

Psychological aspects in children and parents of children with chronic kidney disease and their families

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Pediatric chronic kidney disease (CKD) is a chronic illness that affects the overall quality of life of patients during childhood. This article highlights the psychological and social burden of CKD in patients and their families. Patients with CKD and their families require comprehensive treatment for psychosocial problems. Therefore, it is crucial for pediatricians to screen for these issues and refer patients and their families for therapy. Tools that are short, easy to administer, and easy to score, such as the Pediatric Quality of Life Inventory or the Childhood Depression Inventory, can be utilized during routine clinical appointments. Reducing the negative impact of CKD on the family will improve the well-being and coping skills of patients and their families.

Key words: Pediatric chronic kidney disease, Psychosocial issues, Evaluations, Interventions, Family

Key message

- Childhood chronic kidney disease (CKD) is complex and requires lifetime medical treatment.
- Children with CKD are at risk for emotional, behavioral, social, and academic difficulties that significantly affect their quality of life.
- Caring for children with CKD is stressful for families.
- These unique challenges are crucial and can negatively impact treatment outcomes.
- Awareness of and addressing these evolving psychosocial issues can foster their developing needs.

Introduction

Chronic illnesses that develop in childhood require long-term treatment affect both the child and the whole family.^{1,2)} A meta-analytic review reported that children with “physical disorders” (including asthma, cardiac disorders, cancer, diabetes, inflammatory bowel disease, juvenile idiopathic arthritis, neurological disorders, and sensory disorders) had a higher risk

of developing internalizing (e.g., anxiety, depression, social withdrawal) and externalizing symptoms (e.g., hyperactivity and aggressive behavior) and overall adjustment problems and lower self-concept or self-esteem than healthy children.³⁾ A review that integrated 569 studies that administered the Child Behavior Checklist, Youth Self Report, and Teacher Report Form for children and adolescents with chronic physical illnesses found higher elevations in internalizing problems (withdrawn, somatic complaints, anxious/depressed), externalizing problems (delinquent and aggressive), and total behavior problems than their healthy peers.⁴⁾

Pediatric chronic kidney disease (CKD) is defined as a reduced glomerular filtration rate (<60 mL/min/1.73 m²) for at least 3 months or the presence of structural or functional kidney damage (even if the value is greater than 60 mL/min/1.73 m²).⁵⁾ The global prevalence of CKD is difficult to assess, as children are frequently diagnosed late, especially in low-resource areas. The prevalence of CKD is 15–74.7 cases per one million children.⁶⁾ However, as CKD is often asymptomatic in the earlier stages, it is often underreported or undiagnosed, suggesting an even higher prevalence in children.⁷⁾

The etiology of CKD in children varies with age. Congenital anomalies of the kidneys and urinary tract (CAKUT) are observed in younger patients. The common causes of CAKUT causing CKD are renal hypodysplasia, bladder outlet obstruction (posterior urethral valves), and polycystic kidney diseases. In children older than 12 years, primary and secondary glomerular diseases are the leading causes of CKD.^{6,8)} Regardless of etiology, CKD is associated with progressive loss of kidney function and multiple comorbidities, such as anemia, bone mineral disease, hypertension, cardiovascular disease, and electrolyte/acid-based abnormalities, similar to adult CKD patients. In addition, children experience significant growth failure depending on the age, cause, and onset of CKD.⁹⁾ Those with abnormal lower urinary tracts also require multiple surgeries and interventions to empty the bladder, such as clear intermittent catheterization.

If CKD progresses to kidney failure, children require maintenance dialysis until they receive a kidney transplant. Hemo-

