. Haemodialysis in neonates and infants: A systematic review. *Semin Dial*. 2018;31(3):289-299. doi:10.1111/sdi.12657.
6. Paik KH. Renal replacement therapy in children with acute renal failure. *Korean J. Pediatr*. 2007;50:938-947.
7. Rees L, Schaefer F, Schmitt CP, Shroff R, Warady BA. Chronic dialysis in children and adolescents: challenges and outcomes. *Lancet Child Adolesc Health*. 2017;1(1):68-77. doi:10.1016/S2352-4642(17)30018-4.
8. Shroff R, Calder F, Bakkaloğlu S, Nagler EV, Stuart S, Stronach L, et al. European Society for Paediatric Nephrology Dialysis Working Group. Vascular access in children requiring maintenance haemodialysis: a consensus document by the European Society for Paediatric Nephrology Dialysis Working Group. *Nephrol Dial Transplant*. 2019;34(10):1746-1765. doi:10.1093/ndt/gfz011.
9. Ashby D, Borman N, Burton J, Corbett R, Davenport A, Farrington K, et al. Renal Association Clinical Practice Guideline on Haemodialysis. *BMC Nephrol*. 2019;20(1):379. doi:10.1186/s12882-019-1527-3.
10. Uthup S, Balan S, Lobo V. Monitoring and maintaining quality in the paediatric haemodialysis unit. *Pediatr Nephrol*. 2024. doi:10.1007/s00467-024-06559-3.
11. Ahlmann C, Stronach L, Waters K, Walker K, Oh J, Schmitt CP, et al. Hemodiafiltration for children with stage 5 chronic kidney disease: technical aspects and outcomes. *Pediatr Nephrol*. 2024;39(9):2611-2626. doi:10.1007/s00467-024-06285-w.
12. Chand DH, Swartz S, Tuchman S, Valentini RP, Somers MJ. Dialysis in Children and Adolescents: The Paediatric Nephrology Perspective. *Am J Kidney Dis*. 2017;69(2):278-286. doi:10.1053/j.ajkd.2016.09.023.

5.2.2. Dialysis machine, required equipment, and water quality

The dialysis machine, along with the required equipment and water quality, plays a crucial role in ensuring safe and effective HD for paediatric patients. Proper functioning of the machine that meets children's special needs, use of appropriate supplies, and strict water quality standards are essential to prevent complications and ensure optimal treatment outcomes.

5.2.2.1. Dialysis machine

Long-term Paediatric HD utilizes miniaturized adult-designed devices. While the basic technical requirements are similar for both adults and children, Paediatric adjustments include lower blood flow rates (3–5 mL/kg/min, with a minimum of 50 mL/min) and dialysate flow rates as low as 100 mL/min.¹ No dialysis machine is validated for use in children weighing less than 10 kg.² Notably, CARPEDIEM (Bellco) and NIDUS (Allmed) HD machines can support infants as small as 800 grams, with slow pumps (5–50 mL/min) and a priming volume under 20 mL.³

Key advancements for safe Paediatric HD include improved ultrafiltration (UF) control, which is still inadequate for small children, and single-needle dialysis capability, limited by high extracorporeal blood volumes, and unsuitability for children under 40 kg. Haemodiafiltration (HDF) is feasible only for children over 10 kg with the Fresenius 6008, over 20 kg with the Nikkiso DBB-EXA and DBB-200Si, and over 40 kg with the Fresenius 4008.^{2,4} Additionally, features like urea-clearance monitoring (UCM), real-time UF control, and sodium transfer monitoring are often missing in low-volume blood line HD machines (e.g., Baxter AK98) or restricted to children over 40 kg (e.g., Fresenius 6008).²

5.2.2.2. Equipment

1. Dialyzers

For children, a dialyzer with a surface area suitable for the child's body should be selected, ensuring extracorporeal circulation stays below 10% of blood volume.⁵ The smallest dialyzers, such as Baxter Polyflux2H and Fresenius FxPaed, have priming blood volumes of 17 ml and 18 ml, respectively. Baxter, Fresenius, and Nipro provide

a full range of small dialyzers with membrane surface areas from 0.2 or 0.3 to 1.5 m², some of which support HDF with surface areas under 1 m² and 1.4 m².²

2. Extracorporeal lines

A range of blood lines is available, suitable for infants to large adolescents, with minimum volumes ranging from 36 ml to 143 ml depending on the HD machine.^{2,6} Selection should prioritize biocompatibility, an ethylene oxide-free sterilization method, and the required blood volume.⁶ However, smaller blood lines have higher resistance, which can significantly reduce blood flow and compromise the quality of blood purification. With various line types available, the dialysis team should aim to select lines that balance tolerable extracorporeal blood volume, optimized blood flow, and dialysis efficacy in children.²

3. Dialysate

Dialysate, a solution of water, electrolytes, and salts, removes toxins from the blood via a concentration gradient, balancing electrolytes in the patient's blood.⁷ In children, individualized electrolyte concentrations, including potassium, bicarbonate, and calcium are recommended.⁸

5.2.2.3. Water quality

Purified water in HD is used for mixing the dialysate, disinfecting, rinsing, or reprocessing the dialyzer. Dialysis water treatment uses reverse osmosis with or without deionization, optional storage, ultraviolet irradiator, and ultrafilters/endotoxin-retentive filters, which remove bacteria and endotoxins via size exclusion and charge.⁹ The European Renal Association recommends 100 CFU/ml for bacteria and endotoxin levels of 0.25 EU/ml for regular water, while ultrapure water limits are <0.01 CFU/ml bacteria growth and <0.03 IU/ml endotoxin.¹⁰

Conclusion

Paediatric HD requires adapted devices, precise flow rates, size-appropriate dialyzers, and optimized extracorporeal lines. High water quality is crucial for safety, while advancements in ultrafiltration and dialysis machines improve care but need further refinement.

References

1. Uthup S, Balan S, Lobo V. Monitoring and maintaining quality in the paediatric haemodialysis unit. *Pediatr Nephrol.* 2024. doi:10.1007/s00467-024-06559-3.
2. Ranchin B, Schmitt CP, Warady BA, Hataya H, Jones J, Lalji R, et al. technical requirements and devices available for long-term Haemodialysis in children-mind the gap! *Pediatr Nephrol.* 2024;39(9):2579-2591. doi:10.1007/s00467-023-06233-0.
3. Hothi DK. Designing technology to meet the therapeutic demands of acute renal injury in neonates and small infants. *Pediatr Nephrol.* 2014;29:1869–1871. doi:10.1007/s00467-014-2910-8.
4. Ranchin B, Schmitt CP, Warady B, Craig JC, Licht C, Hataya H, et al. Devices for long-term Haemodialysis in small children - a plea for action. *Kidney Int.* 2023;103(6):1038-1040. doi:10.1016/j.kint.2023.03.018.
5. Paik KH. Renal replacement therapy in children with acute renal failure. *Korean J Pediatr.* 2007;50:938-947.
6. Fischbach M, Terzic J, Menouer S, Provot E, Bergere V. Haemodialysis in children: principles and practice. *Semin Nephrol.* 2001;21:470–479. doi:10.1053/snep.2001.2001.24942.
7. Said N, Lau WJ, Ho YC, Lim SK, Zainol Abidin MN, Ismail AF. A Review of Commercial Developments and Recent Laboratory Research of Dialyzers and Membranes for Haemodialysis Application. *Membranes (Basel).* 2021;11(10):767. doi:10.3390/membranes11100767.
8. Ashby D, Borman N, Burton J, Corbett R, Davenport A, Farrington K, Flowers K, Fotheringham J, Andrea Fox RN, Franklin G, Gardiner C, et al. Renal Association Clinical Practice Guideline on Haemodialysis. *BMC Nephrol.* 2019;20(1):379. doi:10.1186/s12882-019-1527-3.
9. Coulliette AD, Arduino MJ. Haemodialysis and water quality. *Semin Dial.* 2013;26(4):427-438. doi:10.1111/sdi.12113.
10. Lonnemann G. Should ultra-pure dialysate be mandatory? *Nephrol Dial Transplant.* 2000;15 Suppl 1:55-99. doi:10.1093/oxfordjournals.ndt.a027965.

5.2.3. Vascular Access in Paediatric Haemodialysis

Haemodialysis Vascular Access (VA)

There are three main forms of VA used in paediatric HD: arteriovenous fistula, central venous catheter, and, less commonly, arteriovenous graft. Selecting the most appropriate VA for children requiring HD is challenging and requires early planning. Given that these children may need lifelong dialysis, preserving VA is crucial for improving long-term outcomes.^{1,2}

Central Venous Catheter (CVC) are the most used VA in children undergoing maintenance HD, despite their high complication rates. Issues such as poor blood flow, thrombosis, and infection²⁻⁴ often lead to inadequate dialysis, with nearly 45% of paediatric HD patients requiring line replacements.⁵

CVCs remain the preferred initial access method in children,^{6,7} largely due to factors such as:

- Surgical complexity associated with AVF creation
- Shorter waiting times for kidney transplantation
- Psychological factors, including anxiety and pain related to needle use.⁸

However, some of the risks associated with CVCs may be mitigated by advancements in locking solutions and infection prevention measures.^{2,9}

Arteriovenous Fistula (AVF) is created by surgically connecting a vein and an artery, resulting in a high-flow vein suitable for repeated needle insertion.

Although AVFs are the gold standard for VA in adults, growing evidence suggests they may also be the preferred option in paediatric patients.^{8,10,11,13} However, paediatric vascular biology differs from that of adults, making it difficult to determine the ideal vein and artery size, maturation time, and expected blood flow rates for optimal AVF function.^{8,10,11,13}

Potential benefits of AVF include:

- Lower infection, thrombosis, and stenosis rates
- Greater freedom for activities such as bathing and swimming

Possible complications include:

- Stenosis
- Thrombosis
- Steal syndrome
- Bleeding

Arteriovenous Graft (AVG) is created by surgically connecting a native vein and artery using a synthetic graft (commonly made of polytetrafluoroethylene). This graft segment can then be needled similarly to an AVF for HD.

AVGs are rarely used in children, and there is limited data on their formation, needling techniques, complications, and long-term outcomes. They are generally considered a last resort in paediatric patients with difficult VA.²

Preservation of Vascular Access in children with kidney disease is critical for ensuring better long-term outcomes. Healthcare professionals performing venepuncture on these patients should receive specialised training to protect veins that may be needed for future dialysis access. Similarly, dialysis staff should be educated on proper CVC, AVF and AVG management to maintain patency and minimise infection risks.

However, the child and their caregivers play the most crucial role in vascular access preservation through empowerment of knowledge. Providing age-appropriate education, supported by a play specialist, can empower children to advocate for their own care and ensure the longevity of their VA.

References

1. Chand DH, Valentini RP, Kamil ES. Haemodialysis vascular access options in Paediatric s: considerations for patients and practitioners. *Pediatr Nephrol.* 2009 Jun;24(6):1121-8.
2. Shroff R, Calder F, Bakkaloğlu S, Nagler EV, Stuart S, Stronach L, Schmitt CP, Heckert KH, Bourquelot P, Wagner AM, Paglialonga F, Mitra S, Stefanidis CJ. European Society for Paediatric Nephrology Dialysis Working Group, Vascular access in children requiring maintenance haemodialysis: a consensus document by the European Society for Paediatric Nephrology Dialysis Working Group, *Nephrology Dialysis Transplantation*, Volume 34, Issue 10, October 2019, Pages 1746–1765.

3. Bruno C, Moumneh R, Sauvage E, Stronach L, Waters K, Simcock I, Arthurs O, Schievano S, Capelli C, Shroff R. Central Venous Catheter Malfunction in Children: A Bioengineering Approach. *Clinical Journal of the American Society of Nephrology*. 2022. Sep;17(9):1382-1384
4. Borzych-Duzalka D, Shroff R, Ariceta G, Yap YC, Paglialonga F, Xu H, Kang HG, Thumfart J, Aysun KB, Stefanidis CJ, Fila M, Sever L, Vondrak K, Szabo AJ, Szczepanska M, Ranchin B, Holtta T, Zaloszczyk A, Bilge I, Warady BA, Schaefer F, Schmitt CP: Vascular Access Choice, Complications, and Outcomes in Children on Maintenance Haemodialysis: Findings From the International Paediatric Haemodialysis Network (IPHN) Registry. *American Journal of Kidney Diseases* 74: 2019
5. Bruno, Claudia & Moumneh, Rayan & Stronach, Lynsey & Sauvage, Emilie & Simcock, Ian & Schievano, Silvia & Capelli, Claudio & Shroff, Rukshana. (2024). #1967 Towards the design optimisation of catheters for paediatric dialysis using a bioengineering approach. *Nephrology Dialysis Transplantation*. 39. 10.1093/ndt/gfae069.788.
6. Hayes WN, Watson AR, Callaghan N, Wright E, Stefanidis CJ. Vascular access: choice and complications in European paediatric haemodialysis units. *Pediatr Nephrol*. 2012; 27(6):999–1004.
7. Mak RH, Warady BA. Dialysis: vascular access in children-arteriovenous fistula or CVC? *Nat Rev Nephrol*. 2013;9:9–11.
8. Ma A, Shroff R, Hothi D et al. A comparison of arteriovenous fistulas and central venous lines for long term chronic haemodialysis. *Pediat Nephrol*. 2012; 28(2):321–326.
9. Hemmelgarn BR, Moist LM, Lok CE, Tonelli M, Manns BJ, Holden RM, LeBlanc M, Faris P, Barre P, Zhang J, Scott-Douglas N. Prevention of dialysis catheter malfunction with recombinant tissue plasminogen activator. *N Engl J Med*. 2011; 364: 303–312
10. Manook M, Calder F. Practical aspects of arteriovenous fistula formation in paediatric population. *Pediat Nephrol*. 2013; 28(6):885–893.
11. Merouani A, Lallier M, Paquet J, Gagnon J, Lapeyraque AL. Vascular access for chronic haemodialysis in children: arteriovenous fistula or central venous catheter? *Paediatric Nephrol*. 2014; 29:2395–2401.
12. Akturk A, Bakx R, Oosterveld MJS, Wilde JCH, Idu MM. Microsurgery for "wrist" arteriovenous fistula creation in children: a retrospective cohort study. *J Vasc Access*. 2018 Mar;19(2):137-140.
13. Shroff R, Sterenborg RB, Kuchta A, Arnold A, Thomas N, Stronach L, Padayachee S, Calder F. A dedicated vascular access clinic for children on HD: Two years' experience. *Pediatr Nephrol*. 2016 Dec;31(12):2337-2344.

5.2.4. Anticoagulation in the Extracorporeal Circuit

Learning objectives

- Understand the basic principles of HD in paediatric patients.
- Identify and address the limitations and unique considerations of HD in paediatric patients.

Circuit patency is essential for effective HD. Adequate anticoagulation prevents clot formation, ensuring blood flow remains uninterrupted throughout treatment. Most HD machines use an integrated heparin pump, positioned post-arterial blood pump and before the dialyser, to prevent negative pressure from pulling heparin into the system.

Anticoagulation for chronic HD circuits uses two main types of heparin:

1. Unfractionated Heparin (UFH) Infusion
2. Low-Molecular-Weight Heparin (LMWH)

Historically, UFH has been the preferred anticoagulant due to its low cost, ease of use, and reversibility with protamine.¹ The dosing with continuous infusion for UFH has been suggested 20 to 30 IU kg/hr². Some units adjust UFH dosing to maintain an activated clotting time (ACT) of 180–220 seconds or an aPTTr of 1.5–2.0, while others visually inspect the circuit for clots post-dialysis and adjust doses accordingly³. For patients with fistula access, stopping UFH 30 minutes before session end can help prevent post-dialysis bleeding. UFH can give more flexibility if a session needs to be extended.

Low-Molecular-Weight Heparin (LMWH) use in paediatric HD has increased due to its ease of administration, predictable effect, and decreasing cost differential.³

Enoxaparin: A single dose at session start, with an optional top-up at two hours, may be used for extended dialysis sessions.⁴

- Dalteparin: Found to be safe and effective in-home haemodialysis (HHD).⁵
- Tinzaparin: Has the shortest half-life and lowest anti-IIa/Xa ratio, allowing partial reversal with protamine in cases of over-coagulation.³

Some units measure anti-Xa levels to optimise dosing and prevent accumulation. Recommended peak anti-Xa levels include:

- 0.4–0.6 IU/ml.^{3,6}
- More recent guidelines suggest 0.2–0.4 IU/ml.⁷

However, many centres rely on visual inspection of clotting in the venous air detector, dialyser, and needle puncture sites to assess LMWH effectiveness.^{8,9}

Regional Citrate Anticoagulation is sometimes used in acute dialysis or when there is a high risk of bleeding.¹⁰ Citrate binds to calcium, preventing clot formation in the extracorporeal circuit. However, since calcium is essential for coagulation, this method requires continuous calcium infusions and frequent monitoring of plasma ionised calcium levels. These additional requirements make regional citrate challenging to manage in a chronic HD setting.

Heparin-Free HD is sometimes necessary for patients at increased risk of bleeding, whether this be due to recent surgery or an underlying bleeding disorder. Since platelets play a key role in circuit clotting, patients with thrombocytopenia may require little or no heparin during HD. However, maintaining circuit patency can be more difficult in certain groups, such as neonates with smaller circuits and those on single-needle dialysis, who often struggle without anticoagulation. In these cases, careful monitoring and alternative strategies may be necessary to prevent clot formation while minimising bleeding risk.

Catheter Locking Solutions are essential to maintain the patency of a CVC, reduce complications and ultimately preserve vascular access. To aid in the patency of a HD circuit, good functioning vascular access (VA) is pivotal. VA in children is more complex due to the anatomical nature of smaller vessels which can increase the risk of occlusion.¹¹ Most paediatric HD units use heparin as the standard CVC locking solution, though concentrations vary, usually 1000 units/ml or 5000 units/ml. Alternative agents may enhance catheter patency and reduce thrombosis risk.

The use of a fibrinolytic medication such as Alteplase or Urokinase is the preferred choice rather than heparin for initial catheter dysfunction^{12,13,14,15,16} and due to intraluminal tip thrombi causing fibrin sheaths being the predominant cause.¹⁷ While fibrinolytic

medication is more expensive, its ability to extend catheter life, reduce complications, and preserve vascular access makes it a valuable option.

References

1. Borzych-Duzalka D, Harvey E. Non-infectious Complications of Haemodialysis in Children. In: Warady BA, Alexander SR, Schaefer F (eds) *Paediatric Dialysis*. Springer, Cham. 2021. p 445
2. Fischbach M, Edefonti A, Schröder C, Watson A; European Paediatric Dialysis Working Group. Haemodialysis in children: general practical guidelines. *Pediatr Nephrol*. 2005 Aug;20(8):1054-66.
3. Davenport A. Alternatives to standard unfractionated heparin for Paediatric Haemodialysis treatments. *Pediatr Nephrol*. 2012 Oct;27(10):1869-79.
4. Shroff R, Preka E, Ranchin B. Haemodiafiltration: Principles, Technique, and Advantages over Conventional Haemodialysis. In: Warady BA, Alexander SR, Schaefer F (eds) *Paediatric Dialysis*. Springer, Cham. 2021. P 359 -378
5. Lutkin M, Stronach L, Yadav P, Hothi D. Dalteparin anticoagulation in paediatric home haemodialysis. *Pediatr Nephrol*. 2018. 33, 2337–2341.
6. Saltissi D, Morgan C, Westhuyzen J, Healy H. Comparison of low-molecular-weight heparin (enoxaparin sodium) and standard fractionated heparin for haemodialysis. *Nephrol Dial Transplant*. 1999; 14:2698–2703.
7. Davenport A. Anticoagulation options for intermittent haemodialysis. *Minerv Urol. Nefrol*. 2006; 58: 171–80.
8. Seeherunvong W, Rubio L, Abitbol CL, Montané B, Strauss J, Diaz R, Zilleruelo G. Identification of poor responders to erythropoietin among children undergoing Haemodialysis. *J Pediatr*. 2001;138:710–714.
9. Zhang W, Xiaonong Chen X, Chen Y, Chen N. Clinical experience with nadroparin in patients undergoing dialysis for renal impairment. *Hemodial Int*. 2011;15:379–384..
10. Strazdins V, Stefanidis V, Watson AR, Harvey B (2004) Renal replacement therapy for acute renal failure in children: European guidelines. *Pediatr Nephrol*. 19:199–207
11. Ragsdale C, Thompson A, Evans M. Alteplase infusion Versus Dwell for Clearance of Partially Occluded Central Venous Catheters in Critically Ill Paediatric Patients', *Pediatric Critical Care Medicine*. 2014. 15 (6), pp. 253-260
12. United Kingdom Kidney Association (UKKA) (2023b) *UK Kidney Association Clinical Practice Guideline: Vascular Access for Haemodialysis*. Available from: FINAL FORMATTED Vascular access for haemodialysis April 2023.pdf (ukkidney.org) (Accessed on 19th March 2025)

13. Shroff R, Calder F, Bakkaloğlu S, Nagler EV, Stuart S, Stronach L, Schmitt CP, Heckert KH, Bourquelot P, Wagner AM, Paglialonga F, Mitra S, Stefanidis CJ. European Society for Paediatric Nephrology Dialysis Working Group. Vascular access in children requiring maintenance haemodialysis: a consensus document by the European Society for Paediatric Nephrology Dialysis Working Group', *Nephrology Dialysis Transplantation*, 2019. 34(10), pp.1746–1765.
14. Deng J, Luo W, Zhang W, Xiong S, Wang L. Efficacy of urokinase in maintaining patency of Haemodialysis catheters: A meta-analysis. *Clin Nephrol*. 2024 Oct;102(4):212-222.
15. Gittins NS, Hunter-Blair YL, Matthews JN, Coulthard MG. Comparison of alteplase and heparin in maintaining the patency of paediatric central venous haemodialysis lines: a randomised controlled trial. *Arch Dis Child*. 2007 Jun;92(6):499-501.
16. Cho Heeyeon. (2020). Paediatric Haemodialysis. *Childhood Kidney Diseases*. 24. 69-74.
17. Giordano P, Saracco P, Grassi M, Luciani M, Banov L, Carraro F, Crocoli A, Cesaro S, Zanazzo G, Molinari A. Italian Association of Paediatric Hematology and Oncology (AIEOP) Recommendations for the use of long-term central venous catheter (CVC) in children with hemato-oncological disorders: management of CVC-related occlusion and CVC-related thrombosis. On behalf of the coagulation defects working group and the supportive therapy working group of the Italian Association of Paediatric Hematology and Oncology (AIEOP)', *Ann Hematology*, 2015. 94(11), pp.1765-76. DOI: 10.1007/s00277-015-2481-1.

5.2.5 Life threatening complications on Haemodialysis

Paediatric Haemodialysis (HD) is a complex treatment which poses an element of risk and potential complications.

Vascular air embolism (VAE) is a rare but potentially life-threatening event which occurs from air entering the vasculature. It can be arterial or venous. VAE can happen when there is a direct contact between the vein and the air with the addition of a pressure gradient.¹

Haemodialysis Central Venous Catheters (CVCs) are wide bore with a large internal diameter, thus at higher risk than narrower catheters. Factors affecting morbidity and mortality include the rate and volume the air enters the patient, the site of entrance and patient position.^{2,3}

Signs and Symptoms:

- Dyspnoea
- Coughing
- Light headedness
- Chest pain
- Tachypnoea
- Change in colour: blue/purple
- Hypotension
- Tachyarrhythmias
- Agitation/disorientation
- Confusion
- Altered mental status

Prevention is key. Checking equipment prior to use, the use of leur lock syringes and valved bungs, tight connections, double clamping lines and ensuring staff competence is essential. Treatment involves 100% oxygen, Trendelenburg positioning, to allow entrapped air in the heart to be stabilised within the apex of the ventricle.⁴ If CPR is required, the patient should be placed in the supine position with their head down.

Haemolysis is rapid destruction of red blood cells and the release of their contents, such as haemoglobin and potassium into surrounding plasma, it is a rare complication of HD and occurs due to mechanical

or chemical faults, such as kinked tubing, vascular access (VA) occlusion, blood pump faults, contaminated dialysate or water. Red blood cells of a patient in CKD are more fragile and have a shorter life span, thus more at risk of haemolysis.⁵

Signs and symptoms:

- Chest Pain
- Hypertension
- Abdominal Pain
- Nausea, vomiting, diarrhoea
- Back pain
- Headaches
- Cyanosis, pallor
- Discoloured extracorporeal circuit – brighter red
- Blood Leak alarm
- Positive test for blood on dipstick from dialysate
- Sudden loss of Blood Volume Monitoring (BVM) – failure due to drop in haematocrit

If haemolysis is suspected stop HD, without returning the circuit as this may exacerbate symptoms. Check all other patients on the unit for similar symptoms as it may not be an isolated incident.

Life Threatening Haemorrhage (LTH) can be caused from a spontaneous haemorrhage from an arterio-venous fistula (AVF), venous needle dislodgement (VND) or venous catheter disconnection whilst on HD. Both are a clinical emergency and urgent help is required. Warning signs of a high risk AVF include non-healing or pointy needle sites, aneurysms increasing in size, shiny skin over aneurysms, poor skin integrity, signs of infection and prolonged bleeding post needle removal.

VND or venous line disconnection can be catastrophic. It is vital to stop the blood pump immediately to prevent further blood loss, call the clinical emergency team and activate the major haemorrhage protocol. Pressure should be applied to the Venous needle site if it the needle has come out or it is bleeding. The patients' blood circuit can be returned via the Arterial needle site.

Patient risk assessment, correct taping techniques with AVFs, use of a stabilisation device, visibility of connection sites and safe alarm handling including use of VND technology are all essential for prevention of LTH on HD.⁶

Dialysis Disequilibrium Syndrome (DDS) is an acute neurological dysfunction occurring from rapid urea clearance on HD causing an increase in osmotic pressure and subsequent influx of fluid into the brain causing cerebral oedema, occurring due to serum urea levels being reduced more quickly than the urea levels in the CSF and brain.⁷ Symptoms include:

- Headache
- Agitation
- Restlessness
- Vomiting
- Muscle cramps
- Blurred vision
- Disorientation/mental confusion,
- Seizures
- Central pontine myelinolysis (CPM)
- Coma and death.

Prevention of dialysis disequilibrium includes reducing urea levels slowly, aiming for a URR of 0.4 (40%).⁸ To achieve this, use small dialyser sizes, shorter sessions, slower blood flow rates (Qb), lower dialysate flow (Qd) and consider Mannitol, 3% saline or other osmotic solutions.

Seizures can have HD specific causes such as hypertension, change in serum sodium levels, hypocalcaemia, dialysis disequilibrium and medication dosing must be considered as part of the differential diagnosis.

Regular monitoring of electrolytes and medicating appropriately, including keeping the Dialysate Sodium (Na) within 5mmols/litre of serum Na⁹, providing 1g/litre of glucose in the dialysate and ensure correct kidney dosing of all antiepileptic medication are all important factors to prevent seizures on HD.

Anaphylaxis on HD should be managed following local protocols utilising history taking to ascertain cause. Specific HD causes could relate to the extracorporeal circuit or dialyser, more specifically the sterilant or components of the dialyser material or medication given on HD.

Signs and symptoms:

- Dyspnoea
- Chest pain
- Wheezing
- Coughing
- Throat tightness
- Rash
- Tachycardia, weak pulse
- Hypotension
- Abdominal pain,
- Nausea, vomiting, diarrhoea,
- Anxiety, sense of impending doom, headache.

If anaphylaxis is suspected due to the HD circuit (possible recent change to the prescription) stop HD, do not return the extracorporeal circuit and do not administer fluids via the circuit. Be aware that signs and symptoms for haemolysis and anaphylaxis are similar.

References

1. Alzghoul H, Jin P, Vahdatpour C, Alzghoul B. Fatal venous air embolism in the setting of Haemodialysis and pulmonary hypertension: A point of care ultrasound diagnosis. *Respiratory Medicine*. 2023. 42 doi: 10.1016/j.rmcr.2023.101819
2. Mirski M, Lele A, Fitzsimmons L, Toung T. Diagnosis and Treatment of Vascular Air Embolism. *Anesthesiology*. 2007. 106 (1) p164-175.
3. Natal B, Doty C. Venous Air embolis. 2016. Available from: <http://emedicine.medscape.com/article/761367-overview>
4. Gordy S, Rowell S. Vascular Air Embolism. *International Journal of Critical Illness and Injury Science*. 2013. 3 (1) p73-76.
5. Sam R, Haghighat R, Kjellstrand C, Ing T. During Haemodialysis. 2009. 15 (5) pp. 457-466 DOI: 10.1016/B978-1-4160-4197-9.50035-1
6. UKKA (2023) STOP Guidance. Available from: <https://staging.ukkidney.org/sites/default/files/STOP%20Guidance%202023%20Final.pdf>. (Accessed 19th March 2025)
7. Richey, S. Dialysis Disequilibrium Syndrome: Treatment Leading to Fatality. *American society for Clinical Laboratory Science*. 2015. 28 (1). 15-18.
8. Zepeda-Orazco, D and Quigley, R. Dialysis disequilibrium syndrome. *Paediatric Nephrology*. 2012. 27 (12) pp. 2205-2211 Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3491204/>. (Accessed 19th March 2025)
9. Caporale O, Consolo S, Grassi FS, Grassi, MR, Puccio G, Montini G, Paglialonga F. Low dialysate sodium in childre and young adults on maintenance Haemodialysis: a prospective, randomized, crossover study. *Pediatr Nephrol*. 2023. 38(5). pp.1599-1607. DOI: 10.1007/s00467-022-05792-y.

5.3 Kidney Transplantation

Learning objectives

- To understand the role of the nurse in paediatric kidney transplantation.
- To identify key aspects of pre-transplant preparation and post-transplant management.
- To apply nursing strategies to improve post-transplant quality of life.

Introduction

Kidney transplantation (KT) is the KRT of choice for paediatric patients with end-stage kidney disease (ESKD). This therapeutic strategy has led to a significant improvement in both quality of life and long-term prognosis for paediatric patients with chronic kidney disease (CKD), particularly when compared to other KRT such as HD and PD.¹ However, the transplantation process is complex from a medical-surgical, nursing, and psychological perspective, encompassing the preoperative, intraoperative, and postoperative phases.

Nurses play a pivotal role in paediatric kidney transplantation, as they not only provide essential healthcare support but also serve as key figures in patient and family education. Specialized training and the implementation of updated clinical guidelines are therefore crucial to ensuring high-quality care and optimising outcomes for paediatric transplant recipients.

This chapter outlines the essential aspects of nursing care in paediatric kidney transplantation, with a focus on candidate preparation, the living donation process, perioperative nursing interventions, postoperative care, and medium- to long-term monitoring.

5.3.1. Preparing children with ESKD for KT

The therapeutic option of KT should be offered to all children with an eGFR < 15 ml/min/1.73 m² or undergoing dialysis.² The only contraindications to the transplantation process are any concomitant non-nephrological conditions that reduce life expectancy or have a poor prognosis. There is no universal age or body weight limit for recipients; however, kidney transplants performed in children weighing less than 10 kg are uncommon, as they carry a higher risk

of surgical complications (e.g., intraoperative graft hypoperfusion or thrombosis). Therefore, such procedures are performed exclusively in highly specialized centres.³

KT can be performed before the initiation of dialysis (pre-emptive KT) or in patients already undergoing dialysis. Due to the intrinsic characteristics of the underlying disease, patients with non-glomerular nephropathy are the ones most commonly receiving a pre-emptive transplant. Receiving a transplant without having undergone a period of dialysis improves overall patient outcomes and should therefore be encouraged.⁴

Preparation for KT is a complex process, especially in paediatric patients. It involves not only managing physical issues but also addressing psychological and social aspects. This requires close collaboration between various healthcare professionals and an approach that considers the specific needs of each child and their family. Given the unique challenges of this journey, it is advisable to begin preparing the child and their caregivers for KRT as soon as stage 4 CKD is reached.⁵

5.3.1.1 Multidisciplinary assessment of recipient eligibility

The preparation of a patient for the transplantation process begins with a multidisciplinary assessment aimed at identifying and, if necessary, managing any comorbidities that could increase the risk of post-transplant complications and compromise either patient or graft survival.

Nephrologists, transplant surgeons, urologists, anaesthetists, radiologists, immunologists, cardiologists, dietitians, psychologists, specialist nurses, and social workers (along with other specialists in selected cases) collaborate, each contributing their expertise to determine whether the child is a suitable candidate for transplantation. The management of comorbidities (through surgical or pharmacological approaches), the optimisation of nutritional status, and the completion of the vaccination schedule are essential to reducing the risk of complications and ensuring a favourable post-transplant course.

Nurses play an active role in this assessment process by collecting medical history data, evaluating the patient's physical and psychological status, and promptly identifying any potential

issues. Additionally, they contribute to the execution of biochemical and instrumental investigations required for patients with ESKD in preparation for kidney transplantation.⁶

5.3.1.2 Therapeutic education

Another fundamental phase in KT preparation is therapeutic education. In this stage, nurses play a crucial role in providing the child and their family with all the necessary information to navigate the transplantation process. Communication must be tailored to the family's level of understanding and the child's age, using appropriate educational tools and teaching materials.

Nurses must clearly and comprehensibly explain key aspects, including:

- the waiting period before transplantation: how the family will be informed about the possibility of proceeding with the transplant and what steps must be taken from the moment of acceptance until hospital admission (according to protocols established by each transplant centre)
- the surgical procedure: how the operation will be performed, where the graft will be positioned, and which catheters and drains will be placed
- hospitalisation for transplantation: the expected duration and course of hospitalisation, along with organisational aspects of the transplant unit
- immunosuppressive therapy: its purpose and the critical importance of adherence to prevent rejection episodes, along with potential side effects and the necessity of regular monitoring
- post-transplant lifestyle: dietary and behavioural recommendations, emphasising the importance of adopting a healthy lifestyle.

Specialist nurses should also openly discuss with the patient and their family the potential risks associated with transplantation, such as rejection or infections, while balancing these against the expected benefits, including an improved quality of life without the need for dialysis. This approach helps guide families through the transplantation process in an informed and conscious manner.

Actively engaging the patient and their family in the educational process promotes a clearer and more confident understanding of the transplantation pathway, leading to better adherence to medical and behavioural recommendations.⁶

5.3.1.3 Psychological support

The diagnosis of ESKD and the waiting period for a transplant can induce anxiety and stress not only in the child but also in parents and family members. Awareness of the risk of rejection, potential complications, and uncertainties regarding the surgical outcome can further increase the emotional burden. Nurses must be trained to recognise signs of psychological distress and provide emotional support. When necessary, paediatric psychologists should be involved to help address the anxieties and fears of both the child and their family. Creating a compassionate and supportive care environment that fosters a sense of security and hope is essential for psychologically preparing the child and their caregivers for KT.

5.3.2 Types of KT (living donor/deceased donor)

Paediatric KT can be performed using either a living donor or a deceased donor. The choice of donor type has a significant impact on surgical outcomes, recovery duration, and the risk of post-operative complications. The decision between a living or deceased donor is influenced by various factors, including compatibility, donor availability, and the recipient's clinical condition. Previously, ABO incompatibility and the presence of cytotoxic anti-lymphocyte antibodies against the donor were considered absolute contraindications to transplantation. However, subsequent advancements with specific desensitisation protocols have made such transplants feasible in certain centres.⁷ Alternatively, kidney paired donation (KPD), or crossover transplantation strategies can be considered.

A thorough evaluation of the donor, whether living or deceased, is essential to optimise transplant outcomes.

5.3.2.1. Living donor

Living donor KT is one of the preferred therapeutic options for paediatric patients, as it offers several advantages over deceased donor transplantation.⁸ In most countries, parents are the primary

donors, with mothers donating more frequently than fathers, followed by other family members. Altruistic (Samaritan) donors are only occasionally involved.

The most significant benefits of living donor kidney transplantation include:

- reduced waiting time for transplantation: the immediate availability of the organ significantly shortens the patient's time on the transplant waiting list and often enables pre-emptive transplantation, thereby avoiding the need for dialysis
- better immunological compatibility: when the donor is a close relative, such as a parent or sibling, immunological compatibility is generally superior, reducing the risk of rejection and improving long-term graft survival
- faster graft functional recovery: kidneys from living donors tend to function more efficiently than those from deceased donors, as they are not subjected to prolonged ischaemia, thereby lowering the risk of ischaemic-reperfusion injury.

The selection of a living kidney donor is a critical process requiring a comprehensive assessment to ensure the donor is both physically and psychologically fit to undergo donation. Advanced age is not an absolute contraindication to donation. Instead, each potential donor must undergo a thorough series of biochemical, clinical (including psychological), and diagnostic investigations to confirm their overall health status.⁹ Donation is strictly prohibited if there are immediate or long-term medical risks for the donor.¹⁰ It is also necessary to ensure that the weight ratio between the donor and the recipient is in accordance with the criteria established by the multidisciplinary team. Furthermore, it must be confirmed that the donation process is conducted voluntarily and with fully informed consent, free from financial incentives or coercion. Each donor must be informed about the potential risks associated with kidney donation surgery, as well as those that may arise during long-term follow-up.¹⁰ Donating a kidney carries a small risk of perioperative mortality, and after long-term follow-up (15 years), the mortality rate among former donors is slightly higher compared to the general population.¹¹ If the recipient has a nephrological condition with a high risk of post-transplant recurrence (e.g. focal segmental glomerulosclerosis), it is crucial to thoroughly inform the potential donor of this risk. However, evidence

suggests that in this patient population, graft survival rates are independent of donor type.¹²

The role of nurses in the donor selection and preparation process is fundamental. They provide informational and educational support, coordinate necessary clinical and diagnostic assessments, and monitor the physical and psychological well-being of the donor to ensure their suitability and safety throughout the entire process. Additionally, nurses facilitate communication between the multidisciplinary team and the donor, ensuring that the donor fully understands the risks, benefits, and long-term implications of kidney donation. Finally, they play a key role in educating donors on the importance of adopting healthy dietary and behavioural habits post-donation, as well as maintaining regular medical follow-up.⁹

5.3.2.2. Deceased donor

Most children with ESKD are on the waiting list for a deceased donor kidney transplant. The management of the waiting list and organ allocation is typically overseen by a regional or national working group. Kidney allocation is based primarily on immunological compatibility and waiting time on dialysis.²

The determination of whether a deceased donor kidney is suitable for a specific recipient involves both a nephrologist and a transplant surgeon, who assess the quality of the donor organ against potential risks. In general, clinicians receive extensive data on the donor, including infectious risk factors, HLA matching, the presence of donor-specific antibodies (DSA), and associated morbidities, such as body weight, hypertension, diabetes risk, smoking history, kidney function, kidney morphology, and vascular anatomy (including the number of vessels). Additional virological screening includes cytomegalovirus (CMV) status, which necessitates antiviral prophylaxis in non-immune recipients, and Epstein-Barr virus (EBV) status, given its association with a potential risk of post-transplant lymphoproliferative disorder (PTLD).¹³ If the donor presents non-standard risk factors, even if the associated risk is low, the recipient must be adequately informed, and explicit consent must be obtained prior to transplantation. Once the decision to proceed has been made, the retrieval team, comprising physicians, transplant surgeons, intensivists, and specialist nurses, ensures the swiftest possible transport of the kidney to the recipient.

Unlike living donor transplantation, a deceased donor kidney transplant is not a scheduled procedure. Waiting times for an organ from a deceased donor are unpredictable, and children may remain on the list for months or even years, often requiring dialysis and facing its associated complications. Nurses play a central role in the management of these patients, coordinating biochemical and instrumental investigations to confirm their ongoing eligibility for the waiting list and providing psychosocial support to both the child and their family in coping with the challenges and emotional burden of the prolonged waiting period.

5.3.3 Surgery and recovering after KT

The surgical and post-surgical phase of paediatric KT is a pivotal stage in the transplant process, requiring a highly coordinated, multidisciplinary approach. This phase encompasses the surgical procedure itself, as well as the immediate post-operative period, which is crucial for ensuring graft survival and minimising complications. Nurses play an essential role in preoperative preparation, intraoperative assistance, and post-operative monitoring, ensuring patient safety and optimising recovery.^{14,15}

5.3.3.1 Pre-surgical preparation

The surgical phase of paediatric KT is a critical stage in the overall transplant process and requires meticulous preoperative nursing preparation to ensure patient safety and optimise surgical outcomes.

The nurse's role in pre-surgical preparation includes:

- preoperative assessment: reviewing the patient's medical records to check for comorbidities, allergies, ongoing pharmacological therapy, and updated laboratory data (blood tests, kidney function, coagulation profile)
- pre-surgical therapy management: administering dialysis sessions if required and preoperative medications, including immunosuppressive drugs, prophylactic antibiotics, or therapies to correct potential electrolyte imbalances
- physical preparation of the patient: ensuring the patient has fasted for the required time, performing body hair removal (if necessary), and preparing the insertion of venous access for intraoperative fluid and medication administration

- coordination with the surgical and anaesthetic team: ensuring that all necessary equipment and devices are available, including venous catheters for HD and the donor kidney, with relevant information such as HLA typing, cross-matching, and donor-recipient compatibility
- educational and psychological support: providing clear and comprehensible information to the child and their family regarding the surgical procedure, addressing any concerns and reducing preoperative anxiety and stress.

5.3.3.2 The kidney transplant surgical procedure

The surgical technique for KT varies depending on the child's anatomy, overall condition, and the size of the donated organ. In most cases, the kidney is placed in the extraperitoneal iliac fossa, allowing optimal vascular access and facilitating post-operative monitoring.

During the procedure, the child is placed under general anaesthesia with continuous monitoring of vital functions. A specialised nursing team is responsible for intraoperative management, assisting the surgical and anaesthetic teams throughout the different phases of the operation.

5.3.3.3 Immediate post-operative care

Following surgery, the child is transferred to a paediatric intensive care unit (PICU) or a high-dependency care unit, where close monitoring and dedicated nursing care are crucial to ensuring transplant success, optimal recovery, and the prevention of complications.

Key aspects of post-operative nursing management include:

- monitoring vital parameters: frequent assessment of blood pressure, heart rate, body temperature, and oxygen saturation to detect early signs of haemodynamic instability or post-operative complications
- fluid balance management: accurate monitoring of fluid intake and output is essential to evaluate graft function, nurses must record urine volume and characteristics, promptly reporting any abnormalities (e.g., oliguria, haematuria, changes in urine colour or clarity)

- pain management: administering analgesics in accordance with pain management protocols, assessing the patient's individual response, and using paediatric pain assessment scales to ensure effective monitoring
- medication administration: ensuring timely administration of immunosuppressive therapy, antibiotics, electrolyte-balancing treatments, and anticoagulant or antiplatelet therapy when indicated
- monitoring and prevention of complications: early recognition of acute rejection signs (fever, hypertension, changes in urine output), post-operative infections (monitoring temperature and white blood cell count), and surgical complications (bleeding, vascular or urinary issues);
- management of drains and catheters: the child may require surgical drains for bleeding assessment and a ureteral stent and/or bladder catheter for urine output evaluation, nurses must ensure correct management, preventing infections or accidental dislodgement
- psychological support and family education: the post-operative period can be stressful for both the child and their parents, nurses must provide regular updates on the patient's clinical progress, reassure the family, and address concerns, particularly in cases of delayed graft function requiring temporary dialysis.

5.3.4 Post-KT management of care

Regular long-term follow-up after KT is essential to ensure the longevity of the graft, prevent complications, and maintain the overall health and well-being of the recipient. Continuous monitoring also plays a crucial role in optimising immunosuppressive regimens, managing comorbidities, and promoting adherence to lifestyle modifications that support kidney function. A multidisciplinary approach, involving nephrologists, transplant surgeons, nurses, dieticians and psychologists is fundamental in providing comprehensive post-transplant care. Through structured follow-up and patient education, long-term monitoring helps improve graft survival rates and enhances the recipient's quality of life. Nurses therefore play a key role not only in providing immediate post-transplant care and support during the

initial hospitalisation but also in the long-term follow-up of transplant recipients.

5.3.4.1 Monitoring of clinical and biochemical progress

After hospital discharge, each transplant recipient undergoes regular clinical, biochemical, and instrumental follow-ups at the Transplant Centre, with the frequency determined by the time elapsed since transplantation and the presence of any complications.

The nurse's role includes:

- collecting anamnestic data, measuring vital signs (blood pressure, heart rate, temperature), and monitoring body weight
- assessing urine output and characteristics
- performing blood tests to evaluate kidney function, serum electrolytes, and immunosuppressive drug levels.

At this stage, it is crucial for specialised nurses to promptly recognise any clinical or biochemical signs of potential complications and report them to the medical team. The most significant post-transplant complications include: immunological complications (rejection episodes, which may present with hypertension, reduced urine output, generalised oedema, and altered kidney function tests), infectious complications (urinary tract infections, systemic bacterial infections, and viral infections caused by CMV, EBV and BK virus), iatrogenic complications secondary to immunosuppressive therapy (calcineurin inhibitor-induced nephrotoxicity, dyslipidaemia, hyperglycaemia, and hypertension).

5.3.4.2 Therapeutic education and psychological support

Adapting to life post-transplant represents a challenge for both the child and their family. Nurses play a fundamental role in providing psychological support and continuous education, helping the patient and their caregivers understand the importance of long-term transplant management.

From an educational perspective, nurses train patients and families about:

- the importance of immunosuppressive therapy, the necessity of strict adherence to the prescribed regimen, and its potential side effects

- early identification of possible complications
- circumstances requiring urgent contact with the transplant centre
- essential hygiene practices, including personal and domestic hygiene, the importance of vaccinations, proper food handling, and avoiding contact with individuals with viral or bacterial infections
- healthy lifestyle choices post-transplant, particularly regarding dietary recommendations, the necessity of regular physical activity, and avoiding risky behaviours such as smoking, alcohol and drug use, and taking non-prescribed medications
- the importance of regular medical follow-ups.

In addition to education, nursing staff provide emotional support to the child and their family through active listening techniques, reassurance, and strategies to manage anxiety and stress associated with their new medical condition.

5.3.4.3 Transition to adulthood

A crucial aspect of post-transplant care is preparing the patient for the transition from paediatric to adult healthcare services. As the child matures, it is essential that they develop an awareness of their condition and attain autonomy in managing their health. Nurses play a pivotal role in this transition by: enhancing the patient's self-awareness, helping them recognise warning signs of potential complications; gradually promoting self-management of medication regimens, encouraging the patient to take responsibility for adhering to prescribed treatment schedules; educating and guiding the family in progressively transferring responsibility to their child, not only in medical aspects but also in the organisational and administrative elements of their condition.

For an effective transition, nurses must collaborate with paediatric nephrologists, adult nephrologists, psychologists and social workers within a multidisciplinary team. This ensures a structured and gradual transition at the most appropriate time, providing continuity of care and long-term support for the patient.¹⁶

Conclusion

Paediatric KT is a complex process that presents significant challenges and requires highly specialised nursing care, yet it also provides extraordinary opportunities to enhance the quality of life for children with ESKD.

Nurses play a fundamental role at every stage of the transplantation pathway, from multidisciplinary evaluation and patient preparation to perioperative and postoperative care and the long-term follow-up. Additionally, they hold a key responsibility in patient and family education, ensuring adherence to medical recommendations and optimising post-transplant outcomes.

Evidence-based care, effective communication and empathetic support is crucial to ensuring transplant success, minimising complications, and enhancing both short- and long-term quality of life in paediatric transplant recipients.

References

1. Amaral S, Sayed BA, Kutner N, Patzer RE. Preemptive kidney transplantation is associated with survival benefits among Paediatric patients with end-stage kidney disease. *Kidney Int.* 2016 Nov;90(5):1100-1108.
2. Dello Strogolo L, Grenda R. Renal Transplantation: Evaluation of Children and Donors. *Paediatric Nephrology*. VII Edition, Chapter 79: 1901-1914.
3. Weitz M, Laube GF, Schmidt M, Krupka K, Murer L, Muller D, et al. Outcome of renal transplantation in small infants: a match-controlled analysis. *Pediatr Nephrol.* 2018;33:1057–68.
4. Cransberg K, Smits JM, Offner G, Nauta J, Persijn GG. Kidney transplantation without prior dialysis in children: the Eurotransplant experience. *Am J Transplant.* 2006;6(8):1858.
5. National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis.* 2002;39(2 Suppl 1):S1-266.
6. Bloom Rd, Doyle AM. Evaluation of the Kidney Transplant Candidate and Follow-Up of the Listed Patient. *Kidney Transplantation: A Guide to the Care of Kidney Transplant Recipients*. I Edition, Chapter 13: 191-206.
7. Shishido S, Hasegawa A. Current status of ABO-incompatible kidney transplantation in children. *Pediatr Transplant.* 2005;9(2):148.
8. Lentine KL, Smith JM, Lyden GR, Miller JM, Dolan TG, et al. OPTN/SRTR 2022 Annual Data Report: Kidney. *Am J Transplant.* 2024 Feb;24(2S1):S19-S118.
9. Lentine KL, Kasiske BL, Levey AS, Adams PL, Alberù J, Bakr MA, et al. KDIGO clinical practice guideline on the evaluation and care of living kidney donors. *Transplantation.* 2017;101:S1–S109.