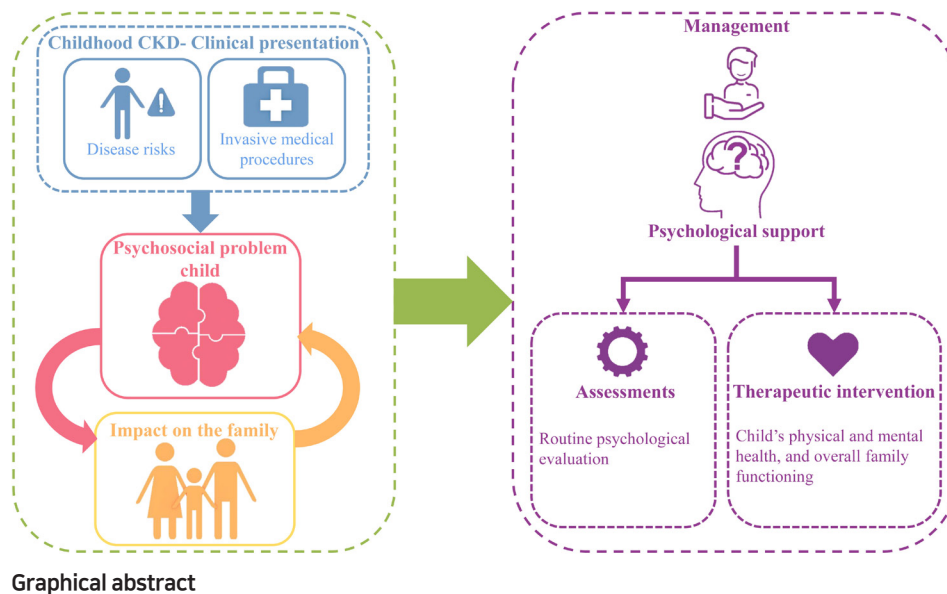
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Graphical abstract

Conceptual framework

It is essential to understand and examine the various factors that influence the lives of children with chronic illnesses. Theoretical approaches aid in the identification and understanding of the associated psychological risks and guide clinicians in decision-making and planning psychosocial interventions.³⁵⁾ Bronfenbrenner's ecological model has been central in guiding the understanding of risk and resilience as development unfolds and supports a contextualized view of child development and treatment (Fig. 1).³⁶⁾ It also provides insight into working with children who have a chronic medical illness and their families and the influence of multiple systems, such as the extended family, school, neighborhood health care system, and community, on the child's interactions and development. This model ensures that a clinician examines the subsystems of the child's world that play prominent roles in their adjustment and outcomes.³⁷⁾

Need for psychosocial evaluation

Routine psychological evaluations should be integrated to ensure better understanding of the illness and the child's overall quality of life. It helps establish a therapeutic alliance with the child and family and provides an opportunity for the parent or family to reflect upon and work through their difficulties.³⁸⁾ Psychosocial issues reported by the child and parents, or elicited by the clinician, help determine the key areas to be addressed, and the information obtained must be shared across professionals involved in caring for the child and family.^{38,39)} During an evaluation, if problems such as anxiety, withdrawn behavior, low self-esteem, school refusal, attention deficit, poor scholastic performance, or poor treatment adherence are perceived or reported, the primary physician can refer the child to a mental health professional or a medical social worker for further

dialysis is typically performed thrice weekly at a dialysis facility via a catheter or an arteriovenous fistula. Peritoneal dialysis is performed at home daily using an automated cyclor machine or manually by a caregiver. Children undergoing dialysis have multiple dietary restrictions.

Given the extent of the comorbidities of pediatric CKD and the challenges of lifelong treatment, the following unique psychological and social problems may occur.

Psychological and social problems in children and families with CKD

With modern medical advances, such as dialysis and kidney transplantation, the survival of children and young people with CKD has noticeably increased.^{10,11)} While long-term survival improves among children with CKD, their overall quality of life remains hampered and often continues in adulthood.¹²⁻¹⁴⁾ The prolonged need to take medications, frequent contact with medical professionals, and interruptions in schooling and everyday activities may be mechanisms through which the illness increases affected children's psychological problems.¹⁵⁾ Caregivers often experience emotional, marital, social, and financial burdens, which may leave families feeling unable to deliver the complex care that children with CKD require.^{16,17)} Moreover, studies of siblings with other chronic conditions revealed that siblings also experience various feelings and reactions, such as sadness, anxiety, stress, or guilt over their good health.^{18,19)} Some of the problems commonly associated with CKD are summarized in Table 1.²⁰⁻³⁴⁾

Nonetheless, given the condition's effects on this vulnerable patient population's physical and emotional well-being, steps must be taken to provide intensive and ongoing psychological support for children with CKD and their families.