10. Allen MB, Abt PL, Reese PP. What are the harms of refusing to allow living kidney donation? An expanded view of risks and benefits. *Am J Transplant.* 2014;14: 531–7.
11. Segev DL, Muzaale AD, Caffo BS, Mehta SH, Singer AL, Taranto SE, et al. Perioperative mortality and long-term survival following live kidney donation. *JAMA.* 2010;303:959–66.
12. Baum MA, Stablein DM, Panzarino VM, Tejani A, Harmon WE, Alexander SR. Loss of living donor renal
13. allograft survival advantage in children with focal segmental glomerulosclerosis. *Kidney Int* 2001; 59:328.
14. Wu DA, Watson CJ, Bradley JA, Johnson RJ, Forsythe JL, Oniscu GC. Global trends and challenges in deceased donor kidney allocation. *Kidney Int.* 2017;91:1287–99.
15. Hocker B, L Smith JM. Renal Transplantation: Surgical and Perioperative Management. *Paediatric Nephrology.* VII Edition, Chapter 80: 1915-1925.
16. Pham PTT, Pham PCT, Danovitch GM. Evaluation of the Kidney Transplant Candidate and Follow-Up of the Listed Patient. *Kidney Transplantation: A Guide to the Care of Kidney Transplant Recipients.* I Edition, Chapter 14: 207-236.
17. Ingulli E. Transitioning Between Paediatric and Adult Clinics. *Kidney Transplantation: A Guide to the Care of Kidney Transplant Recipients.* I Edition, Chapter 23: 383-394.

Chapter 6

Advantages and disadvantages of kidney replacement therapy modalities

Learning objectives

- To recognize indications for KRT in acute kidney failure and CKD.
- To be aware of the advantages and disadvantages of the different KRT modalities depending on patient's families and dialysis centres' conditions.

Introduction

Kidney replacement therapy (KRT) refers to medical treatments designed to replace the function of kidneys when they are no longer able to effectively filter waste, balance fluids, or regulate electrolytes. KRT includes the different forms of dialysis - either haemodialysis (HD) or peritoneal dialysis (PD) - and kidney transplantation (KTx). KRT is critical for managing acute kidney injury (AKI) aiming to offer a path to kidney function restoration or for managing CKD as a lifelong therapy. In the current chapter the advantages and disadvantages of the different KRT modalities are discussed regarding the paediatric population in the different age groups.

Acute kidney injury – a critical condition

AKI occurs in nearly one third of critically ill children and has a significant influence on the patient's outcome.^{1,2} AKI in general is associated with a relatively high mortality and morbidity in critically ill children, especially in severe AKI requiring dialysis. For this reason factors which influence the outcome of severe AKI requiring dialysis has been investigated in different paediatric studies.¹⁻³ These studies showed that the most important factors for overall prognosis are the time point of initiating dialysis and the amount of fluid overload.

Banigan et al showed that the mortality rate was significantly lower in children who started dialysis within the first two days after diagnosis of AKI stage 3 in comparison to the ones who started dialysis later (5% versus 65%).³

Acute kidney injury – dialysis modalities

There are three different modalities of KRT which can be performed in the occurrence of AKI:

- continuous kidney replacement therapy (CKRT) either as hemofiltration (HF), HD or hemodiafiltration (HDF)
- intermittent HD or HDF
- PD

There is limited data on which KRT modalities are used in paediatric dialysis centres. The prospective multicentre European AKI registry (EurAKId) collected data on implementation of the different modalities.¹ Most children received CKRT (64%), followed by PD (14%) and HD (14%). In 84% of cases KRT was performed in the PICU. In this registry, there was no difference in mortality with respect to the three different modalities¹ which is confirmed by adults with dialysis dependent AKI.⁴

CKRT is the most used modality in AKI with increasing incidence especially in the last years due to better suitability even for toddlers and neonates.⁵ CKRT requires the most experience of the multidisciplinary team especially among the nurses. In most centres, CKRT can be implemented only in the PICU. CKRT enables the best clearance and fluid withdrawal, and careful monitoring of fluid and electrolyte levels is mandatory. Nurses must accurately record intake and output, monitor vital signs, and assess for signs of fluid overload or dehydration. Systems set up for CKRT can be carried out by dialysis or PICU nurses according to centre specific operating procedures, while CKRT maintenance is usually performed by the PICU team (see table 1).

Intermittent HD or HDF probably requires a specialised dialysis team, with a dialysis trained nurse and a paediatric nephrologist. This modality is most suitable for older children with a haemodynamically stable condition e.g. tubulointerstitial nephritis. Intermittent dialysis can be performed on the dialysis ward. Dialysis nurses must be proficient in operating dialysis machines and monitoring treatment parameters. They must be able to recognize and manage complications such as hypotension, muscle cramps, and disequilibrium syndrome (see table 1).

PD is a specialized dialysis modality which requires specific training for the carers.

After surgical insertion of a PD catheter, PD can be performed by a PICU, dialysis or ward nurse. However, despite the relatively simple technical handling, knowledge of exact fluid and vital signs monitoring is still challenging (see table 1). PD is the preferred modality in infants and toddlers, e.g. haemolytic uremic syndrome. This modality is quite feasible for lower income countries or in exceptional medical situations like the Covid-19 pandemic.⁶

Table 1. Advantages and disadvantages in AKI.

	PD	Intermittent HD/HDF	CKRT
Advantages	No systemic anticoagulation Haemodynamic stability No PICU necessary	Precise fluid removal + Best mobilization No PICU necessary	Precise fluid withdrawal ++ Highest clearance
Disadvantages	Placement by surgeons Surgical catheter expertise No exact/limited fluid withdrawal	Systemic anticoagulation + Hemodynamic instability ++ Dialysis specialist required	Systemic anticoagulation ++ Citrate intoxication Hemodynamic instability + Most expensive procedure

The outcome after AKI is probably more dependent on the time point of initiation than on the dialysis modality. Keeping this in mind the decision of which modality will be used in AKI should be driven by practical aspects, centre experience and the patient's condition.

Kidney replacement therapy in CKD

Management of CKD in the paediatric population has improved significantly over the past two decades. However, the morbidity and mortality of affected children and adolescents is considerable.^{7,8} In children and adolescents with chronic KRT (dialysis or transplantation), the mortality rate is 30 times higher compared to the general population.⁹ Mortality rate depends on the modality, and in children with kidney transplants it is approximately ten times higher in comparison to the general age-related population. In children on dialysis the mortality rate is 100 times higher in comparison to the

age-related population.⁸ Children and adolescents with KRT have a significantly reduced health-related quality of life (HRQOL) compared to both healthy people and children and adolescents with other chronic conditions such as diabetes mellitus, cardiac disease, severe obesity or asthma.^{10,11} When considering the different modalities KTx and PD patients reported better HRQOL than those on HD.¹²

Timing initiation of kidney replacement therapy

The optimal time point to initiate KRT is rather difficult to determine. In recent years there is growing evidence that the absolute kidney function estimated by glomerular filtration rate (eGFR) is not the best parameter. The ERA-EDTA/ESPN registry found no difference in mortality between children who started dialysis with higher eGFR versus the ones who started with a lower eGFR¹³; the US Renal Data registry showed even a higher mortality in children who started dialysis with a higher eGFR in comparison to the ones who started with a lower eGFR.^{14,15}

The presence of clinical and biochemical abnormalities that cannot be managed by medical therapy or dietary modifications should drive the decision to initiate KRT.^{16,17} These abnormalities include hyperkalaemia, fluid overload, metabolic acidosis, arterial hypertension, malnutrition and impaired growth. Symptoms like fatigue, loss of appetite, and impaired cognitive and physical performance are clinical indications for initiating KRT.¹⁶ However, these symptoms may be rather difficult to evaluate because of the slow progression of CKD, especially in children with CAKUT as the underlying kidney disease. Therefore, the affected child might have adapted to the uremic symptoms and accept them as their normal condition.

Kidney transplantation

KTx represents the KRT modality with the best overall outcome. KTx in comparison to dialysis is associated with better survival,⁸ lower morbidity¹⁸ and better HRQOL¹² in children and adolescents. For these reasons, a pre-emptive transplantation (without previous dialysis) should be the preferred KRT. There might be certain circumstances, especially in children with additional severe comorbidities and critically limited life expectancy, where KTx might not be feasible or reasonable.¹⁹

Choice of dialysis modality

In most children and adolescents with CKD, pre-emptive KTx is only feasible if there is a living donor available due to the shortage of organs and the resulting long waiting time.^{20,21}

In general, children and adolescents undergoing dialysis may experience a range of physical and emotional symptoms.²² Growth retardation, anaemia, bone disease, and cardiovascular complications are common.²³ Furthermore, the impact of chronic illness on their social development and emotional well-being can be profound.^{10,11}

Dialysis as KRT in paediatric and adolescent populations presents unique challenges, requiring a multi-professional team that takes care of the whole family. Nurses play a crucial role in addressing these multifaceted needs. Nurses are pivotal in ensuring the success of dialysis therapy, not only by providing technical care but also by addressing the holistic needs of the patient and their family.

Both modalities HD and PD can be performed in the paediatric population. In children, there may be little or no difference between HD and PD on all-cause death and cardiovascular death.²⁴ Options to improve the outcome represent HD schedules with elongation of overall dialysis time²⁵ and HDF.²⁶

The choice of dialysis modality should be guided by the individual patient's medical condition, clinical needs, the family's preferences and dialysis centre's specific factors. In the following paragraph, we will discuss the aspects that should be tailored when the dialysis modality is chosen.

Peritoneal dialysis

PD is the most common dialysis modalities in infants and small children.²⁷ They often benefit from PD due to technical difficulties with HD access and their sensitivity to fluid shifts. PD, especially with automated systems (APD), offers more flexibility. Families can manage PD around school and daily activities. Usually, fluid restrictions are less strict in comparison to the ones on HD due to continual fluid removal. However, the burden on care givers can be enormous.²⁸ Care givers may feel a great responsibility for the treatment, and night-time sleep is often disturbed by alarms from the cyclor. For adolescents, PD may reflect a stronger dependency to

their parents due to assistance in performing PD. The long duration of dialysis session is also often unsuitable for the everyday life of an adolescent (see table 2).

Nurses play a pivotal role in educating patients and families on performing PD at home. They must provide comprehensive training on sterile catheter care, including exit site cleaning and dressing changes. Nurses train parents in solution exchange procedures and troubleshooting techniques. The support provided by the permanent availability of an on-call dialysis nursing service helps to relieve families enormously.

Table 2. Advantages and disadvantages of PD.

Advantages	Disadvantages
Home based treatment	Burden of care for the families
Resource saving	Risk of non-adherence (e.g. skipping cycles)
Preservation of kidney function	Long time on dialysis
No systemic anticoagulation	Risk of infection
Integration into regular school schedule	Limited contact possibilities in the evening
No painful puncture	Altered body image due to the catheter

Hemodiafiltration and haemodialysis

Usually, HDF or HD is performed in the dialysis centre 3 to 4 times a week with sessions lasting between 4-5 hours. However, home HD is also a feasible option for children.²⁹ The issues on caregivers' burden mentioned in the PD section also hold true when HD is performed at home.

HD and especially HDF are the techniques with the best overall clearance. HDF combines the two clearance principles - diffusion and convection – of HD and HF (Hemofiltration). This modality offers the best overall clearance and may have a positive impact on survival.²⁶ Children on HDF report fewer symptoms such as headaches, dizziness, and cramps. Therefore, HDF should be the preferred method if the infrastructure is available in the dialysis centre.

In-centre HDF or HD is often the preferred method for adolescents. The time spent on dialysis is usually shorter in comparison to PD. When using an AV fistula, there is no permanent catheter to disrupt

the body-image. With regard to adherence, HDF and HD offer the possibility to support the patient during the in-centre dialysis sessions (see table 3).

When performing HDF or HD, nurses must accurately record intake and output and monitor vital signs. They must be able to recognize and manage complications such as hypotension, muscle cramps, and disequilibrium syndrome. Regarding dialysis access, care of the fistula or catheter is crucial.

Another aspect is the impact of chronic illness on a child's or adolescent's social and emotional well-being. While being treated with HDF or HD, nurses see the patients, especially the older children, probably for more hours than the parents do during weekdays. They can provide emotional support and address concerns about body image and peer relationships. Adolescents may struggle with adherence to treatment regimens. Nurses should try to establish a trusting relationship and be able to address their concerns.

Table 3. *Advantages and disadvantages of HDF and HD.*

Advantages	Disadvantages
Relief of the care givers	Painful puncture
No daily treatment	Exhausting dialysis sessions
Shorter dialysis sessions	No mobility during sessions
No permanent catheter	Regular school attendance limited
Medical supervision	Fluid restrictions
Autonomy from care givers	

Both HD and PD have distinct advantages and disadvantages in the paediatric population. The decision-making process should be collaborative, involving the child (when appropriate), care givers, and the healthcare team to ensure the best possible outcome—both medically and in terms of quality of life.

References

1. Guzzo I, de Galasso L, Bayazit AK, Yildizdas D, Schmitt CP, Hayes W, u. a. Acute paediatric KRT in Europe: demographic results from the EurAKId Registry. *Nephrol Dial Transplant.* 25. März 2022;37(4):770–80.
2. Kaddourah A, Basu RK, Bagshaw SM, Goldstein SL, AWARE Investigators. Epidemiology of Acute Kidney Injury in Critically Ill Children and Young Adults. *N Engl J Med.* 5. Januar 2017;376(1):11–20.

3. Banigan MA, Keim G, Traynor D, Yehya N, Lindell RB, Fitzgerald JC. Association of continuous kidney replacement therapy timing and mortality in critically ill children. *Pediatr Nephrol.* Juli 2024;39(7):2217–26.
4. Liu L, Zhang L, Liu GJ, Fu P. Peritoneal dialysis for acute kidney injury - Liu, L - 2017 | Cochrane Library. [zitiert 8. April 2025]; Verfügbar unter: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011457.pub2/full>
5. Battista J, De Luca D, Eleni Dit Trolli S, Allard L, Bacchetta J, Bouhamri N, u. a. CARPEDIEM® for continuous kidney replacement therapy in neonates and small infants: a French multicenter retrospective study. *Pediatr Nephrol.* August 2023;38(8):2827–37.
6. Caplin NJ, Zhdanova O, Tandon M, Thompson N, Patel D, Soomro Q, u. a. Acute Peritoneal Dialysis During the COVID-19 Pandemic at Bellevue Hospital in New York City. *Kidney360.* 31. Dezember 2020;1(12):1345–52.
7. Chesnaye NC, Schaefer F, Groothoff JW, Bonthuis M, Reusz G, Heaf JG, u. a. Mortality risk in European children with end-stage renal disease on dialysis. *Kidney Int.* 2016;89(6):1355–62.
8. Mitsnefes MM. Cardiovascular disease in children with chronic kidney disease. *J Am Soc Nephrol.* April 2012;23(4):578–85.
9. Kramer A, Stel VS, Tizard J, Verrina E, Rönholm K, Pálsson R, u. a. Characteristics and survival of young adults who started renal replacement therapy during childhood. *Nephrol Dial Transplant.* März 2009;24(3):926–33.
10. Splinter A, Tjaden LA, Haverman L, Adams B, Collard L, Cransberg K, u. a. Children on dialysis as well as renal transplanted children report severely impaired health-related quality of life. *Qual Life Res.* Juni 2018;27(6):1445–54.
11. Tjaden LA, Grootenhuis MA, Noordzij M, Groothoff JW. Health-related quality of life in patients with Paediatric onset of end-stage renal disease: state of the art and recommendations for clinical practice. *Pediatr Nephrol.* 2016;31(10):1579–91.
12. Doshi K, Raina R, Ng KH, Koch V, Bhatt GC, Nada A, u. a. Health-related quality of life for Paediatric patients with end-stage kidney disease: A systematic review and meta-analysis of the Paediatric Quality of Life Inventory (PedsQL). *Hemodial Int.* April 2024;28(2):198–215.
13. Preka E, Bonthuis M, Harambat J, Jager KJ, Groothoff JW, Baiko S, u. a. Association between timing of dialysis initiation and clinical outcomes in the paediatric population: an ESPN/ERA-EDTA registry study. *Nephrol Dial Transplant.* 30. April 2019;
14. Okuda Y, Soohoo M, Tang Y, Obi Y, Laster M, Rhee CM, u. a. Estimated GFR at Dialysis Initiation and Mortality in Children and Adolescents. *Am J Kidney Dis.* Juni 2019;73(6):797–805.
15. Winnicki E, Johansen KL, Cabana MD, Warady BA, McCulloch CE, Grimes B, u. a. Higher eGFR at Dialysis Initiation Is Not Associated with a Survival Benefit in Children. *J Am Soc Nephrol.* 18. Juli 2019;
16. Preka E, Rees L. Should we abandon GFR in the decision to initiate chronic dialysis? *Pediatr Nephrol.* September 2020;35(9):1593–600.

17. Daugirdas JT, Depner TA, Inrig J, Mehrotra R, Rocco MV, Suri RS, u. a. KDOQI Clinical Practice Guideline for Haemodialysis Adequacy: 2015 Update. *American Journal of Kidney Diseases*. 1. November 2015;66(5):884–930.
18. Schmidt BMW, Sugianto RI, Thurn D, Azukaitis K, Bayazit AK, Canpolat N, u. a. Early Effects of Renal Replacement Therapy on Cardiovascular Comorbidity in Children With End-Stage Kidney Disease: Findings From the 4C-T Study. *Transplantation*. März 2018;102(3):484–92.
19. Thumfart J, Reindl T, Rheinlaender C, Müller D. Supportive palliative care should be integrated into routine care for paediatric patients with life-limiting kidney disease. *Acta Paediatr*. März 2018;107(3):403–7.
20. Thumfart J, Wagner S, Kirchner M, Azukaitis K, Bayazit AK, Obrycki L, u. a. Timing and Modality of Kidney Replacement Therapy in Children and Adolescents. *Kidney Int Rep*. September 2024;9(9):2750–8.
21. Atkinson MA, Roem JL, Gajjar A, Warady BA, Furth SL, Muñoz A. Mode of initial renal replacement therapy and transplant outcomes in the chronic kidney disease in children (CKiD) study. *Pediatr Nephrol*. Juni 2020;35(6):1015–21.
22. Jacob Z, Plumb L, Oni L, Mitra S, Reynolds B. A systematic review of symptoms experienced by children and young people with kidney failure. *Pediatr Nephrol*. Januar 2025;40(1):53–68.
23. Nair N, Prashant Kadamane S, Yaacoub RM, Sandhu JM, Bhavaraju S, Raina R. Challenges and unique considerations of adolescents with chronic kidney disease. *Acta Paediatrica*. 2023;112(6):1165–76.
24. Ethier I, Hayat A, Pei J, Hawley CM, Johnson DW, Francis RS, u. a. Peritoneal dialysis versus haemodialysis for people commencing dialysis. *Cochrane Database Syst Rev*. 20. Juni 2024;6(6):CD013800.
25. Thumfart J, Pommer W, Querfeld U, Müller D. Intensified Haemodialysis in adults, and in children and adolescents. *Dtsch Arztebl Int*. 4. April 2014;111(14):237–43.
26. Ahlmann C, Stronach L, Waters K, Walker K, Oh J, Schmitt CP, u. a. Hemodiafiltration for children with stage 5 chronic kidney disease: technical aspects and outcomes. *Pediatr Nephrol*. September 2024;39(9):2611–26.
27. Chua AN, Kumar R, Warady BA. Care of the Paediatric patient on chronic peritoneal dialysis. *Pediatr Nephrol*. 1. Dezember 2022;37(12):3043–55.
28. Wightman A. Caregiver burden in Paediatric dialysis. *Pediatr Nephrol*. 21. August 2019;
29. Hothi DK, Stronach L, Sinnott K. Home Haemodialysis in children. *Hemodial Int*. Juli 2016;20(3):349–57.

Chapter 7

Special nutritional requirements for infants and children with chronic kidney disease on haemodialysis

Learning objectives

- To gain knowledge and understanding of the importance of diet in the management and treatment of paediatric patients with chronic kidney disease (CKD) stage 5 on dialysis.
- To understand the role of dietary interventions in optimizing overall health and reducing long term complications associated with paediatric CKD stage 5.
- To understand the role of dietary interventions in optimizing nutritional status and fluid balance.

Introduction

CKD in infants and children poses distinct nutritional challenges affecting growth, metabolism, and health. Adequate nutrition is essential for mitigating disease progression, preventing complications, and promoting optimal growth and development. Malnutrition is a significant problem that requires careful monitoring and intervention. This chapter examines the nutritional needs of paediatric patients with CKD, the risks and management of malnutrition, nutritional strategies, management challenges and the role of healthcare professionals in ensuring adequate nutritional support.¹

CKD is a progressive condition that affects kidney function over time, leading to a need for careful management of diet and nutrition. Unlike adults, children with CKD face growth and developmental challenges, making nutritional therapy a cornerstone of treatment. Malnutrition and protein-energy wasting are common in paediatric CKD and significantly contribute to poor outcomes, including increased morbidity and mortality. Nutritional strategies must balance protein intake, energy needs, electrolyte management, and micronutrient supplementation to prevent malnutrition and support overall health.

The prevalence of CKD in children is estimated to be between 15 and 75 per million children, depending on geographical and demographic factors.^{2,3} The most common causes include congenital anomalies of the kidneys and urinary tract (CAKUT), glomerulopathies and inherited diseases such as polycystic kidney disease.⁴ Due to its

progressive nature, CKD requires early and consistent intervention to mitigate the adverse effects on growth and metabolic function.

Common nutritional problems in children on haemodialysis

Children undergoing haemodialysis (HD) face several nutritional challenges that can impact their health and quality of life. The most common problems

- **Protein-Energy Wasting (PEW).** Poor nutritional intake, anorexia and increased catabolism and losses of nutrients during dialysis increase the risk of weight loss, muscle wasting and malnutrition.⁵
- **Growth Failure and Stunting:** CKD disrupts normal growth due to metabolic acidosis, hormonal imbalances, and inadequate nutrition.⁶⁻⁸
- **Electrolyte Imbalances:** Hyperkalemia, hyperphosphatemia, and hyponatremia are common due to impaired kidney function and dialysis inefficiencies.⁶
- **Poor Appetite and Gastrointestinal Symptoms:** Uremia, side effects of the medication, and strict dietary restrictions contribute to anorexia, nausea and reduced food intake.^{6,9,10}

Nutritional assessment in paediatric population with CKD

Nutritional assessment is a critical component of managing paediatric population with CKD, as it allows for early detection of growth failure, malnutrition, and metabolic imbalances.^{10,11} This assessment should be performed regularly and include:

- **Anthropometric Measurements:** Monitoring weight, length or height, and body mass index (BMI) to assess growth patterns. Mid-upper arm circumference and skinfold thickness can provide additional information on muscle and fat stores.
- **Biochemical Markers:** Albumin, prealbumin, transferrin, and nitrogen balance are evaluated to assess protein status. Electrolyte levels, including sodium, potassium, phosphorus, and calcium, are measured to prevent imbalances.
- **Dietary Intake Evaluation:** A detailed dietary history helps assess caloric and nutrient intake, ensuring that dietary recommendations align with the child's needs. This information

can be acquired by the parents or the child if it is in age to provide reliable information.

- **Clinical Assessment:** A physical examination can identify signs of malnutrition, muscle wasting, and vitamin deficiencies.

Regular nutritional assessments enable early intervention, ensuring that appropriate dietary modifications and supplementation strategies are implemented to support growth and prevent complications.¹¹ **Table 1** presents the recommended parameters and the frequency of nutritional assessment.

Table 1. Recommended parameters and frequency of nutritional assessment for children with CKD stage 5 on HD.⁶

Parameter	Minimum interval (month)		
	Age 0 to <1 year	Age 1 to 3 years	Age >3 years
	CKD 5D	CKD 5D	CKD 5D
Dietary intake	0.5 to 2	1 to 3	3 to 4
Height or length-for-age percentile or SDS	0.5 to 1	1	1 to 3
Height or length velocity-for-age percentile or SDS	0.5 to 1	1 to 2	6
Estimated dry weight and weight-for-age percentile or SDS	0.25 to 1	0.5 to 1	1 to 3
BMI-for-height-age percentile or SDS	0.5 to 1	1	1 to 3
Head circumference-for-age percentile or SDS	0.5 to 1	1 to 2	N/A
nPCR	N/A	N/A	1*

CKD: chronic kidney disease; SDS: standard deviations score; BMI: body mass index; N/A: not applicable; nPCR: normalized protein catabolic rate.