Table 1. Summary of psychosocial problems of children with CKD and their families

Study	Sample	Measures	Key findings
Children with CKD			
Fukunishi and Honda ²⁰⁾ (1995)	65 (35 kidney transplant and 30 CAPD); mean age: 9.9 years (transplant group), 9.7 years (CAPD)	Diagnostic interviews for children and adolescents	Academic problems and nonacademic problems (missing school, absenteeism from school events such as picnic, excursion, and relationship with peers) were highest in the CAPD group, followed by transplant children.
Fielding and Brownbridge ²¹⁾ (1999)	60; less than 22 years of age	Measure of the health status of the sick child, CDI, STAI-CH	Children who suffered more significant functional impairment due to their illness were likely to show more behavioral disturbance.
Madden et al. ²²⁾ (2003)	16; 1.6–12.1 years	GMDS, WISC-III, SDQ	The majority of the children undergoing long-term peritoneal dialysis had IQ scores within the average to low average range. There were problems in the conduct, peer relationships, and hyperactivity domain.
Bakr et al. ²³⁾ (2007)	38; 9–15 years	SCICA	The prevalence rate of psychiatric disorders in children with kidney failure was 52.6%. Adjustment disorders were more common. Anxiety and elimination disorders were reported.
Duquette et al. ²⁴⁾ (2007)	30; 6–18 years.	WASI, WIAT-II	Children with CKD had more absenteeism and grade retention. Lower scores on IQ tests and math reasoning and word reading. Renal function was a significant predictor of academic scores.
Gerson et al. ²⁵⁾ (2010)	402; 2–16 years.	PedsQL 4.0	The health-related quality of life (HRQoL) was lower in children with CKD. They had significantly lower physical, school, emotional, and social domain scores.
Lande et al. ²⁶⁾ (2011)	383; 6–17 years	WASI, WIAT-II-A, CPT-II, BRIEF	Children with CKD had poorer scores on visuospatial and planning tasks as well as overall scores on WASI.
Parents			
Wiedebusch et al. ²⁷⁾ (2010)	195 Parents of children suffering from the renal disease	IFS, SOEBEK, FKV, ULQIE	Parents of children undergoing dialysis experienced more limitations in the quality of life than children living with a kidney graft or undergoing conservative treatment. Mothers had lower HRQoL. The most frequent coping strategies used by parents were improving partnership, support, and focusing on the child.
Tong et al. ²⁸⁾ (2010)	Parent of 20 children with CKD	In-depth interviews	Parents had difficulty accepting the diagnosis and were traumatized watching their child undergo invasive medical procedures. They depended on health care providers for support and learned from other parents of CKD children.
Kili -Pstruska et al. ²⁹⁾ (2014)	388 Parent-proxies of children with CKD.	Questionnaire referring to changes in the family after diagnosing the child with CKD	The child's illness changes the social connections of parents - they had fewer social interactions. Half the parents have never had any contact with the social workers.
Geense et al. ³⁰⁾ (2017)	20 Families of children with CKD	Focus group interviews	Parents expressed the need to have reported needing more information on about their child's disease, medication-related information, and diet plan. They also needed information on how to balance work and life and practical support on child's medical care, support in transport, financial management, and their child at school.
Nicholas ³¹⁾ (2017)	22 Fathers of children with CKD.	Semistructured interviews	Most fathers identified themselves as their child's coprimary caregiver, especially with giving medication, transport to and fro from the hospital. They felt a loss of personal control and emotional isolation.
Siblings			
Batte et al. ³²⁾ (2005)	15 Siblings of children undergoing chronic renal failure treatment.	SCAS	There were no indicators of clinically significant anxiety. However, siblings had concerns about their health worried about changes in the family routine, felt more protective towards their chronically ill siblings and needed to be more grown-up.
Velasco et al. ³³⁾ (2020)	136 Siblings: 65 siblings of KT patients, 35 siblings of LT patients, 36 siblings of CRDs.	KIDSCREEN-52.	The healthy siblings of kidney transplant patients had a lower subjective perception of physical well-being and financial resources.
Agerskov et al. ³⁴⁾ (2020)	Siblings and parents of children with ESRD Parents: 7 Siblings: 5	Semistructured interviews.	The healthy siblings monitored, worried about, and felt for their sick sibling; they expressed annoyance when they could not share experiences. Siblings needed support when the ill child was hospitalized.

CKD, chronic kidney disease; CAPD, continuous ambulatory peritoneal dialysis; CDI, Children's Depression Inventory; STAI-CH, state-trait anxiety inventory for children; GMDS, Griffiths Mental Development Scales for children; WISC-III, Wechsler Intelligence Scale for children third edition; SDQ, strengths and difficulties questionnaire; IQ, intelligence quotient; SCICA, semistructured clinical interview for children and adolescents; WASI, Wechsler Abbreviated Scale of Intelligence; WIAT-II, Wechsler Individual Achievement Test—second edition; PedsQL 4.0, Pediatric Inventory of Quality of Life Core Scales; WIAT-II-A, Wechsler Individual Achievement Test-II-abbreviated; CPT-II, Conners' Continuous Performance Test-II; BRIEF, behavior rating inventory of executive functions; IFS, impact on family scale; SOEBEK, social orientations of parents of handicapped children questionnaire; FKV, freiburg questionnaire of coping with illness; ULQIE, Ulm Quality of Life Inventory for Parents; SCAS, Spence Children's Anxiety Scale; KT, kidney transplant; CRD, chronic renal disease; ESRD, end stage renal disease.

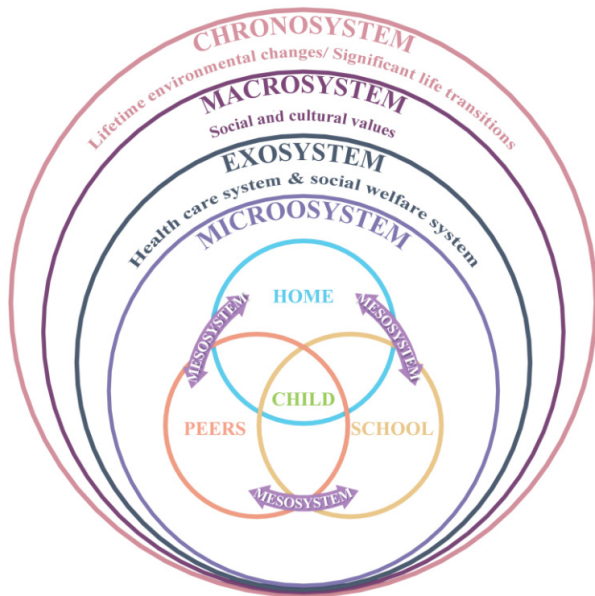


Fig. 1. Bronfenbrenner's ecological model.

evaluation. Thus, it ensures early identification and intervention, which lead to better outcomes. Clinicians must also pay attention to the well-being of the siblings, as they are likely to be at risk of adjustment problems. In addition, acknowledging the burden and providing emotional support to the parents or caregivers will help reduce stress.

Some commonly used tools for assessing psychosocial issues and quality of life of children and their parents are provided in Table 2.⁴⁰⁻⁵¹⁾

Psychosocial management

Interventions with children are based on various frameworks, such as cognitive-behavioral, art, storytelling, workbooks, games, music, and play, which decrease distress, anxiety, and pain and enhance adjustment.⁵²⁻⁵⁶⁾ Furthermore, a child's age, developmental level, and cognitive ability should be considered in planning interventions to allow their families to understand

Table 2. Tools for assessing psychosocial issues and quality of life of children and their parents/caregivers

Tools	Purpose/primary use	No. of items and administration time	Target population	Strengths and limitations
CBCL/6-18 YSR/11-18, and TRF/6-18) ⁴⁰⁾	It measures internalizing behavior problems, externalizing behavior problems and social competence in children and adolescence based on the preceding 6 months.	113 Behavioral items, scored as (0) not true, (1) somewhat true, (2) very true or often true. 15 to 20 minutes	CBCL/6-18 parents YSR/11-18 youths TRF/6-18 teachers familiar to the child	Strengths: Multiple CBCL information can be collected on the same child. It is a reliable and valid measure used for both clinical interventions and research purposes. Translated in other languages. Limitations: It takes a long time to fill the form. Scoring is complex.
SDQ ⁴¹⁾	It screens children's emotional problems, conduct disorder, hyperactivity, peer problems, and pro-social behaviors over the last 6 months.	25 Items, scored as 0 (not true), 1 (sometimes true), 2 (certainly true). 5 Minutes	Children between ages 4 to 17 years; parent, teacher, and self-report versions are available	Strengths: reliable and valid measure. It can be used for both clinical interventions and research purposes. Easy to administer. Translated in other languages. Limitation: children below 11 years cannot self-report.
RSE ⁴²⁾	It measures global self-esteem	10 Items rated on a 4-point scale as strongly agree, agree, disagree, and strongly disagree. 5 Minutes	Children above 12 years	Strengths: There is considerable evidence of its reliability and validity. Translated in other languages. Quick and easy to administer. Limitation: Validity not established for children below 12 years of age.
CFSEI ⁴³⁾	It is a self-report inventory to identify children who may require psychological evaluation and intervention. It is also applicable in research studies.	Primary form- 29 items, Intermediate form- 64 items, Adolescent form- 67 items. The responses are in yes or no format. 1015 Minutes	Ages between 6-18.11 years. Primary form for 6 to 8 years of age Intermediate form for 9 to 12 years of age Adolescent form for 13 to 18 years of age.	Strengths: It is a culture fair test that has good reliability and validity. Limitations: Sometimes responses may not reflect their actual emotional state, and there are chances of giving socially desirable answers.
CDI-2 ⁴⁴⁾	It assesses the cognitive, affective, and behavioral signs of depression.	CDI 2: Self report has 28 items and CDI 2: Self-report short version has 12 items. The responses are marked as 0 (absence of symptoms), 1 (mild symptom), 2 (definite symptom). CDI 2: Teacher has 12 items, and CDI 2: parent has 17 items. The responses are marked as 0 (not at all), 1 (sometimes), 2 (often), 3 (most of the time). 5-15 Minutes	Parent, teacher, and self-report (7-17 years) are available	Strengths: Reliable and valid tool and can be used in settings such as schools and clinics. Translated in other languages. Limitations: test results must be corroborated with other findings such as clinical interview and must be confirmed by a qualified clinician.