* Only applies to adolescents receiving HD.

Nutritional needs of infants and children with CKD on HD

Infants and children on HD require individualized nutrition plans to address the metabolic and dietary challenges associated with kidney failure. The key nutritional components include regulation of energy and protein intake, fluid and electrolyte management, and micronutrients.

Energy requirements

Infants and young children have higher energy demands due to rapid growth and development. Energy intake should be 100-140% of the recommended dietary allowance (RDA) for healthy infants and children to support growth and prevent wasting. Additional energy support may be required for children experiencing protein-energy wasting (PEW). Caloric intake must be balanced to prevent both undernutrition and obesity.^{6,12} Indirect calorimetry and double labeled water are considered the gold standards for the measurement of energy requirements.¹³ In case this is not available or feasible, energy requirements can be estimated. In Table 1 the Suggested Dietary Intakes (SDI) of energy based on age and sex are presented. SDI is based on the Physical Activity Level (PAL) used by the international bodies: 1–3 year PAL 1.4; 4–9 year PAL 1.6; and 10–17 year PAL 1.8.⁶

In children with suboptimal growth and linear growth, energy intake should be adjusted to the higher ends of SDI. For children with poor growth, reference to the SDI for height age may be appropriate. Height age is the age that corresponds to an individual's height when plotted on the 50th centile on a growth chart. On the other hand, in children with overweight or obesity energy intake should be adjusted to achieve appropriate weight gain, without posing risks of malnutrition or PEW.¹³

Protein requirements

HD leads to protein losses, necessitating a higher protein intake than children with earlier-stage CKD. The recommended intake is 100-140% of the RDA for age, with at least 50-60% from high biological value proteins such as breast milk, infant formulas, meat, eggs, dairy, and fish. Protein intake must be monitored to prevent excessive urea accumulation while ensuring adequate nutrition. Increased protein intake is needed in post-dialysis to compensate for dialysis-related losses. SDIs for protein according to the age and sex are presented in Table 2.^{6,13}

Table 2. Energy and protein requirements for infants, children and adolescents with CKD2–5D aged 0–18 years.¹³

SDI for energy and protein: birth ^a to 18 years				
Month	SDI energy (kcal/kg/day)		SDI protein (g/kg/day)	SDI protein (g/day)
0	93–107		1.52–2.5	8–12
1	93–120		1.52–1.8	8–12
2	93–120		1.4–1.52	8–12
3	82–98		1.4–1.52	8–12
4	82–98		1.3–1.52	9–13
5	72–82		1.3–1.52	9–13
6–9	72–82		1.1–1.3	9–14
10–11	72–82		1.1–1.3	9–15
12	72–120		0.9–1.14	11–14
Year	SDI energy (kcal/kg/day)		SDI protein (g/kg/day)	SDI protein (g/day)
	Male	Female		
2	81–95 ^c	79–92 ^c	0.9–1.05	11–15
3	80–82	76–77	0.9–1.05	13–15
4–6	67–93	64–90	0.85–0.95	16–22
7–8	60–77	56–75	0.9–0.95	19–28
9–10	55–69	49–63	0.9–0.95	26–40
11–12	48–63	43–57	0.9–0.95	34–42
13–14	44–63	39–50	0.8–0.9	34–50
15–17	40–55	36–46	0.8–0.9	Male: 52–65 Female: 45–49

^aThirty-seven/40 weeks gestation. Premature infants have higher energy and protein requirements. The increased need for these and other nutrients (sodium, potassium, calcium, and phosphorus) must be balanced against the nutritional interventions to control the effects of CKD.

Fluids and electrolyte requirements

Fluid and electrolyte management is critical for children on HD. Sodium intake must be controlled to prevent hypertension and fluid overload, typically at 1–2 mEq/kg/day. Potassium intake should be limited to prevent hyperkalemia, with careful monitoring of potassium-rich foods. Phosphorus intake must be restricted to prevent bone disease, and phosphate binders may be required. Calcium intake should be adequate to support bone health, often necessitating supplementation. Fluid restriction is essential to prevent excessive retention between dialysis sessions.^{6,13}

Micronutrient Considerations

Micronutrients should be provided according to Dietary Recommended intakes (DRIs) or adequate intakes (AI) based on the age of the children. Micronutrient considerations include vitamin D supplementation due to altered metabolism in CKD, and vitamin C, thiamine and folate supplementation to compensate for dialysis losses. Moreover, suboptimal levels of zinc and selenium have been reported in children on HD. Vitamin A should not be given in a supplementary form as children with CKD are at risk of toxicity.¹⁴

Dietary fibre

Dietary fibre is an important part of the diet of a child with CKD. As in any other child dietary fibre plays a significant role in gut function, preventing constipation, reducing inflammatory response and decreasing the production of uremic toxins from the gut microflora.¹⁵ According to the most recent guidelines, fibre intake in children with CKD should not differ from the healthy children of the same chronological age.^{16,17} The suggested dietary intake of fibre is presented in **Table 3**.

Table 3. Suggested dietary intake (SDI) for fibre.¹⁷

Age (years)	SDI (g/day)	SDI (g/1000 Kcal)
1-3	14-19	8.3-14
4-8	18-25	8.3-14
9-13	24-31 (male)	
20-26 (female)	8.3-14	
14-18	28-38 (male)	
22-26 (female)	8.3-14.2	

Breastfeeding in infants with CKD

An infant's oral reflexes provide a foundation for safe and protected oral feeding. According to the World Health Organization (WHO) and various national Paediatric and nutrition organizations, it is recommended that healthy infants be exclusively breastfed during the first six months of life.^{18,19} Breast milk, with its low kidney solute load, is also the optimal source of nutrition for nearly all infants with CKD.²⁰

For fluid management purposes, some infants with CKD may not be permitted to breastfeed directly and instead receive breast milk via bottle to accurately monitor intake and output volumes. If a mother cannot express sufficient amounts of breast milk, the infant may require bottle feeding with fortified breast milk or an appropriate infant formula. Considering any necessary kidney diet restrictions, breast milk can be fortified by adding one or more modular components such as carbohydrates, protein, and/or fat modules, as well as regular or low-electrolyte infant formula. Similarly, infant formula can be modified to meet these specific needs.²⁰

If breastfeeding is not possible, low-phosphorus and low-protein kidney-specific formulas may be recommended. These formulas are designed to meet the unique needs of infants with CKD while preventing metabolic imbalances.²⁰

Weaning in infants with CKD

Weaning should be introduced gradually, following standard paediatric guidelines, but with modifications based on CKD severity.^{13,20}

- **Introduction of Solid Foods:** Pureed fruits, vegetables, and low-phosphorus grains can be introduced around 4-6 months of age, based on individual tolerance.
- **Avoiding High-Phosphorus and High-Potassium Foods:** Dairy, processed meats, and high-potassium fruits like bananas and oranges should be given in moderation to prevent electrolyte imbalances.
- **Monitoring Growth and Nutrient Intake:** Regular follow-ups with a dietitian are essential to ensure proper growth and prevent deficiencies during this transition period.

Nutritional Support and Malnutrition in Paediatric CKD

Malnutrition is a serious concern in Paediatric CKD, affecting growth, immune function, and overall health. In children with suboptimal growth and malnutrition several steps can be taken to improve nutritional status and prevent stunting.

Food fortification is one of the main ways to improve nutritional intake. Breastmilk and formulas can be fortified with modular supplements (protein, carbohydrates and lipids) to make them more energy dense.

In children with signs of malnutrition energy dense foods should be provided. These foods include choices not regularly included in children's healthy diet choices, such as sweets, butter, candies etc., but they have a place in the diet of children with CKD and anorexia, as they can benefit from the energy these foods provide.¹⁷

In that point it should be stressed that children with CKD are at increased risk for oral health complications due to the interplay of systemic factors, altered metabolism, and medical treatments.²¹ Common findings include enamel hypoplasia, delayed tooth eruption, xerostomia, and an elevated incidence of dental caries and gingival overgrowth—particularly in those receiving immunosuppressive therapy. Uremic toxins and dietary restrictions may also influence oral microbial flora and salivary composition. Poor oral health in these patients can negatively impact nutrition, quality of life, and even systemic inflammation. Therefore, early and regular dental evaluation should be an integral component of multidisciplinary care in Paediatric CKD management.^{21,22}

Apart from food fortification, oral nutritional supplements (ONS) can be used in children who are failing to thrive. ONS provide additional protein, calories, and essential nutrients. These supplements are low in electrolytes and energy dense, to cover the needs of children with fluid intake restriction.^{6,7,23}

For children with disturbed growth patterns or inadequate oral intake, enteral nutrition via nasogastric or gastrostomy feeding should be considered. Special kidney formulas with controlled protein, electrolyte, and mineral content should be used. For short term enteral nutrition support nasogastric (NG) tube is the preferred, while a gastrostomy is preferable for long-term enteral feeding.¹⁷ In severe cases of malnutrition, intravenous nutrition may be required, especially in children with gastrointestinal problems or severe anorexia due to uremia.¹⁷

Other Challenges in Nutritional Management of children on dialysis

Managing nutrition in Paediatric CKD is complex due to CKD-related uremia and dietary restrictions that can lead to inadequate food intake and malnutrition. Strategies to enhance palatability and nutritional intake include modifying food textures, flavours, and meal timing. Moreover, dietary restrictions may have a negative

impact on a child's quality of life, requiring family and psychological support. Parental education and counseling are essential in ensuring adherence to dietary guidelines. As adherence to these dietary guidelines can be difficult for both children and caregivers, interactive education programs and regular follow-up with dietitians can improve compliance.²⁴

Conclusion

Nutritional management in paediatric CKD is essential for maintaining growth, preventing complications, and improving quality of life. Malnutrition is a major concern that requires early intervention, close monitoring, and individualized dietary strategies. Further research and improved access to specialized nutritional support can enhance outcomes for children with CKD.

References

1. VanSickle JS, Warady BA. Chronic Kidney Disease in Children. *Paediatric clinics of North America*. 2022;69(6):1239-1254.
2. Harambat J, Madden I. What is the true burden of chronic kidney disease in children worldwide? *Paediatric Nephrology*. 2023;38(5):1389-1393.
3. IPNA. IPNA Global Registry for Kidney Replacement Therapy in Children. Annual Report. 2018 (assessed 23-3-2025). 2018.
4. Whyte DA, Fine RN. Chronic kidney disease in children. *Paediatric s in review*. 2008;29(10):335-341.
5. Carrero JJ, Stenvinkel P, Cuppari L, et al. Etiology of the protein-energy wasting syndrome in chronic kidney disease: a consensus statement from the International Society of Renal Nutrition and Metabolism (ISRNM). *Journal of renal nutrition: the official journal of the Council on Renal Nutrition of the National Kidney Foundation*. 2013;23(2):77-90.
6. KDOQI Clinical Practice Guideline for Nutrition in Children with CKD: 2008 update. Executive summary. *American journal of kidney diseases: the official journal of the National Kidney Foundation*. 2009;53(3 Suppl 2):S11-104.
7. Mak RH, Iyengar A, Lai WM, et al. Nutrition in Children With Chronic Kidney Disease: How to Thrive? *Journal of renal nutrition: the official journal of the Council on Renal Nutrition of the National Kidney Foundation*. 2023;33(6s):S49-s55.
8. de Camargo MF, Henriques CL, Vieira S, Komi S, Leão ER, Nogueira PC. Growth of children with end-stage renal disease undergoing daily Haemodialysis. *Paediatric nephrology* (Berlin, Germany). 2014;29(3):439-444.
9. Stevens PE, Levin A. Evaluation and management of chronic kidney disease: synopsis of the kidney disease: improving global outcomes 2012 clinical practice guideline. *Annals of internal medicine*. 2013;158(11):825-830.

10. Suárez-González M, Ordoñez-Álvarez F, Gil-Peña H, et al. Nutritional Assessment and Support in Children with Chronic Kidney Disease: The Benefits of Working with a Registered Dietitian. *Nutrients*. 2023;15(3).
11. Mastrangelo A, Paglialonga F, Edefonti A. Assessment of nutritional status in children with chronic kidney disease and on dialysis. *Paediatric nephrology (Berlin, Germany)*. 2014;29(8):1349-1358.
12. Terrill CJ. Nutrition and the Paediatric patient with CKD. *Nephrology nursing journal: journal of the American Nephrology Nurses' Association*. 2007;34(1):89-92.
13. Shaw V, Polderman N, Renken-Terhaerd J, et al. Energy and protein requirements for children with CKD stages 2-5 and on dialysis-clinical practice recommendations from the Paediatric Renal Nutrition Taskforce. *Paediatric nephrology (Berlin, Germany)*. 2020;35(3):519-531.
14. Harshman LA, Lee-Son K, Jetton JG. Vitamin and trace element deficiencies in the Paediatric dialysis patient. *Paediatric nephrology (Berlin, Germany)*. 2018;33(7):1133-1143.
15. Snauwaert E, Paglialonga F, Vande Walle J, et al. The benefits of dietary fiber: the gastrointestinal tract and beyond. *Paediatric nephrology (Berlin, Germany)*. 2023;38(9):2929-2938.
16. Desloovere A, Polderman N, Renken-Terhaerd J, et al. The Management of Dietary Fiber Intake in Children With Chronic Kidney Disease – Clinical Practice Recommendations From the Paediatric Renal Nutrition Taskforce. *Journal of Renal Nutrition*. 2025;35(1):207-220.
17. Shaw V, Anderson C, Desloovere A, et al. Nutritional management of the child with chronic kidney disease and on dialysis. *Paediatric nephrology (Berlin, Germany)*. 2025;40(1):69-84.
18. WHO. World Health Organization. The optimal duration of exclusive breastfeeding: report of an expert consultation. Geneva, Switzerland. 2000. http://www.who.int/maternal_child_adolescent/documents/nhd_01_09/en/. Accessed March 24, 2025.
19. Gartner LM, Morton J, Lawrence RA, et al. Breastfeeding and the use of human milk. *Paediatric s*. 2005;115(2):496-506.
20. Samaan S, Secker DJII, Child,, Nutrition A. Oral feeding challenges in infants with chronic kidney disease: assessment and intervention. 2014;6(3):164-171.
21. Elhusseiny GA, Saleh W. Oral Health in Children with Chronic Kidney Disease, Haemodialysis, and Renal Transplantation: A Comprehensive Narrative Review of the Oral Manifestations and Dental Implications. *Clinical medicine insights Paediatric s*. 2024;18:11795565241271689.
22. Velan E, Sheller B. Oral health in children with chronic kidney disease. *Paediatric nephrology (Berlin, Germany)*. 2021;36(10):3067-3075.
23. Mak RH, Iyengar A, Wang AY. Nutrition Management for Chronic Kidney Disease: Differences and Special Needs for Children and Adults. *Seminars in nephrology*. 2023;43(4):151441.
24. Apostolou A, Karagiozoglou-Lampoudi T. Dietary adherence in children with chronic kidney disease: a review of the evidence. *Journal of renal care*. 2014;40(2):125-130.

Chapter 8

Impact on Quality of Life of children on long-term Kidney Replacement Therapy

Learning objectives

- To acknowledge the impact of long term KRT to children's Health Related Quality of Life.
- To understand the principles of individualised medical management in paediatric dialysis patients.
- To recognise the importance of systematic HRQoL assessment in children receiving long-term KRT, using validated generic and disease-specific tools.
- To identify key factors affecting HRQoL in paediatric KRT patients.
- To appreciate the role of caregiver perspectives and response shift in the assessment of a child's quality of life over time.
- To describe the value of patient-reported outcomes and individualised care planning based on child and adolescent lived experiences and treatment burdens.
- To promote adolescent empowerment by encouraging development of self-care skills and active participation in care planning and decision-making.
- To support family resilience and parent-child communication through psychosocial counselling and structured family support programs.
- To apply a multidisciplinary, child-centred approach to integrate medical, psychological, palliative, and educational support in the care of paediatric KRT patients.
- To develop strategies to support educational and cognitive development.
- To plan for a structured and supportive transition to adult care, focusing on patient independence and treatment adherence.
- To identify and address health disparities in access to transplantation, home dialysis, psychological care, and culturally appropriate interventions.

Introduction

Chronic kidney disease (CKD) in children is a life-altering condition, with many progressing to end-stage kidney disease requiring long-term kidney replacement therapy (KRT), which significantly impacts

not only physical health but also psychosocial and developmental outcomes. Dialysis (haemodialysis [HD] or peritoneal dialysis [PD]) and kidney transplantation are the primary modalities of KRT. Although these therapies are lifesaving, they impose a substantial burden on a child's quality of life (QoL), affecting physical functioning and growth, mental well-being and social life. The advances in knowledge in the last years provide a new perspective regarding management and long-term outcomes.¹⁻³

This chapter explores the impact of long-term KRT on paediatric QoL and the importance of holistic care strategies on evaluating and improving health-related quality of life (HRQoL) in this vulnerable population.

Quality of life in children with CDK is a very important and multifactorial issue, influenced both by the disease itself and by its therapeutic management.⁴ Quality of life in children with CKD is understood as a multidimensional construct encompassing physical, emotional, social, and academic domains of well-being. It reflects the child's subjective experiences and functional status as shaped by both the disease and its intensive management requirements, such as dialysis, dietary restrictions, and medication regimens. Health-related quality of life (HRQoL), a subset of QoL, focuses specifically on the impact of disease and treatment on physical and mental health domains. In paediatric populations, HRQoL also considers developmental appropriateness, school participation, and family dynamics.⁵⁻⁷

Although KRT techniques have advanced, research indicates that kidney transplantation is the most effective KRT for children, offering lower rates of mortality and morbidity, enhanced quality of life, and improved growth.^{8,9} A successful kidney transplantation enhances children's normal growth and development and assists them in achieving a "normal" everyday life. Nonetheless, children who have undergone kidney transplantation often report a lower quality of life than their healthy counterparts, with increased mental health concerns, sleep disturbances, and ongoing pain.¹

Children diagnosed with CKD encounter a dual challenge encompassing both the physiological demands of a long-term medical condition and the psychological strain associated with it. More specifically, they often face physical, psychological, and

social challenges, such as growth retardation, fatigue, frequent hospitalizations, and limitations in daily activities.¹⁰ For example, their daily lives are frequently dominated by ongoing medical appointments, adherence to complex dietary and therapeutic regimens, and restrictions on activities typical for their age group. These persistent stressors often contribute to feelings of isolation and emotional distress that are influenced more from the chronic nature of the disease and the long-term treatments that often lead to emotional strain, reduced self-esteem, and social isolation. Notably, there is a growing prevalence of depressive disorders among paediatric patients with CKD, which can further hinder their ability to manage the disease effectively.^{10,11}

The younger a child is at the time of diagnosis, the higher the risk of developing depressive symptoms. Being diagnosed with a chronic illness early in life can disrupt critical stages of emotional and psychological development. Younger children may struggle more with adapting to their condition, often feeling a heightened sense of powerlessness and lack of control. This early loss of autonomy can lead to feelings of helplessness, which may evolve into ongoing symptoms of depression.^{12,13} Living with CKD becomes an increasing psychological burden with each passing year. Over time, children are more deeply affected by the condition, experiencing growing fatigue, restricted daily activities, and often social isolation. Children with advanced kidney disease often experience profound emotional distress and a sense of social isolation. Frequent absences from school, missed recreational activities, and exclusion from peer events such as birthday celebrations underscore the extent to which their daily experiences diverge from those of their peers.^{10,11}

Such psychological comorbidities may adversely impact treatment adherence and are associated with a marked decline in overall quality of life. Therefore, it is not surprising that the quality of life of these children largely depends on early diagnosis, adequate medical care, family support, and the psychosocial support they receive.¹⁴ During such times, psychological support is essential—not only for the affected child but also for their family members, who must navigate the multifaceted challenges associated with managing a chronic illness within the household. Notably, a high prevalence of stress, anxiety, and depression has been observed among caregivers of children with kidney diseases.¹⁵

From a qualitative approach, health professionals need to know how children perceive and manage end-stage kidney disease in their daily life, in order to formulate accordingly a therapeutic plan that would apply to their pragmatic needs. Nicholas, Picone & Selkirk (2011) in their study assessed the lived experiences of children and adolescents with end-stage kidney disease. They performed ethnographic interviews with the participation of twenty-five children and adolescents (7-18 years old). The content analysis indicated that long term kidney disease has a clear impact on children's quality of life and well-being. The children stated that they experience a wide range of challenges including compliance to the therapeutic plan, effective collaboration with health professional, self-management skills and knowledge, school absence management, relying on family, friends and peers, and negative experiences like stigma or feeling of not being "normal". These findings reveal a complex and evolving perspective, shaped by the tensions children and adolescents encounter as they navigate adversity while fostering personal growth and resilience.¹⁶

Chronic Kidney Disease (CKD) imparts significant constraints and restrictions that have a direct impact on normal psychosocial development. The medical requirements for children with CKD, including dietary restrictions and restrictions due to the type of therapy, may isolate them from their healthy peers. Such barriers in the normal daily life of a child are a likely primary cause for the relatively low self-esteem and low rates of independent living in paediatric and young adult survivors of paediatric End Stage Kidney Disease (ESKD). Therefore, behavioural lifestyle interventions to enhance disease self-management are highly recommended.¹⁷ Many recent studies indicate that children who undergo kidney transplantation experience better health-related quality of life (HRQoL) compared to those on dialysis.¹⁸⁻²⁰ As advances in care continue to improve survival rates for children and adolescents with CKD into adulthood, it becomes increasingly important to focus on their HRQoL. Prioritising this aspect of care is crucial to ensure optimal health outcomes and to equip these young patients for a smooth transition into adult healthcare services.^{21,22}

While medical management remains a central component of care for adolescents with CKD, integrating psychological support through a multidisciplinary approach is essential. These patients and their families face the dual challenges of typical adolescent development

and the demands of managing a complex medical condition, contributing to higher rates of treatment non-adherence. Such non-adherence is linked to serious outcomes, including disease progression, prolonged dialysis, and transplant failure. Moreover, adolescents with CKD are at increased risk for psychosocial difficulties, such as depression, anxiety, cognitive impairments, sleep disturbances, and reduced quality of life. Given the impact of these factors on health outcomes, timely psychological assessment and intervention are critical for comprehensive CKD management.²³

Consistent evidence across international literature indicates that young people with CKD experience a significantly lower quality of life compared to their peers with other chronic conditions (e.g., diabetes, cardiac diseases, asthma) as well as the healthy control group. Unfortunately, only a few systematic evaluations of the HRQoL of children who are in the early stages of kidney disease have been performed. Understanding the quality of life in paediatric patients with CKD is therefore, crucial for developing holistic, patient-centred models of care that address the full spectrum of needs beyond clinical and biochemical markers, thus enabling supplementary support.^{23,24}

The concept of QoL and HRQoL in children with long-term KRT

As stressed in the introduction, children and adolescents on long-term KRT experience not only the physiological consequences of kidney failure but also disruptions to school attendance, social interaction, and emotional well-being. While traditional clinical outcomes and symptoms' assessment remain important, they fail to capture the holistic burden of disease. The concepts of QoL and HRQoL offer a broader framework for understanding and improving patient-centred care in paediatric kidney disease.^{10,13}

Children on long term KRT face a uniquely challenging disease trajectory. Frequent hospitalizations, invasive procedures, dietary restrictions, and each replacement therapy regimens significantly impair daily functioning. For example, HD, often administered multiple times per week, can interfere with school attendance and social activities, leading to educational delays and peer isolation. PD, though home-based, still involves lifestyle limitations and potential for complications such as peritonitis. Transplantation is associated with improved HRQoL outcomes compared to dialysis, but it is not without burdens, including lifelong immunosuppression and risk of

graft failure. Emotional distress is common in this population, with increased rates of anxiety and depression reported among paediatric patients on long term KRT compared to healthy peers.²⁵⁻²⁷

Several instruments are used to measure HRQoL in children on long term KRT. The Paediatric Quality of Life Inventory (PedsQL), the Child Health Questionnaire (CHQ), and disease-specific tools like the Paediatric Kidney Disease Quality of Life (PKD-QOL) instrument are commonly implemented (See Table 1 for more tools). These assessments often include both child self-report and parent proxy-report, which can yield differing perspectives. Accurate measurement of HRQoL is essential for evaluating interventions and guiding clinical decision-making.²⁸

Table 1. *Generic and Disease Instruments used in paediatric patients on long term KRT.*

Generic HRQOL
PedsQL™ 4.0 Generic Core Scales
Child Health Questionnaire (CHQ)
KIDSCREEN
PROMIS Paediatric Measures
Health Utilities Index (HUI)
Disease-specific HRQoL instruments (Instruments that include domains or modules that address kidney disease and treatment-specific issues):
PedsQL 3.0 End Stage Kidney Disease Module
Child ESKD-Health Related Quality of Life Instrument
Kidney Disease Quality of Life – Short Form (KDQOL-SF™), adapted for children
Child Health Questionnaire (CHQ) – with kidney-specific add-ons

Based on the 2024 KDIGO guidelines, HRQoL assessment in paediatric CKD should be an integral part of holistic care using a valid instrument.²⁹ Incorporating HRQoL assessments into routine nursing care allows providers to address not only physical or medical needs but also psychosocial and developmental challenges. The physical demands of KRT therapies, along with the restrictions KRT imposes on daily life, create a profound sense of burden. Targeted interventions such as psychological counselling, school reintegration programs, smooth healthcare transition between paediatric and adult nephrology health services and family support services can significantly improve overall well-being.³⁰⁻³³

In research, HRQoL and patients experience assessments serve as key endpoints in evaluating treatment modalities and long-term outcomes. QoL and HRQoL are vital considerations in the care of children on long term KRT. Understanding how the disease affects all dimensions of a child's life enables a more holistic approach to treatment. By integrating HRQoL assessments into clinical practice, healthcare providers can better support this vulnerable population toward improved health outcomes focusing on well-being and life satisfaction. However, we need to keep in mind that children do not perceive health-related quality of life in the same way their parents do. Commonly, parents tend to view their children as doing worse than the children view themselves. Therefore, by assessing both child and parent perspectives, we gain a full understanding of HRQoL.^{29,30,34-36}

Moreover, longer periods in KRT in PD and HD, and the rate of related comorbidities, are associated with poor HRQoL. Surprisingly, it seems that over time, children state doing better emotionally than their parents believed. Nevertheless, long paediatric KRT significantly impacts both the well-being of the patient and caregiver, especially in more intensive treatments.^{29,30,34-37}

A common question is whether a certain type of KRT is better in comparison to the others in terms of HRQoL in paediatric patients with CKD. Dialysis and kidney transplantation are the two primary treatment modalities for end-stage kidney disease, each with unique implications for HRQoL. In the physical domain, dialysis is often associated with fatigue, dietary restrictions, and growth retardation. The frequency of visits (HD) or home burdens (PD) is a major concern that limits their physical activity.^{38,39}

Kidney Transplantation results in better physical well-being post-surgery and improved outcomes regarding growth parameters and energy levels with less dietary and fluid restrictions. A significant number of studies show significant improvement in physical HRQoL scores within 6–12 months post-transplant compared to dialysis patients.⁴⁰⁻⁴²

Regarding psychosocial well-being, children in dialysis treatment show a higher risk of depression and anxiety, especially due to dependency on machines and treatment schedules. In addition, they tend to state greater body image concerns due to catheters or fistulas and that makes them feel different from the norm. In contrary,

children after kidney transplantation seem to have better self-esteem and emotional well-being, with greater independence and social integration. However, research data reveals that after a short period post transplantation, their anxiety levels increase again due to fear of graft rejection or due to the restrictions and symptoms related to lifelong immunosuppression. Transplant recipients also generally report higher scores in emotional and social functioning than dialysis patients.^{38,41,42}

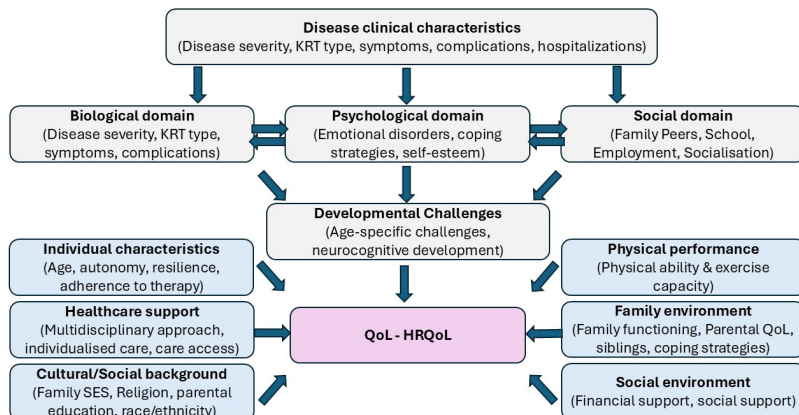
School performance and cognitive outcomes is another area where children in dialysis treatment differ in comparison to transplanted children. Dialysis treatment increases the risk for absenteeism. Furthermore, the uraemia and fluid shifts during dialysis affect the cognitive status of the children, leading to poorer academic performance. After kidney transplantation the children achieve improved school attendance and educational performance. Transplantation changes the life of children with end stage kidney disease as it means fewer hospitalizations and less treatment or test-related interruptions.^{40,43,44}

Family functioning is understandably more stressed for children on dialysis in comparison to transplantation, due to the significant pressure the caregivers face due to time commitment, complexity of care, and financial impact. After transplantation, parental care is mainly focused on adherence and symptom monitoring, which are less disruptive. Kidney transplantation generally results in a significantly better quality of life for paediatric Patients with CKD than dialysis. It is associated with better neurocognitive, academic, and health-related outcomes for recipients across almost all domains. However, access to transplantation, the importance of timely kidney transplantation in children, risks of surgery, and lifelong medication adherence are critical considerations. These partly explain the findings that indicate that children and adolescent kidney transplant recipients report lower overall HRQoL compared to their healthy peers.^{19,45} A recent qualitative study in Australia explored the experiences and perspectives of adolescent kidney transplant recipients. Achieving a sense of normality was the core demand for the participants, along with a need for greater information on various aspects of peri-transplantation care.⁴⁶

A structured theoretical model of Paediatric KRT on children's quality of life, based on existing health-related QoL frameworks

and evidence from current research in long-term KRT in children, is illustrated in Figure 1.

Figure 1. *Impact of Paediatric KRT on Quality of Life: A Biopsychosocial Model.*



In the following sections of the chapter the main domains of HRQoL will be addressed in relation to the impact of long term KRT in each of them as supported from the current evidence.

Impact on physical health and growth

Physical functioning of children as well as their growth, is directly affected by CKD and prolonged KRT. Children face significant somatic challenges such as growth retardation, fatigue, somatic symptoms and sleep disturbances. CKD and long term KRT are associated with various comorbidities, including cardiovascular issues, gastrointestinal problems, neurological symptoms, anaemia, and mineral and bone disorders. These can all contribute to a poorer physical QoL. Depending on the type of KRT, children may face restrictions on diet and travel (especially those on dialysis), and limitations on participation in sports.⁴⁷⁻⁴⁸ Interestingly, in their study, Hamiwka et al. (2009), related daily step count to physical health-related quality of life, physical activity and self-perception, setting the basis for a physical rehabilitation program for children with end-stage kidney disease.⁴⁹

Growth impairment is a common and significant problem in children with CKD, correlated with the severity of kidney insufficiency. Chronic inflammation, malnutrition, acidosis, and disrupted endocrine function

contribute to stunted growth, with many children remaining below the third percentile in height. Management strategies include addressing reversible comorbidities, optimizing nutrition, and ensuring metabolic control. Kidney transplantation improves physical outcomes but does not eliminate growth delays, especially if performed after a prolonged period on dialysis. Even though transplantation can improve growth, some children may still require growth hormone therapy.⁵⁰⁻⁵¹

Symptoms such as fatigue, headaches, and musculoskeletal pain are prevalent, especially in children receiving HD multiple times per week. Fatigue is one of the most common and debilitating symptoms with multiple causes, such as uraemia that affects energy levels, anaemia that leads to low haemoglobin, chronic inflammation that contributes to systemic fatigue, and HD that can cause post-dialysis fatigue. The presence of fatigue leads to reduced physical activity, concentration difficulty and social withdrawal or lack of motivation. Sleep and fatigue disturbances are common, under-recognized, and significantly impact quality of life in children and adolescents with CKD in long term KRT. Early recognition of fatigue remains a challenge in clinical practice, due to the multidimensional aspect of this symptom. A multidisciplinary approach involving paediatric nephrologists, sleep specialists, psychologists, and families, is crucial for effective management.^{5,47} Roumelioti et al. (2010) assessed the sleep and fatigue symptoms in 301 children and adolescents with CKD and the correlation with HRQoL, indicating an association related to the severity between sleep disturbances, low energy, and weakness with decreases in overall HRQoL.⁵²

We should emphasize the essential contribution of nurses in managing the diverse and complex needs of children who are under long term KRT. Given their central role in patient care, nurses are well equipped to deliver comprehensive support that addresses both physical symptoms—such as fatigue, persistent thirst and pain, along with the psychosocial and emotional aspects of recovery. Recommended nursing interventions include systematic evaluation and treatment of somatic complaints, as well as education and support related to body image and weight regulation.^{29,53}

Impact on psychological and emotional well-being

Research evidence supports that children and adolescents with chronic illnesses are more likely to experience mental health issues, including depression, anxiety, mood and behavioural challenges,

when compared to their healthy counterparts and children with pre-dialysis CKD. Although psychological outcomes in adolescents with CKD in long term KRT have not been as widely explored, available studies suggest a pattern of difficulties in psychological adjustment. These include problems with body image and self-esteem, elevated depressive symptoms, and inconsistent findings regarding anxiety and behavioural concerns. Studies indicate that prevalence of mood and anxiety disorders is high among paediatric patients with CDK with a tendency to increase in higher stages of kidney insufficiency. They are mainly associated with body image issues, disease and treatment restrictions and social isolation. Current guidelines support early systematic depression screening for paediatric patients on long term KRT as part of their regular follow up. The association of mental health challenges to major outcomes such as QoL, treatment adherence, and overall well-being makes addressing them a priority.^{23,54-56}

The type of KRT as well as the duration of treatment can affect the occurrence of mood and anxiety disorders. For example, depression and anxiety were less commonly encountered among kidney transplant subjects in comparison to those undergoing HD. Nevertheless, paediatric transplant recipients have increased psychosocial stress related to the chronicity of the disease. Children with emotional or psychiatric disorders often require additional mental health resources including psychiatric care before and after transplant. Moreover, recent data supports that depression and anxiety prevalence was high in comparison to healthy children. This partly indicates that children in long term KRT face increased risk for depression or anxiety (10–35%) independently of the KRT method. Females seem to face these struggles more frequently. Subclinical mood disorders' symptoms may be prevalent among more children and adolescents with CKD and have an influence on their QoL and health outcomes. Subclinical depressive features commonly include anger, guilt, and poor self-worth.^{23,40,54,57}

In the literature, there is an argument about whether mood and anxiety disorders are underdiagnosed or underestimated due to the stigma of mental health conditions among parents and adolescents or due to the focus on the medical aspects of CKD.⁵⁸ Moreira et al. (2016), in their study with twenty-eight children and adolescents with pre-dialysis CKD and twenty eight matched healthy controls, explored psychological well-being, focusing on resilience,

quality of life, and symptoms of anxiety and depression. The CKD group showed a higher prevalence of mental health referrals, elevated separation anxiety, and more frequent clinically significant depressive symptoms. Additionally, they reported lower QoL scores, particularly in psychological, educational, and psychosocial domains. A negative relationship was identified between QoL and both anxiety and depression. While resilience scores did not differ significantly between groups, lower resilience was observed among Patients with CKD with depressive symptoms.⁵⁹ Kogon et al (2016) in their study, argued that parents have limited awareness about depression and mood disorder symptoms in their children. This finding gives insight into the under-recognition and undertreatment of depression in paediatric patients due to multiple factors among which awareness, misconceptions and prioritization of kidney therapy were the most prevalent.⁶⁰

Identifying and treating depression and anxiety among children in long term KRT adds to the holistic approach towards better QoL and long-term outcomes. During their therapeutic journey older children and adolescents may feel that they lose their independence due to the strict treatment schedules and their reliance on their parents. This directly effects their maturation, self-confidence and self-image. Especially during adolescence, the desire for “Normality” is greater.⁶¹ In order to effectively enhance the health-related quality of life of these patients, symptom management of common symptoms such as fatigue, anxiety, depression, stress, pain, and sleep disturbances, as well as poor body image and sexual health, should be addressed.⁶²

Impact on social life & school performance

Long-term KRT can significantly alter the social life and school performance of children and adolescents with CKD. Time-consuming treatments or/and frequent hospital visits and the physical limitations of the disease, limit their time for socialization and peer activities. Moreover, psychosocial challenges such as feeling different, feeling anxious, depressed, with low self-esteem or stigmatized, affect peer relationships.⁶³

Adolescents try to follow their peers and fit in despite the many restrictions due to their disease along with the long term KRT. Their experiences, positively or negatively, influence their resilience and coping, and has been shown in literature that social interaction

has been characterized as both an opportunity and an area for potential challenge. For example, positive social support improves QoL and can serve as a protective factor against mood or anxiety disorders.^{64,65} A significant number of children and adolescents with CKD experience adjustment problems. Among the different KRT, children and adolescents on dialysis were the most likely to have difficulties with social relationships.^{66,67}

Parental overprotection may limit their social activities due to safety concerns, further restricting social development. Due to the perceived vulnerability of their child, parents commonly might adopt an overprotective parenting style, limiting their child's autonomy and consequently his/her social life. Illness uncertainty influences psychological functioning, resilience, family functioning and coping in the context of paediatric CKD.⁶⁸

Overprotective attitudes are typically motivated by genuine concern for the child's health and safety, but they can inadvertently contribute to negative psychosocial outcomes. This limitation on social interaction can impair the development of essential interpersonal skills, reduce opportunities for peer bonding, and foster feelings of isolation or social anxiety. Therefore, parents should be advised to balance their protective behaviour with their child's need for social interaction with peers in the frames of a holistic patient-centred approach.⁶⁹

Finally, they may face challenges with peers such as difficulty maintaining friendships due to frequent absences and mood disorders, or even face bullying or exclusion due to physical appearance or perceived differences. Participation in peer support programs and inclusive activities can help mitigate these effects.⁶⁴ Studies in the early 2000's in children and adolescents with CKD showed that there were no major differences in comparison to healthy peers in academic achievement, memory, behaviour or self-esteem.⁷⁰

The most profound difference from norms was in school functioning. Regular dialysis sessions and associated health problems lead to frequent school absences and reduced academic achievement. In addition, there is evidence that children and adolescents with CKD have an increased prevalence of attention deficit and memory impairment, particularly in children with early-onset disease or prolonged uraemia, proteinuria, and metabolic acidosis, ranging from

mild to severe and correlated with the severity of kidney disease. Although often mild, these cognitive deficits may impact QoL and they are associated with lower high school graduation rates and long-term underemployment among young adults with CKD.^{5,61}

Cognitive functions are not assessed routinely in children with long-term KTR. Therefore, neuropsychological assessment on a regular basis, will ensure counselling regarding cognitive impairment, social participation, school attendance and well-being.⁷¹ Children and adolescents in long term KRT seem to achieve social autonomy and optimal educational attainment at an older age compared with their healthy peers.⁷² Regular evaluation of neurocognitive abilities and educational support services with tailored learning plans are crucial in addressing these barriers and promoting school reintegration to achieve optimal school performance for children in long term KRT.⁴⁰

Impact on family functioning and caregiving burden

In multiple ways long term KRT in children and adolescents affects the family dynamics, roles and routines, and leads to significant burden. The chronicity of the disease along with the prolonged therapies change the demands among the family members, transform the family functioning to adapt to the management of these needs and impacts on family dynamics and on the relationships between family members. Moreover, families have to simultaneously address the needs of healthy siblings. Attention and resources may be disproportionately directed toward the child with CKD, affecting sibling relationships and family dynamics. The well-being of one family member has an impact on the well-being of the whole family.⁷³ Family support and involvement in care is essential, as it predicts increased adherence to treatment regimens. Limited family involvement in therapeutic planning, family conflicts and other barriers in relation to supportive family functioning are among the most important determinants that lead to poor adherence in adolescents in long term KRT. Family members commonly feel vulnerable due to their worry about the patient's health, survival, and disease progression and in need of help and support from relatives, friends and health professionals.⁷⁴ Provision of adequate information, social and emotional support and help in the identification of support resources can facilitate parental adaptation.⁷⁵ Therefore, in cases of long-term KRT, over time the level of parental resilience, impacts and influences family relationships and dynamics.⁷⁶

Family conflicts may arise over care decisions, discrepancies in evaluation of the family situation, and in relation of caregiving responsibilities due to time demands and stress.⁷⁷ Parents of children on long term KRT need to cope to fulfil their dual parental and care provider responsibilities, with negative consequences, due to uncertainties about the future and the extreme healthcare demands.^{78,79} Moreover, families may withdraw from social activities due to caregiving duties or fear of infections (especially in dialysis) and have less time and energy for other relationships or leisure. Families with strong social or community support cope better, and resilient and problem-solving oriented families show better adaptation.⁷⁹

Families of children on long-term KRT often endure significant stress due to financial pressures since they may have to deal with the cost of frequent medical care, travel, out-of-pocket payments, and loss of parental income due to disruption to work related to caregiving responsibilities. Financial pressure affects parents' ability to provide care for their children and their QoL.⁸⁰ Parents from remote and rural areas state higher financial burden related with direct and indirect travel costs and income loss, and in some cases need to move to larger towns leaving their homes.^{81,82}

In literature, several interventions have been proposed to mitigate the impact on family functioning. Provision of adequate information based on parental needs, psychosocial support for families and caregivers, along with their training and education on managing treatment and patient needs, financial support through social programs and workplace flexibility, availability of family therapy or counselling to address role strain and communication issues, and the availability of palliative care services are among the most referenced interventions. We should notice that supportive palliative care services can be implemented in order to relieve somatic and psychosocial suffering and enhance parental caregiving skills.⁷⁵

In a recent qualitative interview study, parental adaptation and palliative care needs were assessed with fifteen interviews in adolescents and young adults and their caregivers. Adolescents and young adults seem to concern more for the limitations to everyday life and they wish to live a normal life. Caregivers are concerned about the future and the management of the disease, along with other responsibilities such as work and family roles. Identifying the factors influencing parental adaptation helps the medical staff to

make the necessary interventions to support the parents. Family-centred care models and psychosocial support services are vital in addressing these systemic issues.⁸³

Health-related quality of life in young adults after paediatric kidney failure

Paediatric kidney failure in many cases will progress to end stage kidney disease that will demand long term KRT. Even after successful replacement therapy, such as dialysis or kidney transplantation, patients may face lasting effects into adulthood. It is evidenced that HRQoL in young adults after paediatric kidney failure is influenced by the disease trajectory during childhood and adolescence. Adults with a history of paediatric kidney failure often report lower physical HRQoL scores due to clinical symptoms that limit their physical activity such as hypertension, anaemia, and pain due to bone disease. However, transplant recipients generally report better physical functioning than those who remained on dialysis, mainly due to less complications and less therapy restrictions.^{47,84,85}

Transplantation has the greatest impact on social development, educational attainment, quality of life and overall well-being. Improvements in psychosocial outcomes have been noted and were associated with advances in graft survival and overall patient survival.⁸⁶ Haavisto et al. (2011) supported that adults who underwent kidney transplantation before the age of five continue to experience challenges such as impaired QoL and difficulties in psychosocial adjustment, even decades after their initial transplant.⁸⁷

In the psychological and emotional domain, young adults present higher rates of depression and anxiety and express concerns about body image and self-perception, particularly for those with growth delays regarding body fitness and weight, as well as scars.⁸⁸ Children with chronic diseases may struggle with identity, self-esteem, social life limitations and in general with a challenging reality.⁸⁹ The changes in everyday life due to the kidney disease or long term KRT threatens their autonomy and influences their identity and self-image.⁸⁸

Family and peer support enhances resilience and the development of coping skills. Therefore, peer and family support during childhood play a crucial role in adult mental health and protection from mood disorders. Findings from a recent and current study highlight the crucial role peer support and school environment may have in promoting mental health and resilience for all children, including both

those with and without supportive home environments.⁹⁰ Delays in psychosocial development, such as forming romantic relationships or achieving financial independence are commonly stated. Moreover, as previously stated, several studies have revealed higher unemployment or underemployment rates in young adults after paediatric CKD.⁹¹

The main factors influencing HRQoL in young adults with a history of paediatric kidney failure are age at kidney failure onset, with earlier onset often associated with more severe long-term effects. Type and duration of treatment with longer dialysis duration before transplant, are associated with worse outcomes, and the presence of family and social support, correlating with strong support systems for better long-term adjustment. Moreover, poor coordination between paediatric and adult nephrology care can negatively impact adherence and outcomes.^{84,92}

The Dutch LERIC study examined the long-term effects of kidney disease treatment in patients in long term KRT who started therapy in childhood. The average length of KRT was 25.5 years. They faced significant health challenges, delays in education and barriers in employment and social independence. The study highlights the importance of early transplantation and psychosocial support to improve outcomes for children with kidney disease.⁹³ Early intervention and mental health support during paediatric treatment, structured transition programs to adult care, educational counselling during adolescence, and long-term monitoring for late effects of paediatric kidney disease and its treatment, along with regular routine assessment of QoL and neuropsychological testing, are among the most important interventions to ensure better HRQoL for young adults.^{87,94}

Clinical implications to improve quality of life

The most significant research findings related to the effect of long-term KRT on child and adolescent HRQoL were critically reviewed in this chapter. The major clinical implications that can be drawn from this review are:

- Optimisation of medical management by individualised dialysis prescriptions, residual kidney function preservation, and nutritional support with personalised diet plans to prevent growth failure, malnutrition, anaemia and bone disease management.

- Systematic assessment of HRQoL in these children with the use of generic or disease specific validated tools.
 - Children in dialysis, as well as their caregivers, systematically report worse QoL than those after kidney transplantation.
 - Age and gender affect the HRQoL in these patients, and especially in the social and emotional domain. Adolescents and females may need particular attention for emotional and self-image concerns.
 - A multi-perspective assessment is vital to understand the HRQoL of children and adolescents in long-term KRT in depth, by using both child and parent reports.
 - The response shift is present in caregivers of children in long-term KRT since their perceptions of their child's QoL change over time as they adjust to the challenges and they develop coping mechanisms and implement alternative strategies.
- Assessment of children's life experiences, patient-reported outcome measures, and the difficulties they face in everyday living, due to the disease and treatment burden, will enable individualised planning of their care based on their active needs.
- Empowering adolescents to promote self-care skills and participate in decision making regarding their care plans.
- Empowering family functioning and improving parent-child communication through counselling and support enhances resilience and improves the coping of both the child and parents.
- A multidisciplinary, child-centred, individualised approach is crucial for adequate medical management, incorporating palliative care, psychosocial support and alleviating mental health burdens.
- Supporting school attendance and coordinate with schools for flexible attendance, tutoring, and understanding of medical needs will enhance educational and cognitive development.
- Necessity for a smooth transition to adult care with structured programs to support independence and minimise non-adherence.
- Address health disparities by ensuring equitable access to transplant listing, home dialysis, and psychological care and culturally sensitive interventions where needed.

Conclusion

Medical advancements have improved survival rates for children with end-stage kidney disease. However, the children and adolescents who undergo long-term KRT, experience significant disruptions across multiple domains of life, impacting their physical growth, mental health, social integration, and academic performance. This chapter reviews the multifaceted impact of long-term KRT on the physical, psychological, educational, and social well-being of paediatric patients.

While kidney transplantation offers improved outcomes compared to dialysis, both modalities present challenges that can diminish quality of life, particularly during adolescence, for example medication adherence. A multidisciplinary approach involving medical, psychosocial, and educational support is essential to optimise outcomes and mitigate the burdens of CKD in children. Moreover, the disease places a substantial burden on families, affecting parental mental health and overall family dynamics. Stressors and challenges related to the disease, the treatment options, and related life changes threaten family functioning and family resilience. Social interactions are frequently disrupted by school absences, activity restrictions, and stigma, contributing to isolation and impaired peer relationships. Addressing these multifaceted challenges is essential to improving HRQoL outcomes in this population. In addition, continuous research is essential for the progress of care to these patients in order to optimize the intervention targets leading to better clinical outcomes, growth and well-being of children.