continued

Table 2. Tools for assessing psychosocial issues and quality of life of children and their parents/caregivers (continued)

Tools	Purpose/primary use	No. of items and administration time	Target population	Strengths and limitations
SCARED ⁴⁵⁾	It screens for childhood anxiety disorder and assesses panic/somatic, separation anxiety, generalized anxiety, and school phobia.	41 Items rated on a 3-point scale 0 (not true) to 2 (very true)	Children between 8-18 years. Both child and parent versions are available.	Strengths: It is a valid measure with good and sensitive to change in short interventions. Translated in other languages. Limitations: It should be used by a trained clinician Insufficient evidence of test-retest reliability over short periods of time.
STAI-CH ⁴⁶⁾	It evaluates the current state of anxiety and also measures the stable aspects of anxiety.	40 Items and responses are rated on a 3-point scale. 20 Minutes	It is applicable for children between 9-12 years. Both parent and child versions are available.	Strengths: It is a widely used measure of anxiety Translated in other languages. Limitations: The ability to detect change in trait anxiety is less responsive as compared to state anxiety.
PedsQL 4.0 ⁴⁷⁾	It can be used across pediatric populations with chronic and acute health conditions, community and school populations. Measures the physical, emotional, social, and school domains.	23 Items; Parent report and child report format: 5-point response scale (0 to 4). Young child self-report format (ages 5-7): 3-point scale. 5 Minutes	It has versions for toddlers (2-4), young children (5-7), children (8-12), and teens (13-18). Child rated version and parent-rated version are available.	Strengths: Quick completion and easy to score. It has good psychometric properties. Translated in other languages. Limitations: Charges applicable for funded research which can be expensive.
PedsQL ESRD Module 3.0 ⁴⁸⁾	It measures end-stage renal disease-specific health-related quality of life-general fatigue about my kidney disease, treatment problems, family and peer interaction, worry, perceived physical appearance, and communication.	34 Items and 7 subscales. Parent report and child report format: 5-point response scale (0 to 4). Young child self-report format (ages 5-7): 3-point scale. 10 Minutes	It has versions for toddlers (2-4), young children (5-7), children (8-12), and teens (13-18). Child rated version and parent-rated version are available.	Strengths: It has good psychometric properties. Translated in other languages. Limitations: Charges applicable for funded research which can be expensive.
GHQ-12 ⁴⁹⁾	Designed to measure the current mental health, GHQ was initially developed as a 60-item instrument, but a range of shortened versions 12, 20, 30 are available.	12 Statements, rated on a 4-point scale (less than usual, more than usual, rather more than usual, and much more than usual). 5 Minutes	Adolescents, parents	Strengths: The GHQ-12 is brief, simple, easy to complete, and scored. Its application in research settings as a screening tool is well documented. Translated in other languages. Limitations: Possibility of response bias on negatively stated items.
ZBI ⁵⁰⁾	It is designed to reflect the caregiver's stresses.	22 Items rated on a 5-point scale from 0 (never) to 4 (nearly always). 5 minutes	Caregivers' self-report	Strengths: It has been widely used in clinical practice and research. Translated in other languages. Limitations: The self-checklist format can be limiting.
FES ⁵¹⁾	It examines the family members' current family as they perceive it, the type of family they prefer, and their expectations of what a family will be like. The FES can be measured in 3 ways Real (form R), Ideal form I) and Expected (form E). The FES is composed of 10 subscales measuring 3 dimensions namely family relationship, personal growth, and system maintenance and change. It is mainly used in clinical settings to facilitate family therapy.	90 True or false items. 15-20 Minutes	Children 11 years and older	Strengths: Widely used tool Translated in other languages. Limitations: Low internal consistency for 5 subscales.