References

1. Demir MHB, Taner S, Demir HB, et al. Quality of Life and Psychological Well-Being in Children and Adolescents After Renal Transplantation. *Transplant Proc.* 2023;55(5):1160-1165. doi:10.1016/j.transproceed.2023.04.022
2. Bonthuis M, Harambat J, Jager KJ, Vidal E. Growth in children on kidney replacement therapy: a review of data from patient registries. *Pediatr Nephrol.* 2021;36(8):2563-2574. doi:10.1007/s00467-021-05099-4.
3. Cirillo L, De Chiara L, Innocenti S, Errichiello C, Romagnani P, Becherucci F. Chronic kidney disease in children: an update. *Clin Kidney J.* 2023;16(10):1600-1611. Published 2023 Apr 24. doi:10.1093/ckj/sfad097
4. McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF. Quality of life in children with chronic kidney disease-patient and caregiver assessments. *Nephrol Dial Transplant.* 2006;21(7):1899-1905. doi:10.1093/ndt/gfl091

5. Gerson AC, Wentz A, Abraham AG, et al. Health-related quality of life of children with mild to moderate chronic kidney disease. *Paediatrics*. 2010;125(2):e349-e357. doi:10.1542/peds.2009-0085
6. Heath J, Mackinlay D, Watson AR, et al. Self-reported quality of life in children and young people with chronic kidney disease. *Pediatr Nephrol*. 2011;26(5):767-773. doi:10.1007/s00467-011-1784-2
7. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics*. 2016;34(7):645-649. doi:10.1007/s40273-016-0389-9
8. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Paediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001;39(8):800-812. doi:10.1097/00005650-200108000-00006
9. Dotis J, Pavlaki A, Printza N, et al. Quality of life in children with chronic kidney disease. *Pediatr Nephrol*. 2016;31(12):2309-2316. doi:10.1007/s00467-016-3457-7
10. Aier A, Pais P, Raman V. Psychological aspects in children and parents of children with chronic kidney disease and their families. *Clin Exp Pediatr*. 2022;65(5):222-229. doi:10.3345/cep.2021.01004
11. Kogon AJ, Hooper SR. Mental health and social-emotional functioning in children and adolescents with chronic kidney disease. *Pediatr Nephrol*. 2024;39(7):2015-2031. doi:10.1007/s00467-023-06151-1.
12. Russo K. Assessment and Treatment of Adolescents With Chronic Medical Conditions. *J Health Serv Psychol*. 2022;48(2):69-78. doi:10.1007/s42843-022-00059-4
13. Dryjańska N, Kiliś-Pstrusińska K. Depression in Children and Adolescents with Chronic Kidney Disease-Review of Available Literature. *J Clin Med*. 2023;12(10):3554. Published 2023 May 19. doi:10.3390/jcm12103554
14. Nibras S, Kentor R, Masood Y, et al. Psychological and Psychiatric Comorbidities in Youth with Serious Physical Illness. *Children (Basel)*. 2022;9(7):1051. Published 2022 Jul 14. doi:10.3390/children9071051
15. Sharma R, Jafra BS, Tiewsoh K, et al. Distress, anxiety, and its correlates among caregivers of children with kidney diseases during COVID-19 pandemic lockdown. *Arch Pediatr*. 2022;29(3):243-248. doi:10.1016/j.arcped.2022.01.003
16. Nicholas DB, Picone G, Selkirk EK. The lived experiences of children and adolescents with end-stage renal disease. *Qual Health Res*. 2011;21(2):162-173. doi:10.1177/1049732310382789
17. Cardol CK, Boslooper-Meulenbelt K, van Middendorp H, Meuleman Y, Evers AWM, van Dijk S. Psychosocial barriers and facilitators for adherence to a healthy lifestyle among patients with chronic kidney disease: a focus group study. *BMC Nephrol*. 2022;23(1):205. Published 2022 Jun 11. doi:10.1186/s12882-022-02837-0
18. Doshi K, Raina R, Ng KH, et al. Health-related quality of life for paediatric patients with end-stage kidney disease: A systematic review and meta-analysis of the Paediatric Quality of Life Inventory (PedsQL). *Hemodial Int*. 2024;28(2):198-215. doi:10.1111/hdi.13138

19. Alaskar M, AlQattan F, Al-Shami S, Hamed A, Alshami A. Quality of Life in Paediatric CKD Patients on Dialysis vs Renal Transplantation: A Comparative Study of the Perspectives of Parents and Children. *Transplant Proc.* 2025;57(2):241-249. doi:10.1016/j.transproceed.2024.12.023
20. Goldstein SL, Gerson AC, Furth S. Health-related quality of life for children with chronic kidney disease. *Adv Chronic Kidney Dis.* 2007;14(4):364-369. doi:10.1053/j.ackd.2007.07.006
21. Bell LE, Ferris ME, Fenton N, Hooper SR. Health care transition for adolescents with CKD-the journey from paediatric to adult care. *Adv Chronic Kidney Dis.* 2011;18(5):384-390. doi:10.1053/j.ackd.2011.04.003
22. Yang Q, Yu G, Fu M, Yang J, Li X. The effectiveness of a transition programme based on the integrated theory of health behavior change in adolescents with chronic kidney disease: a quasi-experimental study. *BMC Pediatr.* 2025;25(1):111. Published 2025 Feb 12. doi:10.1186/s12887-025-05467-1
23. Karczewski, Sabrina A., Keane, Molly, Agarwal Berla, Nishita "Psychological Aspects and Challenges of Living with Chronic Kidney Disease for Adolescents" In *Adolescents with Chronic Kidney Disease*, Springer International Publishing (2019).
24. Sharma S, Kalra D, Rashid I, Mehta S, Maity MK, Wazir K, Gupta S, Ansari SA, Alruqi OS, Khan R, et al. Assessment of Health-Related Quality of Life in Chronic Kidney Disease Patients: A Hospital-Based Cross-Sectional Study. *Medicina.* 2023; 59(10):1788. <https://doi.org/10.3390/medicina59101788>
25. Rees L, Schaefer F, Schmitt CP, Shroff R, Warady BA. Chronic dialysis in children and adolescents: challenges and outcomes. *Lancet Child Adolesc Health.* 2017;1(1):68-77. doi:10.1016/S2352-4642(17)30018-4
26. Schild R, Dupont S, Harnabat J, et al. Disparities in treatment and outcome of kidney replacement therapy in children with comorbidities: an ESPN/ERA Registry study. *Clin Kidney J.* 2023;16(4):745-755. Published 2023 Jan 12. doi:10.1093/cjkj/sfad008
27. de Boer SE, Knobbe TJ, Kremer D, et al. Kidney Transplantation Improves Health-Related Quality of Life in Older Recipients. *Transpl Int.* 2024;37:12071. Published 2024 Apr 15. doi:10.3389/ti.2024.12071
28. Varni JW, Limbers CA, Burwinkle TM. How young can children reliably and validly self-report their health-related quality of life? An analysis of 8,591 children across age subgroups with the PedsQL™ 4.0 Generic Core Scales. *Health Qual Life Outcomes.* 2007;5:1. doi:10.1186/1477-7525-5-1
29. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int.* 2024, 105, S117–S314.
30. Ruidiaz-Gómez, K.S.; Higueta-Gutiérrez, L.F. Impact of chronic kidney disease on health-related quality of life in the Paediatric population: Meta-analysis. *J. Pediatr.* 2021, 97, 478–489.
31. Wang X, Tan DJ, Guan L, et al. Assessment of health-related quality of life of children with idiopathic nephrotic syndrome and their caregivers in China. *Health Qual Life Outcomes.* 2024;22(1):94. Published 2024 Oct 29. doi:10.1186/s12955-024-02310-6

32. Sahu G, Arora P, Tiwari P, D'Cruz S, Tahlan A. The impact of chronic kidney disease on health-related quality of life (HRQoL): key insights from a hospital-based cross-sectional study. *J Bras Nefrol.* 2025;47(3):e20240229. doi:10.1590/2175-8239-JBN-2024-0229en
33. Kinch M, Kroll T, Buckle N, Somanadhan S. Interventions to support young adults and families with the healthcare transition between paediatric and adult nephrology health services: A systematic scoping review. *J Pediatr Nurs.* 2024;78:e346-e363. doi:10.1016/j.pedn.2024.07.026
34. Neul SK, Minard CG, Currier H, Goldstein SL. Health-related quality of life functioning over a 2-year period in children with end-stage renal disease. *Pediatr Nephrol.* 2013;28(2):285-293. doi:10.1007/s00467-012-2313-7
35. Abrão RO, Lopes M, Silva GJS, Ferraro AA, Koch VH. Study of the association between generic and disease-specific quality of life and behavior problems in paediatric patients with chronic kidney disease stage 3 or higher and the quality of life and mental health of their primary caregivers. *Pediatr Nephrol.* 2021;36(10):3201-3210. doi:10.1007/s00467-021-04986-0
36. Mekahli D, Ledermann S, Gullett A, Rees L. Evaluation of quality of life by young adult survivors of severe chronic kidney disease in infancy. *Pediatr Nephrol.* 2014;29(8):1387-1393. doi:10.1007/s00467-014-2785-8
37. Chaichana U, Pooliam J, Jantongsree M, et al. Quality of life in children at different stages of chronic kidney disease in a developing country. *Pediatr Nephrol.* 2025;40(1):177-187. doi:10.1007/s00467-024-06442-1
38. Doan V, Shoker A, Abdelrasoul A. Quality of Life of Dialysis Patients: Exploring the Influence of Membrane Hemocompatibility and Dialysis Practices on Psychosocial and Physical Symptoms. *Journal of Composites Science.* 2024; 8(5):172. <https://doi.org/10.3390/jcs8050172>
39. El-Gamasy MA, Eldeeb MM. Assessment of physical and psychosocial status of children with ESKD under regular Haemodialysis, a single centre experience. *Int J Pediatr Adolesc Med.* 2017;4(2):81-86. doi:10.1016/j.ijpam.2017.01.001
40. Winterberg PD, Garro R. Long-Term Outcomes of Kidney Transplantation in Children. *Pediatr Clin North Am.* 2019;66(1):269-280. doi:10.1016/j.pcl.2018.09.008
41. Oomen L, Bootsma-Robroeks C, Cornelissen E, de Wall L, Feitz W. Pearls and Pitfalls in Paediatric Kidney Transplantation After 5 Decades. *Front Pediatr.* 2022;10:856630. Published 2022 Apr 8. doi:10.3389/fped.2022.856630
42. Ritschl V, Stamm T, Selzer A, et al. Life outcomes after paediatric kidney transplantation: a qualitative, biographical study in long-term survivors. *Arch Dis Child.* 2024;109(3):240-246. Published 2024 Feb 19. doi:10.1136/archdischild-2023-326432
43. Kim S, Van Zwieten A, Lorenzo J, et al. Cognitive and academic outcomes in children with chronic kidney disease. *Pediatr Nephrol.* 2022;37(11):2715-2724. doi:10.1007/s00467-022-05499-0
44. Wightman A, Bradford MC, Smith J. Health-related quality of life changes following renal transplantation in children. *Pediatr Transplant.* 2019;23(2):e13333. doi:10.1111/petr.13333

45. Roberts E, Zelikovsky N. Family Environment, Social Support, and Health-Related Quality of Life in Adolescents Following Kidney Transplant. *Pediatr Transplant.* 2024;28(5):e14824. doi:10.1111/ptr.14824
46. Tong A, Morton R, Howard K, McTaggart S, Craig JC. "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatr Transplant.* 2011;15(3):285-293. doi:10.1111/j.1399-3046.2010.01470.x
47. Karava V, Goutou S, Dotis J, et al. Fatigue and Quality of Life in Children with Chronic Kidney Disease. *Children (Basel).* 2022;9(9):1414. Published 2022 Sep 18. doi:10.3390/children9091414
48. Goldstein SL. Physical functioning in children with end-stage renal disease: small steps first. *Pediatr Transplant.* 2009;13(7):802-804. doi:10.1111/j.1399-3046.2009.01232.x
49. Hamiwka LA, Cantell M, Crawford S, Clark CG. Physical activity and health related quality of life in children following kidney transplantation. *Pediatr Transplant.* 2009;13(7):861-867. doi:10.1111/j.1399-3046.2009.01195.x
50. Todisco T, Ubertini GM, Bizzarri C, Loche S, Cappa M. Chronic Kidney Disease and Growth Failure in Children. *Children (Basel).* 2024;11(7):808. Published 2024 Jul 1. doi:10.3390/children11070808
51. Jagodzinski C, Mueller S, Kluck R, et al. Growth hormone treatment in the pre-transplant period is associated with superior outcome after Paediatric kidney transplantation. *Pediatr Nephrol.* 2022;37(4):859-869. doi:10.1007/s00467-021-05222-5
52. Roumelioti ME, Wentz A, Schneider MF, et al. Sleep and fatigue symptoms in children and adolescents with CKD: a cross-sectional analysis from the chronic kidney disease in children (CKiD) study. *Am J Kidney Dis.* 2010;55(2):269-280. doi:10.1053/j.ajkd.2009.09.021
53. Anthony SJ, Hebert D, Todd L, et al. Child and parental perspectives of multidimensional quality of life outcomes after kidney transplantation. *Pediatr Transplant.* 2010;14(2):249-256. doi:10.1111/j.1399-3046.2009.01214.x
54. Clementi MA, Zimmerman CT. Psychosocial considerations and recommendations for care of Paediatric patients on dialysis. *Pediatr Nephrol.* 2020;35(5):767-775. doi:10.1007/s00467-019-04227-5
55. Heath J, Norman P, Christian M, Watson A. Measurement of quality of life and attitudes towards illness in children and young people with chronic kidney disease. *Qual Life Res.* 2017;26(9):2409-2419. doi:10.1007/s11136-017-1605-6
56. Laube NF, Mader L, Heinzelmann MA, et al. Psychological distress in adults after Paediatric kidney replacement therapy. *Pediatr Nephrol.* 2025;40(4):1049-1057. doi:10.1007/s00467-024-06571-7
57. Alavi NM, Aliakbarzadeh Z, Sharifi K. Depression, anxiety, activities of daily living, and quality of life scores in patients undergoing renal replacement therapies. *Transplant Proc.* 2009;41(9):3693-3696. doi:10.1016/j.transproceed.2009.06.217
58. Kiliś-Pstrusińska K, Medyńska A, Adamczak P, et al. Anxiety in children and adolescents with chronic kidney disease—multicenter national study results. *Kidney Blood Press Res.* 2013;37(6):579-587. doi:10.1159/000355738

59. Moreira JM, Bouissou Morais Soares CM, Teixeira AL, Simões E Silva AC, Kummer AM. Anxiety, depression, resilience and quality of life in children and adolescents with pre-dialysis chronic kidney disease. *Pediatr Nephrol.* 2015;30(12):2153-2162. doi:10.1007/s00467-015-3159-6
60. Kogon AJ, Vander Stoep A, Weiss NS, Smith J, Flynn JT, McCauley E. Depression and its associated factors in Paediatric chronic kidney disease. *Pediatr Nephrol.* 2013;28(9):1855-1861. doi:10.1007/s00467-013-2497-5
61. Johnson RJ, Harshman LA. Neurocognition in Paediatric Chronic Kidney Disease: A Review of Data From the Chronic Kidney Disease in Children (CKiD) Study. *Semin Nephrol.* 2021;41(5):446-454. doi:10.1016/j.semnephrol.2021.09.007
62. House TR, Marks SD, Freeman MA. Holistic care and symptom management for Paediatric kidney transplant recipients. *Pediatr Nephrol.* 2024;39(6):1759-1769. doi:10.1007/s00467-023-06175-7
63. Rocha S, Fonseca I, Silva N, et al. Impact of Paediatric kidney transplantation on long-term professional and social outcomes. *Transplant Proc.* 2011;43(1):120-124. doi:10.1016/j.transproceed.2010.12.011
64. Kerklaan J, Hannan E, Hanson C, et al. Perspectives on life participation by young adults with chronic kidney disease: an interview study. *BMJ Open.* 2020;10(10):e037840. Published 2020 Oct 16. doi:10.1136/bmjopen-2020-037840
65. Kul M, Cengel Kültür E, Senses Dinç G, Bilginer Y, Uluç S, Baykan H. Quality of life in children and adolescents with chronic kidney disease: a comparative study between different disease stages and treatment modalities. *Turk J Pediatr.* 2013;55(5):493-499.
66. Kang NR, Ahn YH, Park E, et al. Mental health and psychosocial adjustment in Paediatric chronic kidney disease derived from the KNOW-Ped CKD study. *Pediatr Nephrol.* 2019;34(10):1753-1764. doi:10.1007/s00467-019-04292-w
67. Pinquart M, Teubert D. Academic, physical, and social functioning of children and adolescents with chronic physical illness: a meta-analysis. *J Pediatr Psychol.* 2012;37(4):376-389. doi:10.1093/jpepsy/jsr106
68. Szulcowski L, Mullins LL, Bidwell SL, Eddington AR, Pai ALH. Meta-Analysis: Caregiver and Youth Uncertainty in Paediatric Chronic Illness. *J Pediatr Psychol.* 2017;42(4):395-421. doi:10.1093/jpepsy/jsw097
69. Hullmann SE, Wolfe-Christensen C, Ryan JL, et al. Parental overprotection, perceived child vulnerability, and parenting stress: a cross-illness comparison. *J Clin Psychol Med Settings.* 2010;17(4):357-365. doi:10.1007/s10880-010-9213-4
70. Bawden HN, Acott P, Carter J, et al. Neuropsychological functioning in end-stage renal disease. *Arch Dis Child.* 2004;89(7):644-647. doi:10.1136/adc.2003.037093
71. Ziengs AL, Buunk AM, van Sonderen L, et al. Long-term cognitive impairments in kidney transplant recipients: impact on participation and quality of life. *Nephrol Dial Transplant.* 2023;38(2):491-498. doi:10.1093/ndt/gfac035

72. Tjaden LA, Maurice-Stam H, Grootenhuis MA, Jager KJ, Groothoff JW. Impact of Renal Replacement Therapy in Childhood on Long-Term Socioprofessional Outcomes: A 30-year Follow-Up Study. *J Pediatr.* 2016;171:189-95.e952. doi:10.1016/j.jpeds.2015.12.017
73. Agerskov H, Thiesson HC, Pedersen BD. Everyday life experiences in families with a child with kidney disease. *J Ren Care.* 2019;45(4):205-211. doi:10.1111/jorc.12297
74. Agerskov H, Thiesson HC, Pedersen BD. The significance of relationships and dynamics in families with a child with end-stage kidney disease: A qualitative study. *J Clin Nurs.* 2020;29(5-6):987-995. doi:10.1111/jocn.15170
75. Khorsandi F, Parizad N, Feizi A, Hemmati MaslakPak M. How do parents deal with their children's chronic kidney disease? A qualitative study for identifying factors related to parent's adaptation. *BMC Nephrol.* 2020;21(1):509. Published 2020 Nov 25. doi:10.1186/s12882-020-02170-4
76. Agerskov H, Thiesson HC, Schultz H, Pedersen BD. Relationships and dynamics in families with a child with a kidney transplant-A study of parents' everyday life experiences. *J Ren Care.* 2024;50(2):151-158. doi:10.1111/jorc.12465
77. Kiliś-Pstrusińska K, Medyńska A, Adamczyk P, et al. Disease-related social situation in family of children with chronic kidney disease--parents' assessment. A multicentre study. *Ann Agric Environ Med.* 2014;21(4):876-881. doi:10.5604/12321966.1129951
78. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Dev.* 2010;36(4):549-557. doi:10.1111/j.1365-2214.2010.01067.x
79. Lima AGT, Sales CCDS, Serafim WFL. Burden, depression and anxiety in primary caregivers of children and adolescents in renal replacement therapy. *J Bras Nefrol.* 2019;41(3):356-363. doi:10.1590/2175-8239-JBN-2018-0039
80. Darwish MM, Hassan SH, Taha SF, Abd El-Megeed HS, Ismail TAM. Family impact and economic burden among caregivers of children with chronic kidney disease in Assiut, Egypt. *J Egypt Public Health Assoc.* 2020;95(1):27. Published 2020 Oct 7. doi:10.1186/s42506-020-00058-7
81. Reddy S, Scholes-Robertson N, Raj JM, Pais P. Catastrophic healthcare expenditure and caregiver burden in Paediatric chronic kidney disease - a mixed methods study from a low resource setting. *Pediatr Nephrol.* 2024;39(10):3079-3093. doi:10.1007/s00467-024-06420-7
82. Scholes-Robertson N, Gutman T, Dominello A, et al. Australian Rural Caregivers' Experiences in Supporting Patients With Kidney Failure to Access Dialysis and Kidney Transplantation: A Qualitative Study. *Am J Kidney Dis.* 2022;80(6):773-782.e1. doi:10.1053/j.ajkd.2022.05.015
83. Kubiak N, Fehrenbach C, Prüfe J, Thumfart J. Do We Need Palliative Care in Paediatric Nephrology? Patients' and Caregivers' Disease Experience. *Children (Basel).* 2023;10(2):324. Published 2023 Feb 8. doi:10.3390/children10020324

84. Heinzlmann MA, Kuehni CE, Roser K, Mader L, Laube GF; Swiss Paediatric Renal Registry (SPRR) group. Health-related quality of life in adults after Paediatric kidney failure in Switzerland. *Pediatr Nephrol.* 2023;38(5):1559-1568. doi:10.1007/s00467-022-05760-6
85. Ferris ME, Miles JA, Seamon ML. Adolescents and Young Adults with Chronic or End-Stage Kidney Disease. *Blood Purif.* 2016;41(1-3):205-210. doi:10.1159/000441317
86. Puma L, Doyle M. Long-term psychosocial outcomes of adults transplanted in childhood: A social work perspective. *Pediatr Transplant.* 2021;25(1):e13859. doi:10.1111/ptr.13859
87. Haavisto A, Jalanko H, Sintonen H, Holmberg C, Qvist E. Quality of life in adult survivors of Paediatric kidney transplantation. *Transplantation.* 2011;92(12):1322-1326. doi:10.1097/TP.0b013e318237062b
88. Lev-Wiesel R, Sasson L, Scharf N, et al. "Losing Faith in My Body": Body Image in Individuals Diagnosed with End-Stage Renal Disease as Reflected in Drawings and Narratives. *Int J Environ Res Public Health.* 2022;19(17):10777. Published 2022 Aug 30. doi:10.3390/ijerph191710777
89. Van Wilder L, Pype P, Mertens F, et al. Living with a chronic disease: insights from patients with a low socioeconomic status. *BMC Fam Pract.* 2021;22(1):233. Published 2021 Nov 18. doi:10.1186/s12875-021-01578-7
90. Butler N, Quigg Z, Bates R, et al. The Contributing Role of Family, School, and Peer Supportive Relationships in Protecting the Mental Wellbeing of Children and Adolescents. *School Ment Health.* 2022;14(3):776-788. doi:10.1007/s12310-022-09502-9
91. Harshman LA, Ward RC, Matheson MB, et al. The Impact of Paediatric CKD on Educational and Employment Outcomes. *Kidney360.* 2023;4(10):1389-1396. doi:10.34067/KID.000000000000206
92. Maurer E, Neuhaus TJ, Weitz M, Kuehni CE, Laube GF. Paediatric end-stage renal disease and renal replacement therapy in Switzerland: survival and treatment trends over four decades. *Swiss Med Wkly.* 2020;150:w20300. Published 2020 Jul 27. doi:10.4414/smw.2020.20300
93. Groothoff JW, Offringa M, Grootenhuys M, Jager KJ. Long-term consequences of renal insufficiency in children: lessons learned from the Dutch LERIC study. *Nephrol Dial Transplant.* 2018;33(4):552-560. doi:10.1093/ndt/gfx190
94. Laube GF, Heinzlmann MA, Roser K, Kuehni CE, Mader L; Swiss Paediatric Renal Registry (SPRR) group. Long-term social and professional outcomes in adults after paediatric kidney failure. *Pediatr Nephrol.* 2023;38(11):3769-3777. doi:10.1007/s00467-023-06029-2

Chapter 9

Psychological care approach to children with chronic kidney disease.

Learning objectives

- To identify common psychological and social problems experienced by children with chronic kidney disease.
- To describe the potential mental health conditions and considerations associated with paediatric CKD.
- To recognize the psychosocial support required for children and families and the impact of chronic illness on family dynamics.

Introduction

Supporting children from a psychological perspective who are born or diagnosed with chronic kidney disease (CKD) requires evaluating the impact it can have on them at all stages of their development. A chronic kidney illness will have different treatment methods at different stages. It is important to take the family dynamic into consideration. Looking at what supports if any do they have? There are a number of issues that can arise at any given time when working with children. The most recurrent of these are procedural distress (intense anxiety in situations that require hospital procedures), medical trauma, adherence difficulties, body image, self-identity difficulties, emotional difficulties, and transition to adult hospital at the age of sixteen years (in Ireland). There are resources and information available to the parents/guardians informing them of possible ways they can support their children. Some situations families may come into contact with are times of high stress, preparations for procedures, school liaison and end of life concerns. The author made contact with a play therapist in a children's hospital called Temple Street. They advised that their psychosocial care includes a play therapist, medical social worker and hospital schoolteachers supporting children and their family with CKD.¹ 'Treating children with CKD requires a multidisciplinary care team that includes medical, psychological, family, educational and religious support'.²

Psychological and social problems

Children with CKD can develop certain issues, in part due to their age at diagnosis. Physical and emotional development and dependency on parents, guardians and/or family. No matter the age at diagnosis a child's quality of life is extremely relevant. Problems may arise in any or all of the following areas, medical, educational, psychological, and social supports, all at once or separately. 'Disabling osteodystrophy (defective bone development) and protein-calorie malnutrition (in this situation when a child is unable to eat enough protein and energy to meet their nutritional needs) these are associated with end-stage CKD and can be severe in children with kidney disease'.² That is why it is so important to have people in the child's life that can be aware of and control their reactions and emotions. By looking after their physical and mental health can attribute to this. Along with the support of the multidisciplinary hospital team. 'The goals of the chronic kidney failure treatment are currently grouped into two large directions: decreasing morbidity and mortality and increasing the patients' quality of life'.²

Mental health conditions and considerations

Morbidity and mortality have decreased due to the advancements in the treatment of CKD for children. These young children are now living longer and becoming teenagers and young adults. The mental health concerns for this cohort needs to be recognised. 'Mental health concerns can be influenced by a range of physiological, psychological, and environmental factors'.³ Contributing factors for children with CKD specifically can be due to the medical regime adherence, non-adherence to treatment, risk of transplant rejection and quality of life concerns. They can also be at an increased risk for mood disorders, neurodevelopmental disabilities, and trauma stress disorders due to their chronic illness.⁴ The author believes that the psychological health of children with chronic illness and their families should be assessed on a regular basis.

Figure 1. Paediatric Psychosocial Preventative Health Model (PPHM).



The above figure is the Paediatric Psychosocial Preventative Health Model (PPHM), it provides a framework for integrating assessment based on social ecology, understanding of posttraumatic stress and resilience. Along with the factors that influence adaptation over time. Then based on family risks and resources the level of risk will identify and match the required clinical intervention to support families, as can be seen clearly in the above diagram.⁵ The largest group of patients and families are seen at the base of the pyramid. They demonstrate that although they are experiencing distress due to medical needs, they are able to adjust to the challenging situation thereby showing resilience. In the middle section of the pyramid the distress is acute and there is psychological risk factors present. The clinical/treatment category at the very top are those that require more extensive support.⁶

Psychosocial support for children and families

Due to the extreme strain that can be put on a child receiving kidney replacement therapy/treatment for CKD and their family psychosocial supports are pertinent.

Socio-economic issues – having a child with a chronic illness can have a monetary impact. There can be additional costs due to travel for treatment and hospital appointments. Modifications may be required in the home. Where both parents were working previously one parent may have to leave their employment to care for their child. Where the child is fortunate to receive a living related donor transplant this can also incur further expense. A social worker can

assess a child's and family's needs and advise them of available grants and financial aid where appropriate.^{7,8,9} Education – Research has shown that children/young people with CKD education can be impaired due to absenteeism from school.^{10,11} This in turn can have an effect on going onto third level education and long-term employment. There are qualified teachers employed in the children's Hospitals however, the health and symptoms experienced by these patients may affect their ability to attend schooling either in the Hospital or their local school, the author believes.

Holidays – It can be difficult to organise a family holiday or a short break away when you have a child with CKD. This affects everyone in the family. There are organisations that support families and offer breaks away. Barretstown in County Kildare in Ireland was founded in 1994, it is specially designed providing residential camps and programmes for children and their families living with serious illnesses. The camps and programmes are free of charge. With twenty-four hour on-sight medical and nursing care. It is open to people from all over the world. It offers all the children in the family an opportunity to participate in activities and socialise with their peers in a safe environment where there are few restrictions.¹² The Irish Kidney Association have three holiday homes in Ireland which are available free of charge for transplant and dialysis patients and their families to use. They also assist in organising dialysis abroad.¹³ Hospice care specifically for children is also available. These organisations assist by giving respite to all in the family Healthcare companies such as Baxter will deliver home dialysis supplies direct to countries you are visiting and will have at you location on your arrival.

Play therapists – Therapeutic play, learning through games, can be used to enable children to express how they are feeling. This teaches them how to cope with their illness. They can begin to be able to accept their illness and the different forms of treatment they experience as part of their life. Thereby enabling them to improve their quality of life.¹⁵

Conclusion

It is important to promote interventions that support positive outcomes. It can develop strengths and skills in patients and family members, allowing them to prevail over the challenges of living with and managing a long-term medical condition that is constant and constantly changing.⁶

References

1. Conversation had with Play Therapist in Temple Street Hospital, Dublin Ireland in February 2025.
2. Iorga M, Starcea M, Munteanu M, Zoltan-Sztankovsky L. Psychological and social problems of children with chronic kidney disease. *Journal of Science and Theology*. 2014 Feb; 10(1):179-188.
3. Mai K, Dawson AE, Gu L, LaMotte JE, Molitor S, Zimmerman CT. Common mental health conditions and considerations in Paediatric chronic kidney disease. *Paediatric nephrology*. 2024 Mar 8;
4. Pinquart M, Shen Y. Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *Pediatr psychology*. 2011 36:375-384
5. <http://www.psychosocialassessmenttool.org/pphm>
6. Amatya K, Monnin K, Steinberg-Christofferson E. Psychological function and psychosocial issues in Paediatric kidney transplant recipients. 2020 25:1/e13842
7. Lindley LC, Mark BA. Children with special health care needs: impact of health care expenditures on family financial burden. 2010 *Journal child family study* 19:79-89
8. Gordon EJ. Informed consent for living donation: A review of key empirical studies, ethical challenges, and future research. *American Journal of Transplantation*. 2012 Sept;12(9):2273– 80. doi:10.1111/j.1600-6143.2012.04102.x
9. Roodnat JI, Laging M, Massey EK, Kho M, Kal-van Gestel JA, IJzermans JNM, et al. Accumulation of unfavorable clinical and socioeconomic factors precludes living donor kidney transplantation. *Transplantation*. 2012 Mar 15;93(5):518–23. doi:10.1097/tp.0b013e318243030f
10. Icard PF, Hower SJ, Kuchenreuther AR, Hooper SR, Gipson DS. The transition from childhood to adulthood with ESKD: Educational and social challenges. *Clinical Nephrology*. 2008 Jan 1;69(01):1–7. doi:10.5414/cnp69001
11. Duquette PJ, Hooper SR, Wetherington CE, Icard PF, Gipson DS. Brief report: Intellectual and academic functioning in Paediatric chronic kidney disease. *Journal of Paediatric Psychology*. 2007 Apr 9;32(8):1011–7. doi:10.1093/jpepsy/jsm036
12. Rebuilding lives affected by childhood illness [Internet]. 2025 [cited 2025 Mar 1]. Available from: <https://barretstown.org/>
13. Patient holidays [Internet]. 2025 [cited 2025 Mar 1]. Available from: <https://ika.ie/patient-holidays/>
14. Watson AR. Strategies to support families of children with end-stage renal failure. *Paediatric Nephrology*. 1995 Oct;9(5):628–31. doi:10.1007/bf00860961
15. Mert ZT, Bayat M. The effect of structured play therapy training on metabolic control, psychological adjustment, and quality of life in children with type 1 diabetes mellitus. *International Journal of Diabetes in Developing Countries*. 2025 Jan 17; doi:10.1007/s13410-025-01441-w

Chapter 10

Impact on the lives of families with a child on KRT and their need for family support

Learning objectives

- To provide a brief overview of how paediatric chronic kidney disease and kidney replacement therapy have a substantial impact on the lives of children and their families
- To understand the complexity of how relationships and dynamics in families are challenged on individual and family level
- To gain understanding about family function and resilience
- To provide nephrology nurses guidance in how to support families through family conversations

Introduction

This chapter describes the impact of chronic kidney disease (CKD) in a child receiving kidney replacement therapy (KRT) and the need for support on both an individual and family level. “The family” will be addressed from the perspective of parents, the child with CKD and, siblings. However, the perspectives of the inclusion of other informal caregivers close to the child and the family is highly relevant. The role of healthcare professionals will be addressed from a family nursing perspective as described by Wright and Leahey,^{1,2} and findings will be included from empirical research to underline the families support needs.

Paediatric CKD is a life-long complex medical and psychosocial disease with several factors that differ from adults. KRTs do not only have a substantial impact on the lives of children with CKD, it also calls for intensive activities, a lot of attention and responsibility from the parents and other adults who take responsibility for the child.³ The parents play a pivotal role in delivering care which is directly associated with successful adherence to treatment thus improving the child's well-being, survival rate and quality of life. The high expectations of the parents are often accompanied by prominent and intense feelings of losing the child and uncertainty about the future.

KRT offers different treatment options to consider, HD, PD, and kidney transplantation. Paediatric kidney transplantation improves clinical outcomes substantially hence why this is the preferred treatment of

choice globally.^{4,5} It is challenging undergoing clinical examinations to be approved as a donor. Parents are often first in-line for donation. Their child's transplantation warrants consideration of options such as a living kidney donation. To most parents, the experience and considerations are positive for living kidney donation for their child; however, it is challenging undergoing clinical examinations to be approved as a donor. There is a lot at stake given not all parents are able to donate. This subjects them to asking other family members such as grandparents of the child or parents' siblings, or friends about being a kidney donor. Otherwise, the only possibility is referral on to the transplant waiting list where there is an unknown waiting time.⁶

Having a child on dialysis results in almost consistent concerns and distress among parents. Not only is dialysis a complicated treatment, the child is very often in need of other home-based clinical care and nutritional support with the parents having the full responsibility to follow-up on daily basis. Nevertheless, the parents are often dependent on other adults to take care of the child in kinder garden or school, or trust the child to manage treatment related actions on their own, e.g. manage medication, intake of sufficient fluid, toilet visits.^{7,8,9,10} Thus, adult family life is accompanied by concerns, monitoring of the child disease progression (however often slow) and well-being, hospital visits and demanding KRT. Moreover, they are depending heavily on collaboration with the healthcare professionals.

From a healthcare perspective, function and family well-being, the overall health of the family concerns the relationships and dynamics within the family and the importance of providing support during the long-term care of a child.

Relationships and dynamics in families with a child on KRT

Illness in a child on KRT has a long-term impact on psychosocial life including the parents' well-being and relationship.^{11,12} Parents experience overwhelming demands of caregiving, and they often adopt a double role as both healthcare provider with the daily responsibility for treatment and observation of the child's well-being in addition to their usual role as parent. As a result, caregiver burden, distress, depression and low quality of life levels are commonly experienced by parents of children with CKD.¹³ Knowing about individual family member's strengths and weaknesses make it possible to complement each other both emotionally and practically.¹⁴

As described above, CKD in a child is a serious condition, which require attention from adults close to the child. Children receiving KTR experience poor prospects surrounding school and education.

Dialysis is a time-consuming treatment, which often causes side effects that impacts their daily life. As a result, low self-esteem and reduced quality of life is commonly experienced.¹⁵

The healthy children in the family – the siblings - are in a special and often neglected position. They are particularly affected by circumstances surrounding the unwell child and the parent's attention and engagement in long-term care and treatment.¹⁶ Their health-related quality of life is significantly lower compared to healthy siblings.¹⁷ Furthermore, they experience negative psychological and emotional symptoms, which are characterised as posttraumatic stress.¹⁸ Social resilience, difficulties in relationships, their functioning at school and, their well-being are often influenced by circumstances in the over-all family situation. However, it is important to mention that responding to the illness of a brother or sister very much depends on the ages and cognitive stages of the child.¹⁹ Furthermore, the sibling relationship is an important element in the role as a sister or brother when growing up. Nevertheless, being part of a family is significant for the promotion of well-being and self-development.^{16,20}

The severity of the child's health situation causes individual emotional difficulties among adults. Research have shown that parents of a child with a kidney transplant experience unmet emotional needs and stress, which continued years after the transplantation.²¹ These emotional issues can have a negative impact on family relationships. Care-giving and intensive support of a sick child does in periods, disrupt family dynamics and results in multiple losses such as reduced time spent with children and spouses.

CKD in a child is also associated with transitions, which over time changes the family relationships, dynamics and interactions. How healthy children react to or experience chronic illness in a sibling also depends on the parental- and sibling relationships, family resources and communication between family members.²⁰ Parent's over-protection of the sick child and neglecting siblings' needs influences family dynamics.^{9,22,23} Further, sibling jealousy and resentment also influence and challenge relationships between family members. Thus, CKD in a child who receive KRT have effects on both physical, psychological, emotional and behavioural level for all family members.

These are factors, which often lead to vulnerability and reduced family functioning.²⁴ As such, being part of a family with a child who need KPT influences everyday life on a family level. However, coping with challenges is essential – not only on an individual level, but also on a family level. Above all, relations, interactions and dynamics in and outside the nuclear family constitute an important part of daily life.

Because parents play a key role in the care of their child and at the same time are responsible for well-being and everyday life of all family members it is important that nurses adapt a broad perspective on how to support not only the child and parents, but also the family as a unit. This perspective is highly relevant when focusing on paediatric nephrology nursing.

Family nursing perspective to provide support

Providing care for a child on KRT includes wider perspectives than achieving “traditional” treatment goals. The complexity of treatment and the close connectedness between all family members, and children’s dependency on adults asks for care, which enhance the overall well-being of the family. The care demand on parents requires a collaborative attitude with the inclusion of attention and support from nurses. Knowledge about and guiding on what characterizes families’ vulnerability and resilience is crucial for achieving the care and treatment goals. We will now describe and argue how a family nursing approach is an option in paediatric kidney care support.

Nurses are the group of healthcare professionals who can work close to families and thus, provide care that enhance specific needs. Support from nurses on how to manage the child’s treatment is highly important however, nurses, have an important role when it comes to preventing mental health problems among all members of the family. Nurses have a special view when uncovering family issues, and in their work, they have unique possibilities to facilitating, supporting and helping families.

Nurses, who take care of children receiving KRT have highly specialised knowledge. The following areas describe expert paediatric nurses’ competencies in their work with families:

- They can generate information about the family on both individual and unit level

- They can analyse complex relational problems
- They have an overview of the disease trajectory
- They can mediate expert knowledge during the trajectory, and they are the unifying point in the multi-disciplinary teamwork around the child and the family

In the following, essential and selected theoretical areas in family nursing will be described followed by guidance in how nephrology nurses can use and provide support to families through family conversations. The selected theoretical areas are the family as a system and family function, family assessment (genogram/ecomap), family resilience and beliefs, family intervention (family dialogue/conversation).^{1,2}

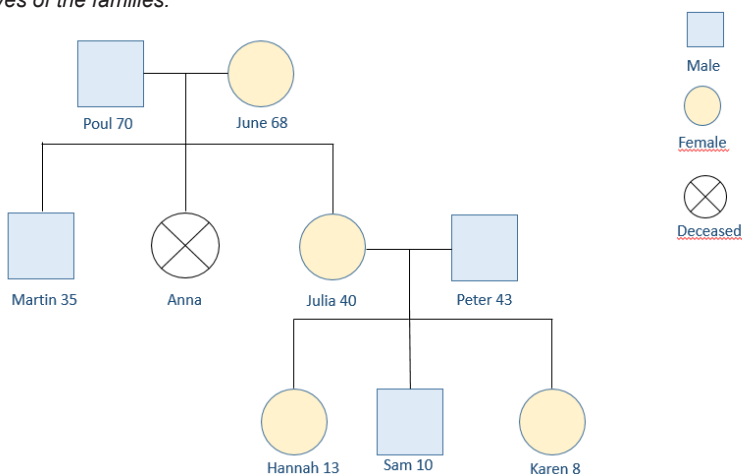
The family can be viewed as “a system” where members mutually affect each other, and where events cause reactions from individual family members, which then leads to further reactions from other family members.²⁵ Wright and Leahey^{1,2} describe that the family should be seen as a unit in care with family members interacting with each other and the environment based on their beliefs and perceptions of the situation. It is essential to all family members to be connected and for nurses to be aware that changes, dynamics and conflicts can arise even in stable and “healthy” family systems. A family must be viewed as an open system with different connections between family members. Families always try to adjust to changes in the family e.g. during disease progression, hospitalisation, change in KRT. A family is not an isolated unit; all sorts of behavioural and actions within or outside the family will influence the family. This is a reciprocity in the family which best can be described as a baby’s mobile; all toys in the mobile are connected by a string. When one toy is moved, it causes the entire mobile to move.²⁵ Stability in the mobile/the family unit will occur over time depending on the level of activity in the mobile. The intensity of problems and suffering may vary from family to family depending on the situation; however, the dynamics in families are very important to understand and should thus be part of nurses’ approach to providing care and support.

The family functioning is divided into two categories; *an instrumental level*, which relates to the family’s everyday living and activities, and *an expressive level*, which relates to the family’s way to communicate, their beliefs and problem solving. These parameters

are of particular interest when nurses engage with the family unit to uncover and assess the family's resources, challenges, problems and suffering.

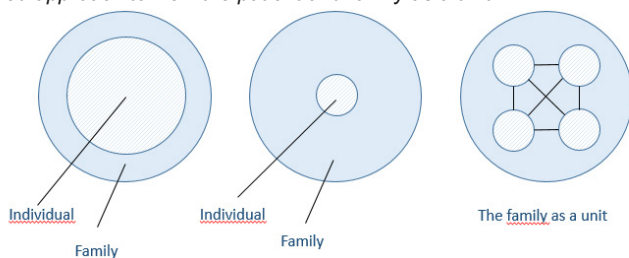
To support the work of uncovering and achieve an overview of the family's system, the nurse can initiate a drawing of a Genogram/Ecomap (see figure 1). An illustration of the family system in a genogram or ecomap includes both the close family and the extended family and illuminates thereby the broader system that might be supportive to the family.²⁶ This is an assessment tool, which is helpful for the nurse to get insight and understanding of the family's social and cultural structure. Put in another way, when a child is on KRT, it does not only influence the child, it also affects close and distant relationships.

Figure 1. Illustration of a genogram/ecomap. When creating an genogram/ecomap together with the family it becomes visible who are close and important persons in the lives of the families.



Nursing care to families with a child on KRT, must concentrate on both the individual and the family simultaneously with focus on the interaction and the family as a unit (see figure 2). Furthermore, family resilience play an important role in everyday life in families with a child on KRT. As described by Rutter,²⁷ 'resilience is the ability to bounce back or cope successfully, despite substantial adversity'. When taking a family nursing approach, focus is directed towards strength and resources in the family and as such, it is not directed towards family dysfunction.

Figure 2. Different ways to approach patient and family with the third model illustrating an aligned approach to view the patient and family as a unit.²⁶



To provide guidance to nephrology nurses in how to support families, family nursing conversations are a way to communicate with the family. The conversations are based on three key domains: the cognitive, the affective and the behavioural. The domains serve to change the family function.^{1,2} We will now shortly describe each domain and how they can facilitate changes the family function.

The cognitive domain is about how the family think and make sense of the situation in order reflect and to achieve a new understanding of the situation. It also serves as the foundation for family members to come up with new solutions to solve and manage a problem or a situation. This domain enhances family strengths and vulnerability, and it gives the nurse the opportunity to offer information and opinions.

The affective domain is about how the family manage and cope emotionally. It serves to make them be more caring for each other to improve individual and family well-being. This domain offers the nurse the possibility to normalize and validate emotions and to provide family support.

The behavioral domain is about how the family acts to being more supportive to each other, implementing new activities and engaging with other significant others. Thus, this domain is about how the nurse can provide caregiver support and support to all family members.¹

Facilitating a family conversation is about letting family members creating their own story through narratives.²⁸ In paediatric nephrology nursing, a close and trustful relationship between healthcare professionals and parents is important, however children need protection and of having responsible adults in their life.²⁹ Responsibility from adults includes listening to the narrative of all children in the family. Through narration, the other family members listen, reflect and get an understanding of the other family members'

understanding of a situation or problem. This is also referred to as cybernetic; if a change occurs in one family member, this change will most likely affect the rest of the family.³⁰ Furthermore, flexibility and open-minded communication serves as foundation for changes in the family function. The nurse is supposed to navigate in a balanced and non-hierarchical conversation with all family members. She uses open, explorative and circular questions, which creates reflection among family members (see figure 3).

Figure 3. Examples of questions in family nursing conversation

- | |
|---|
| • Who in your family is most affected by the disease right now? |
| • How will you be able to support each other in the future? |
| • Who is most important for change to happen? |

The nurse's role is NOT to give directions, lectures or insist on changes, which she might think is relevant for the family to make. Nor should she show partiality. She must focus on creating a collaborative supportive environment and show interest in the family's experiences, perceptions and beliefs. During family conversations, the nurse embraces all new and different perceptions which each family member considers important to share. It is herein the ability to support change and improve family functioning lies.

Conclusion

KRTs have a substantial impact on the lives of children with CKD. The parents have a pivotal role of delivering care however, healthy siblings are vulnerable and in position of being neglected. The disease and long-term treatment influence everyday life and have effects on both physical, psychological, emotional and behavioural level for all family members.

To provide support during long-term care of a child on KRT, it is highly important that nephrology nurses focus on function and well-being of the family as unit. Flexibility and open-minded communication serve as foundation for changes and support of resilience and coping during critical periods with suffering. By assessing family function, resilience and resources, nurses can facilitate family conversations, where each family member narrate their unique perceptions. When creating a collaborative supportive environment with the inclusion of circular questions, and by showing interest in the family's experiences, perceptions and beliefs, the conversation could change and improve family functioning.