CBCL/6-18, child behavior checklist; YSR/11-18, youth self-report; TRF/6-18, teacher's rating form; SDQ, strengths and difficulties questionnaire; RSE, Rosenberg Self-esteem Scale; CFSEI-3, culture free self-esteem inventory 3rd edition; CDI-2, Children's Depression Inventory-2nd edition; SCARED, screen for child anxiety related emotional disorders; STAI-CH, state-trait anxiety inventory for children; PedsQL 4.0, Peds Quality of Life Questionnaire; PedsQL ESRD Module 3.0, ESRD-specific module; GHQ-12, general health questionnaire; ZBI, Zarit burden interview; FES, family environment scale.

Table 3. Psychological management plan for children with chronic kidney disease and their families

Intervention with the child
<p>Psycho-education. When therapeutic work is done with a younger child, often modelling is used. The care provider may, for example, educate a doll about the doll's problems and how thinking affects behavior. In this manner, the care provider may teach skills and alternative behaviors.</p> <p>Self-care skills related to their illness include taking medicine following a proper daily routine, self-monitoring calendar or using alarm clocks or a checklist or sticker charts for young children and the importance of diet. Involve older children in health-related discussions (concerns about illness, treatments).</p> <p>Relaxation skills training such as controlled breathing and muscle relaxation exercises as stressful events can increase physiological arousal and maintain or exacerbate symptoms.</p> <p>Cognitive coping strategies such as distraction techniques, positive self-talk (can use storybooks in young children) help children manage their pain and other problems.</p> <p>Cognitive restructuring to help children replace maladaptive thoughts with more adaptive and productive thoughts.</p> <p>Group interventions allow children to share their experiences and challenges, help other sick children, learn problem-solving, increase self-confidence and self-efficacy, and facilitate a healthy adjustment to one's illness.</p> <p>School readjustments</p> <ul style="list-style-type: none"> - Attending school for shortened periods. - May benefit from tuition or attending a temporary classroom aid to assist them in learning concepts they may not have learned. - Identify a peer who can be a 'buddy' to support the child reintegrating into the classroom's social networks. - Provide medical information to the teacher.
Family intervention
Parents
<p>Connecting a parent with another parent who visits the medical team.</p> <p>Help support parents in balancing their responsibilities as a caregiver and in their personal lives.</p> <p>Parent training program. Reduce dysfunctional parenting styles, improve communication patterns, increase parental self-efficacy and decrease parenting stress, promote parent-child support for autonomy, reinforce positive behaviors.</p> <p>Practical guidance and assistance regarding transport, financial management, and child's school reintegration.</p>
Siblings
<p>Psycho-education about chronic diseases.</p> <p>Brief involvement in counseling sessions may assist a child in dealing with his or her feelings related to the troubles and pain his or her sibling is facing.</p> <p>Support groups for siblings may help them cope with grief and trauma related to a brother or sister's illness.</p>

and prepare. VanLeeuwen and Mathews highlighted the need for psychological preparation, mental health consultation, therapeutic intervention, and continuous counseling to prevent unnecessary psychological stress in a pediatric dialysis program.⁵⁷⁾ Warady and Chadha⁵⁸⁾ reported that therapeutic camps organized for children with kidney failure were successful, indicating reduced depression, improved self-esteem and self-confidence, and overall promotion of emotional maturity. Meade et al. explored the development and implementation of a self-management program designed to address noncompliance in adolescents with kidney failure on renal replacement therapy.⁵⁹⁾ They found that the program effectively created a supportive environment for patients and their parents and addressed health-related concerns. Hashim et al.⁶⁰⁾ described a dialectical behavior therapy adaptation to improve adherence in adolescent patients with kidney failure. Families also require intervention to help them cope with the stress while providing care. Some aspects of psychological management are shown in Table 3.

Conclusion

Despite medical advances, CKD can take a toll on a child's social and emotional functioning. Primary care physicians must

become proficient at recognizing psychosocial issues, assume a more supportive role, and collaborate with families to address these issues. Awareness and understanding of the child's condition will improve medication adherence. In addition, screening and monitoring psychological status and referrals for mental health services will enable comprehensive treatment. The best care for children with CKD in addition to medication should involve identifying and managing psychosocial factors, which will facilitate a successful transition to adult life.

Footnotes

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