References

1. Wright, L., & Leahey, M. (2019). *Nurses & families: A guide to family assessment and intervention*. Philadelphia, PA: F.A. Davis Company.
2. Shajani Z, Snell D. Wright & Leahey's nurses and families. A guide to family assessment and intervention. 7 ed: F.A. Davis Company; 2019.
3. Boateng EA, Bisiw MB, Agyapomah R, Enyemadze I, Kyei-Dompim J, Kumi SP et al. A qualitative study on the experiences of family caregivers of children with End Stage Kidney Disease (ESKD). *BioPsychoSocial Medicine* (2024) 18:17. <https://doi.org/10.1186/s13030-024-00314-8>
4. Pickles CW, Brown C, Marks SD, Reynolds BC, Kessaris N, Dudley J. Long term outcomes following kidney transplantation in children who weighed less than 15 kg - report from the UK Transplant Registry. *Pediatr Nephrol*. 2023 Nov;38(11):3803-3810. doi: 10.1007/s00467-023-06024-7. Epub 2023 May 20. PMID: **37209174**. DOI: 10.1007/s00467-023-06024-7
5. Jahnukainen T, Bjerre A, Larsson M, Tainio J, Thiesson HC, Jalanko H, et al. The second report of the Nordic Paediatric Renal Transplantation Registry 1997–2012: More infant recipients and improved graft survivals. *Paediatric Transplantation*, 2016 20, 364–371. doi: 10.1111/petr.12686.
6. Agerskov H, Specht K, Thiesson H, Pedersen BD. Parents' experiences of donation to their child before kidney transplantation. *Journal of Clinical Nursing* 2019 May;28(9-10):1482-1490. doi: 10.1111/jocn.14734.
7. Ong ZH, Ng HC, Tok PL, Kiew MJ, Huso Y, Shorey S et al. Sources of Distress Experienced by Parents of Children with Chronic Kidney Disease on Dialysis: A Qualitative Systematic Review. *Journal of Paediatric Nursing* 2021, 57 (2021) 11–17.
8. Agerskov H, Thiesson HC, Pedersen B D. Everyday life experiences in families with a child with kidney disease. *Journal of Renal Care*. 2019 Dec;45 (4):205-211. doi: 10.1111/jorc.12297.
9. Agerskov H, Thiesson HC, Pedersen BD. The significance of relationships and dynamics in families with a child with end-stage kidney disease: A qualitative study. *Journal of Clinical Nursing* 2020 Mar;29 (5-6):987-995. doi: 10.1111/jocn.15170.
10. Cousino MK. & Hazen RA. Parenting stress among caregivers of children with chronic illness - a systematic review. *Journal of Paediatric psychology* 2013, 33(8), 809–828.
11. Tong A, Lowe A, Sainsbury P et al. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Paediatric s*, 2008 121(2), 349–360.
12. Tong A, Lowe A, Sainsbury P. et al. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Development*, 2010, 36(4), 549–557.
13. Gençler A & Kılıçaslan F. Assessment of Caregiver Burden, Depression and Quality of Life Levels Among Mothers of Children with Chronic Kidney Disease, *Psychiatry*, 2024, 87:3, 227-240, DOI: 10.1080/00332747.2024.2372182

14. Agerskov H, Thiesson HC, Schultz H, Pedersen BD. Relationships and dynamics in families with a child with a kidney transplant-A study of parents' everyday life experiences. *Journal of Renal Care*, 2023, Mar, 1-8.
15. Francis A, Didsbury MS, Van Zwielen A et al. Quality of life of children and adolescents with chronic kidney disease: a crosssectional study. *Archives of Disease in Childhood*, 2018, 104, 1-7.
16. Agerskov H, Thiesson HC, Pedersen BD. Siblings of children with chronic kidney disease: A qualitative study of everyday life experiences. *Journal of Renal Care*, 2021, Dec 47(4):242-249. doi: 10.1111/jorc.12389. Epub May 26. DOI: 10.1111/jorc.12389
17. Dinleyici M, Carman KB, Özdemir C, Harmancı K, Eren M, Kirel B. et al. Quality-of-life evaluation of healthy siblings of children with chronic illness. *Balkan Medical Journal*, 2019, 37, 34-42.
18. Gan LL, Lum A, Wakefield CE, Nandakumar B, Fardell JE. School experiences of siblings of children with chronic illness: a systematic literature review. *Journal of Paediatric Nursing*, 2017, 33, 23-32.
19. Batte S, Watson AR & Amess K. The effects of chronic renal failure on siblings. *Paediatric Nephrology*, 2006, 21, 246-250.
20. Knecht C, Hellmers C, Metzinger S. The perspective of siblings of children with chronic illness: a literature review. *Journal of Paediatric Nursing*, 2015, 30, 102-116.
21. Walker RC, Naicker D, Kara T & Palmer SC. Parents' perspectives and experiences of kidney transplantation in children: a qualitative interview study. *Journal of Renal Care*, 2019, 45(3), 193-200.
22. Deavin A, Greasley P. & Dixon C. Children's perspectives on living with a sibling with a chronic illness. *Paediatric s*, 2018, 142, 2.
23. Lummer-Aikey S. & Goldstein S. Sibling adjustment to childhood chronic illness: an integrative review. *Journal of Family Nursing*, 2021, 27(2), 136-153.
24. Toledano-Toledano F. & Domínguez-Guedea MT. Psychosocial factors related with caregiver burden among families of children with chronic conditions. *BioPsychoSocial Medicine*, 2019, 13, 6.
25. von Bertalanffy L.v (1984). *General System Theory: Foundations, Development, Applications*. New York, NY: George Braziller.
26. Wright LM, & Leahey M. Trends in family nursing. *Journal of Advanced Nursing*, 1990, 15, 148-154.
27. Rutter M. Resilience in the face of adversity: protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry*, 1985, 147, 598-611.
28. Ricoeur P. Narrative Identity. *Philosophy today*, 1991, 35(1), 73.
29. Agerskov H, Thiesson HC, Pedersen BD. Parenting a child with a kidney transplant – A study of everyday life experiences. *Journal of Renal Care*, 2022; 1-10. First pub. Feb 1. doi: 10.1111/jorc.12410.
30. Bateson N. and Jaworska-Witkowska M. (2017). Gregory Bateson's cybernetic methodology: The ecosystem approach in empirical research. In: *steps to an Ecology of mind*. The University Of Chicago Press.

Chapter 11

Challenges nephrology nurses face while caring for children with AKI or CKD

Learning objectives

- To identify the clinical, technical, organisational, and communication challenges faced by paediatric nephrology nurses
- To understand the role of the nephrology nurse in providing psychological and educational support and facilitating multidisciplinary collaboration
- To recognise the emotional stress factors and risk of burnout in the care of Paediatric nephrology patients

Introduction

Paediatric nursing is recognised as one of the most demanding and highly specialised fields of clinical practice, requiring advanced technical expertise, strong interpersonal sensitivity, and a high degree of adaptability. Within this domain, paediatric nephrology is a particularly demanding subspecialty in which nurses are required to care for children affected by acute and chronic kidney diseases, managing clinical scenarios of significant complexity.

Acute kidney injury (AKI) and chronic kidney disease (CKD) in childhood are pathological conditions that necessitate a dedicated, continuous, and multidimensional approach to care.

The fragility of these young patients, the unpredictability of clinical progression, and the need for advanced therapeutic interventions place nurses in front of numerous professional challenges: not only of a technical and clinical nature but also concerning communication, education, and psychological support. Nurses working in this field must be able to combine in-depth clinical knowledge with refined interpersonal skills, intervening promptly and accurately in critical situations, while also supporting the child and their family throughout a care pathway that is often prolonged, complex and emotionally charged.

This chapter aims to explore the main challenges faced by paediatric nephrology nurses in the care of children with AKI and CKD, highlighting the essential value of their role within the multidisciplinary team.

Clinical complexity in paediatric nephrology

Caring for a child affected by AKI or chronic CKD represents a highly complex challenge for nephrology nurses due to the unique pathophysiological, therapeutic, and developmental characteristics of the paediatric age group. A child is not simply a “small adult”: their clinical responses are often less predictable, their physiological reserves more limited, and their clinical signs more subtle, requiring an even more refined capacity for observation and assessment.¹

Paediatric AKI may present in a wide range of clinical contexts, from primary kidney diseases (KD) to systemic conditions such as sepsis, severe dehydration, or postoperative complications.² One of the most critical aspects is the speed at which the condition can progress. Nurses must therefore monitor vital signs, urine output, body weight, blood pressure, hydration status, and serum electrolyte levels continuously, recognising any signs of clinical deterioration promptly. Timely nursing intervention can make the difference between effective stabilisation and unrecognised acute clinical decline.³

On the other hand, CKD introduces further layers of complexity due to its chronic nature. CKD does not typically present with striking symptoms in its early stages but progresses insidiously, affecting multiple organ systems. The child may experience growth delays, anaemia, metabolic disturbances, hypertension, and difficulties with concentration.⁴ Therefore, the nursing care plan must not be limited to clinical management alone, but must also include therapeutic education, nutritional support, medication management (often involving complex regimens with weight- and age-based dosing), and monitoring of family adherence to treatment protocols.⁵

A central element in care is fluid balance assessment. In children, even minor fluid shifts can have significant clinical implications. Daily monitoring of weight, urine output, stool consistency, and dietary intake is thus essential.⁶ Furthermore, the nurse must be able to identify subtle symptoms such as irritability, sleep disturbances, or changes in appetite, which may be early indicators of clinical instability.

Effective communication is another key aspect in the approach to paediatric patients with KD. Younger children often struggle to articulate their symptoms or discomfort, particularly in younger

age groups. Nurses must therefore refine their observational and relational sensitivity, learning to "read" non-verbal cues or reports from parents, and adjust their communication strategies according to the patient's cognitive development.⁷

Finally, it is essential to remember that a child with CKD is a continuously developing patient. Physical, cognitive, and psychosocial growth necessitates constant adjustments to the care plan. The nephrology nurse must therefore engage in continuous professional development and collaborate synergistically with the multidisciplinary team, including doctors, psychologists, dietitians, physiotherapists and hospital school teachers, in order to provide holistic and patient-centred care.⁸

Psychological and educational support

Children with KD and their families face significant emotional and psychological burdens. The diagnosis of AKI or CKD, especially when it occurs in early childhood, is often perceived as a traumatic event that generates anxiety, guilt, frustration, and fear.⁹ This emotional impact can affect the child's well-being and the entire family system, potentially leading to parental stress, reduced coping capacity, and impaired family functioning.¹⁰

In this context, the nephrology nurse plays a central role in providing psychological support. By establishing a trusting and empathetic relationship, the nurse becomes a point of reference, helping families understand and process the disease, while encouraging open dialogue and emotional expression.¹¹ Involving the family in care planning and decision-making can improve their sense of control, decrease anxiety, and enhance adherence to treatment.¹² Furthermore, in the paediatric setting, the child's emotional needs are deeply intertwined with the caregiver's emotional state, making a holistic and family-centred approach essential.

Equally important is educational support, which should be tailored to the child's cognitive development and the family's socio-cultural background.¹³ Nurses must be able to explain procedures, therapeutic goals, and expected outcomes using age-appropriate and culturally sensitive language. Informed families are more likely to feel empowered, engaged, and capable of collaborating effectively in the care process.¹⁴ Particularly in CKD, where treatment often involves complex and long-term regimens such as dialysis, multiple

medications, and dietary restrictions, promoting the child's autonomy becomes fundamental. Encouraging children to gradually participate in their own care, such as monitoring fluid intake or managing medication schedules, fosters independence and helps prepare them for transition into adult care services later in life.¹⁵ For adolescents, tailored education also supports self-management skills, emotional resilience, and improved quality of life.¹⁶

Ultimately, the nephrology nurse's role goes beyond clinical competence: it requires communication skills, cultural awareness, and psychological sensitivity to effectively support the emotional and educational needs of both the patient and their family throughout the disease trajectory.

Multidisciplinary collaboration

The care of children with AKI or CKD requires an integrated approach involving various healthcare professionals. Paediatric nephrologists, intensivists (in cases of severe AKI), dietitians, psychologists, physiotherapists, social workers, and hospital schoolteachers all contribute to building an effective, patient-centred therapeutic pathway. Within this context, the paediatric nephrology nurse plays a pivotal role as a communication facilitator and coordinator of care interventions.¹⁷

The nurse is not merely an executor of medical prescriptions but a professional capable of collecting, interpreting, and communicating clinical, psychosocial, and behavioural information to other team members. Due to their close contact with both the child and their family, nurses are often able to identify issues that may escape the notice of other specialists, thus contributing to a holistic and continuous assessment of the patient.¹⁸ Regular and structured information-sharing, through multidisciplinary briefings, shared clinical records, and team meetings, is essential to ensure coherent and timely care delivery.

Effective interprofessional communication significantly reduces the risk of errors, improves adherence to the treatment plan, and enhances family satisfaction, as families perceive a coordinated and consistent approach to care.¹⁹ Indeed, families feel more reassured and involved when they observe that the healthcare team works in synergy, guided by clear and shared goals.

However, multidisciplinary collaboration is not without its challenges. Differences in professional language, the perception of care priorities, and organisational models can lead to misunderstandings and delays. In such situations, the nurse must demonstrate advanced communication, mediation and organisational skills and a thorough understanding of relational and institutional dynamics.²⁰ It is crucial for nurses to participate actively in team meetings, taking on a proactive role and contributing their unique nursing perspective, which is often focused on the daily and holistic aspects of care.²¹ An effective care pathway should be developed through true integration of competencies and a shared vision. This pathway should be centred on the child and focused on improving quality of life.

Management of advanced technologies and procedures

The care of children with AKI or CKD involves the use of advanced technologies and complex procedures that require specific technical skills from nursing staff. The paediatric nephrology nurse plays a central role in the safe and effective management of devices such as dialysis machines, infusion pumps, multiparameter monitors, and vascular access devices. Handling these tools demands a high level of technical competence and continuous clinical vigilance, making the nurse a key figure in ensuring the efficacy and safety of kidney therapies.²²

In dialysis care, nurses must be fully capable of preparing and managing the entire process appropriately. For PD, this includes maintaining a sterile environment, handling the peritoneal catheter, and continuously monitoring the child's clinical response to promptly detect signs of peritonitis, hypotension, or fluid and electrolyte imbalances.²³ In HD, the nurse is responsible for managing the dialysis machine, the filter, the extracorporeal circuit, and dialysis parameters, while also monitoring for acute complications such as dialysis disequilibrium syndrome, hypovolaemia, or bleeding risks.²⁴

A crucial element in HD is the proper management of vascular access, particularly central venous catheters (CVCs) and arteriovenous fistulas (AVFs). CVCs require strict sterile techniques, regular patency checks, and prompt recognition of potential infections or occlusions. AVFs, though less common in paediatrics, demand constant surveillance to ensure they remain functional and infection-free.²⁵

In addition to conventional dialysis, new extracorporeal purification strategies are emerging for critically ill paediatric patients. These innovative techniques allow for highly individualised solute and toxin removal, tailored to the specific needs of the patient, and are increasingly employed in paediatric intensive care units.²⁶ In this context, the nurse plays a pivotal role in balancing treatment parameters, constantly monitoring vital signs, and working collaboratively with intensivists and nephrologists.

Beyond dialysis, nurses must also be proficient in using non-invasive monitoring devices to track blood pressure, oxygen saturation, fluid balance, and respiratory conditions. Such tools are essential for continuous and dynamic patient assessment. Additionally, safe administration of intravenous therapies, which are often complex and high-risk, requires meticulous attention to drug dilution, infusion timing, and compatibility.

Continuous professional development is therefore essential. The constant evolution of healthcare technologies compels nurses to regularly update their skills through courses, simulation training, specific workshops, and sharing of best practices. Moreover, collaboration with other professionals, such as technicians and clinical engineers, enhances equipment management and helps prevent errors.²⁷ Ultimately, advanced technological competence enables nurses not only to perform procedures safely, but also to anticipate and prevent critical situations, providing care that is both child-centred and therapeutically effective.

Organisational challenges and professional growth

Paediatric nephrology nursing operates within a highly complex organisational framework, where the intensity of care, the clinical fragility of patients, and the use of advanced technological interventions demand an efficient and flexible system. Paediatric nephrology nurses often work under considerable pressure due to high workloads, a shortage of specialised staff, and continuous shift work, including night and weekend shifts.²⁸

These operational conditions increase the risk of chronic occupational stress and deterioration of psychological well-being, aspects that are well documented among healthcare professionals working in high-complexity clinical settings.²⁹ Shift scheduling, emergency management, on-call responsibilities, and the need to respond

promptly to urgent care needs require nurses to demonstrate resilience and adaptability. Nevertheless, within this challenging context, significant opportunities for personal and professional growth can emerge for highly motivated nurses.³⁰

Continuous professional development is essential to maintain high levels of competence and to ensure safe and high-quality care. Specialised training in paediatric nephrology, access to courses on new dialysis technologies, clinical simulation, and hands-on practice with advanced techniques, such as vascular access management and extracorporeal devices, provide valuable opportunities for professional enrichment and recognition of the nursing role.³¹

In addition to technical training, the development of transversal skills such as leadership, problem-solving, effective communication, and team management is increasingly relevant. These competencies can open career paths in management, education, or research.³² Experienced nurses may become clinical educators, team leaders, members of multidisciplinary working groups, or contributors to the development of protocols and clinical guidelines. They may also initiate and lead projects in nursing research.³³

Therefore, although paediatric nephrology presents significant organisational challenges, it also constitutes a highly stimulating environment where nurses can provide advanced, specialised care and pursue continuous professional development.

Emotional impact and burnout risk

Nursing care in paediatric nephrology is shaped by emotional involvement, particularly in cases involving children with AKI or CKD in critical clinical conditions. Daily contact with suffering, the vulnerability of young patients, the uncertainty surrounding clinical outcomes, and, in the most severe cases, the potential loss of a child, are psychologically significant stressors for nursing staff.³⁴

Nurses must maintain a delicate balance between professionalism, empathy, and managing their own emotional responses. Continuous exposure to high emotional intensity may lead to burnout syndrome, characterised by emotional exhaustion, depersonalisation, and a reduced sense of personal accomplishment, which is widely documented among healthcare professionals, especially in high-intensity care environments.³⁵

Burnout compromises the psychological and physical well-being of the nurse and may also negatively affect the quality of care delivered, the effectiveness of communication with patients and families, and the cohesion of the care team.³⁶ For these reasons, healthcare organisations must implement preventive policies against psychological distress, including access to listening spaces, psychological support programmes, and training pathways focused on workplace well-being.

Promoting a culture of self-care is crucial in this context. This includes emotional awareness, stress management, and the ability to recognise one's limits. Resilience, defined as the capacity to face and overcome difficult experiences without losing personal balance, emerges as a fundamental competence for nursing staff, to be developed through training and institutional support.³⁷

Peer support, clinical supervision, and working within cohesive teams also significantly reduce the risk of burnout. The sharing of experiences, opportunities for dialogue, and emotional support from colleagues enhance the sense of belonging and foster a healthier and more sustainable work environment.³⁸

Recognising and addressing the emotional impact of paediatric nephrology care is not only an ethical necessity but also an essential condition for safeguarding the health of healthcare providers and ensuring excellence in the care delivered to young patients.

Conclusion

The paediatric nephrology nurse plays an essential role in the care pathway of children affected by AKI and CKD, serving as a key point of reference both for young patients and their families. This role takes place within a highly complex care setting, where advanced clinical expertise, relational abilities, technological proficiency and emotional management are required daily.

The nurse is involved in a wide range of activities: from clinical assessment and the management of sophisticated dialysis technologies to the care of vascular access and the safe administration of complex intravenous therapies. Equally important is the relational dimension, which demands empathetic and constructive communication with parents, as well as close collaboration with the multidisciplinary team. In this context, the quality of care depends not

only on technical competence, but also on the nurse's ability to act in a coordinated, integrated, and reflective manner.

These key responsibilities are accompanied by significant challenges: emotional burden, the risk of psychological fatigue, demanding shifts, and the ongoing need for professional development. To ensure the sustainability of this role, it is crucial to promote favourable organisational conditions, continuous education pathways, and psychological support spaces for the staff. Strengthening resilience and enhancing nurses' well-being are key elements to ensuring both patient safety and quality of working life.

Therefore, investing in the paediatric nephrology nurse is not merely a desirable option, but a strategic priority for delivering safe, competent, and truly child-centred care. By formally recognising and investing in the complex, multidimensional role of the paediatric nephrology nurse, healthcare systems can ensure a care model that is not only clinically effective, but also resilient, humane, and truly centred on the needs of children and their families.

References

1. Warady BA, Chadha V. Chronic kidney disease in children: The global perspective. *Pediatr Nephrol*. 2007;22(12):1999–2009.
2. Bragadottir G, Coggins C. Paediatric acute kidney injury: Recognition and management. *Crit Care Nurs Clin North Am*. 2020;32(2):157–71.
3. Wong CJ, Warady BA. The role of the Paediatric nephrology nurse in CKD management. *Nephrol Nurs J*. 2019;46(1):55–61.
4. KDIGO Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease in Children. *Kidney Int Suppl*. 2013;3(1):1–150.
5. Royal College of Nursing. Caring for Children and Young People with Renal Conditions: An RCN Competence Framework for Nursing. London: *RCN Publishing*; 2021.
6. Flynn JT, Kaelber DC, Baker-Smith CM, et al. Clinical practice guideline for screening and management of high blood pressure in children and adolescents. *Paediatrics*. 2017;140(3):e20171904.
7. National Kidney Foundation. Kidney Disease: Improving Global Outcomes (KDIGO) Paediatric CKD Guidelines. *Kidney Int Suppl*. 2013;3(1):e1–e150.
8. World Health Organization. Standards for improving quality of care for children and young adolescents in health facilities. Geneva: *WHO*; 2018.
9. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Dev*. 2010;36(4):549–57.

10. Aydın Y, Efe E. School-age children's problems in adaptation to chronic kidney disease and coping strategies. *J Clin Nurs*. 2019;28(21-22):3906–17.
11. Foster K, Whitehead L, Maybee P. The parents', hospitalized child's, and health care professionals' perceptions and experiences of family-centred care within a paediatric critical care setting: A qualitative systematic review. *JBIM Libr Syst Rev*. 2010;8(17):691–758.
12. Coyne I. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. *J Child Health Care*. 2008;12(4):312–22.
13. Judd A, Hashemi M, Bull C, et al. Educational and social needs of children with chronic kidney disease: a national survey of professionals' perspectives. *BMJ Paediatr Open*. 2018;2(1):e000164.
14. Tong A, Cheung KL, Nair SS, et al. Children's experiences of dialysis: a systematic review of qualitative studies. *Arch Dis Child*. 2014;99(10):903–9.
15. Bell LE, Ferris ME, Wuhl E, Warady BA, Joly D, Layton AT, et al. Transitioning adolescents with kidney disease: New consensus recommendations. *Pediatr Nephrol*. 2021;36(2):327–35.
16. Bell LE, Ferris ME. Transitioning adolescents with renal issues from Paediatric to adult health care. *Pediatr Clin North Am*. 2010;57(2):593–610.
17. Coyne I, Hallström I, Söderbäck M. Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *J Child Health Care*. 2016;20(4):494–502.
18. Jack K, Hamshire C, Chambers A. The influence of role models in undergraduate nurse education. *J Clin Nurs*. 2017;26(23-24):4707–15.
19. Reeves S, Lewin S, Espin S, Zwarenstein M. Interprofessional Teamwork for Health and Social Care. *Oxford: Wiley-Blackwell*; 2010.
20. Lingard L, Espin S, Evans C, Hawryluck L. The rules of the game: interprofessional collaboration on the intensive care unit team. *Crit Care*. 2004;8(6):R403–8.
21. Paradis E, Reeves S. Key trends in interprofessional research: A macrosociological analysis from 1970 to 2010. *J Interprof Care*. 2013;27(2):113–22.
22. Warady BA, Bakkaloglu S, Newland J, Schaefer F. Paediatric peritoneal dialysis. *Pediatr Nephrol*. 2021;36(1):3–17.
23. McCulloch M, Dart A, Harvey E. Infection prevention in Paediatric peritoneal dialysis. *Nephrol Nurs J*. 2020;47(4):353–360.
24. Flynn JT, Kaelber DC, Baker-Smith CM, Blowey D, Carroll AE, Daniels SR, et al. Clinical practice guideline for screening and management of high blood pressure in children and adolescents. *Paediatric s*. 2017;140(3):e20171904.
25. D'Angio CT, Ryckman FC, Grinsell MM. Central venous catheter care in Paediatric patients receiving Haemodialysis. *Nephrol Nurs J*. 2019;46(3):267–274.
26. Goldstein SL, Selewski DT, Bunchman TE. Paediatric renal replacement therapy in the ICU. *Blood Purif*. 2020;49(1-2):25–31.

27. Kanagasundaram NS, Paglialonga F, Edefonti A, Ranchin B, Ariceta G, Shroff R. Continuous education and training in Paediatric dialysis. *Pediatr Nephrol.* 2019;34(3):381-389.
28. Manara DF, Bagnasco A, Catania G, et al. La complessità dell'assistenza infermieristica in area critica. *Prof Inferm.* 2018;71(1):35-42.
29. Giorgi F, Mattei A, Notarnicola I, et al. Burnout tra gli infermieri italiani: una revisione sistematica. *Acta Biomed.* 2020;91(Suppl 12):e2020011.
30. Maslach C, Leiter MP. Understanding the burnout experience: recent research and its implications for psychiatry. *World Psychiatry.* 2016;15(2):103-111.
31. De Marinis MG, Piredda M, Pascarella MC, et al. Continuous professional development and competency maintenance in Italian nurses. *J Contin Educ Nurs.* 2019;50(3):123-129.
32. Fagerström L. The impact of advanced practice nursing roles on quality, cost and access to healthcare: a systematic review. *Scand J Caring Sci.* 2021;35(2):370-382.
33. Watson R, Jones M, Barrett D. *Nursing Research: Design and Methods.* Elsevier, 2017.
34. Mealer M, Jones J, Moss M. A qualitative study of resilience and posttraumatic stress disorder in United States ICU nurses. *Intensive Care Med.* 2012;38(9):1445-51.
35. Maslach C, Leiter MP. Burnout in the health professions: a crisis in care. *The Lancet.* 2016;388(10057):2272-4.
36. Garcia CL, Abreu LC, Ramos JLS, Castro CFD, Smiderle FRN, Santos JAD, Bezerra IMP. Influence of burnout on patient safety: systematic review and meta-analysis. *Medicina (Kaunas).* 2019;55(9):553.
37. Rushton CH, Batcheller J, Schroeder K, Donohue P. Burnout and resilience among nurses practicing in high-intensity settings. *Am J Crit Care.* 2015;24(5):412-20.
38. Figley CR. Compassion fatigue: psychotherapists' chronic lack of self care. *J Clin Psychol.* 2002;58(11):1433-41.



JOIN EDTNA/ERCA NOW

INDIVIDUAL AND CORPORATE MEMBERSHIP

BE PART OF AN ASSOCIATION THAT

Specializes in Renal Care
Cares about the Environment
Translates Strategy into Action
Fosters Team Success
Welcomes Transformation on & Innovation

TAKE THE OPPORTUNITY TO

Enhance Professional and Personal Growth
Learn Valuable Leadership Skills
Gain an Evidence-Based Education
Share Knowledge and Experience
Make Your Daily Work Visible

JOIN OUR COMMUNITY TO NETWORKING
WITH RENAL CARE PROFESSIONALS AROUND THE GLOBE
WWW.EDTNAERCA.ORG

