Psychosocial aspects of children with chronic kidney disease and their families

Running title: Psychosocial aspects of children and families with chronic kidney disease

Alemsungla Aier, PhD¹, Priya Pais, MD², Vijaya Raman, PhD¹

¹Department of Psychiatry, St. John’s Medical College and Hospital, Bangalore, India
²Department of Paediatric Nephrology, St. John’s Medical College and Hospital, Bangalore, India

Corresponding Author: Vijaya Raman, PhD
Department of Psychiatry, St. John’s Medical College, Sarjapur Road, Bangalore 560034, India
Email: vijaya.r@stjohns.in
https://orcid.org/0000-0003-0578-5276
Abstract

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.
Graphical abstract
Introduction

Chronic illnesses that develop in childhood require long-term treatment affect both the child and the whole family. 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. 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.

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). 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. However, as CKD is often asymptomatic in the earlier stages, it is often underreported or undiagnosed, suggesting an even higher prevalence in children.

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. 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.\textsuperscript{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. Hemodialysis 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 cycler 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.\textsuperscript{10, 11} While long-term survival improves among children with CKD, their overall quality of life remains hampered and often continues in adulthood.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{18, 19} Some of the problems commonly associated with CKD are summarized in Table 1.

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.

**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.\textsuperscript{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).\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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 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.

**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 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 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.\(^{58}\) 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. 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**

**Funding:** The authors received no financial support for the research, authorship, and publication of this article

**Conflicts of interest**

No potential conflict of interest relevant to this article was reported.

**ORCID**

Vijaya Raman https://orcid.org/0000-0003-0578-5276
References


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

**Children with CKD**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample</th>
<th>Measures</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fukunishi and Honda (1995)</td>
<td>65 (35 kidney transplant and 30 CAPD). Mean age 9.9 years (Transplant group), 9.7 years (CAPD).</td>
<td>Diagnostic Interviews for children and adolescents.</td>
<td>Academic problems and non-academic 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.</td>
</tr>
<tr>
<td>Fielding and Brownbridge (1999)</td>
<td>60; Less than 22 years of age.</td>
<td>Measure of the health status of the sick child, CDL, STAI-CH</td>
<td>Children who suffered more significant functional impairment due to their illness were likely to show more behavioural disturbance.</td>
</tr>
<tr>
<td>Madden et al. (2003)</td>
<td>16</td>
<td>GMDS, WISC-III, SDQ</td>
<td>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.</td>
</tr>
<tr>
<td>Bakr et al. (2007)</td>
<td>38; 9-15 years</td>
<td>SCICA</td>
<td>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.</td>
</tr>
<tr>
<td>Duquette et al. (2007)</td>
<td>30; 6-18 years</td>
<td>WASI, WIAT-II</td>
<td>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.</td>
</tr>
<tr>
<td>Gerson et al. (2010)</td>
<td>402; 2-16 years</td>
<td>PedsQL-4.0</td>
<td>The Health-related QOL was lower in children with CKD. They had significantly lower physical, school, emotional and social domain scores.</td>
</tr>
<tr>
<td>Lande et al. (2011)</td>
<td>383; 6-17 years</td>
<td>WASI, WIAT-II-A, CPT-II, BRIEF</td>
<td>Children with CKD had poorer scores on visuospatial and planning tasks as well as overall scores on WASI.</td>
</tr>
</tbody>
</table>

**Parents**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample</th>
<th>Measures</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

15
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.

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.

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.

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.

Most fathers identified themselves as their child's co-primary caregiver, especially with giving medication, transport to and fro from the hospital. They felt a loss of personal control and emotional isolation;

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample</th>
<th>Measures</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Batte et al. (2005)</td>
<td>15 siblings of children undergoing chronic renal failure treatment.</td>
<td>SCAS</td>
<td>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.</td>
</tr>
<tr>
<td>Velasco et al. (2020)</td>
<td>136 siblings: 65 siblings of KT patients, 35 siblings</td>
<td>KIDSCREEN-52.</td>
<td>The healthy siblings of kidney transplant patients had a lower subjective perception of physical well-being and financial resources.</td>
</tr>
</tbody>
</table>
of LT patients, 36 siblings of CRDs.

<table>
<thead>
<tr>
<th>Authors (Year)</th>
<th>Participants</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agerskov et al. (2020)</td>
<td>Siblings and parents of children with ESRD</td>
<td>Semi-structured interviews.</td>
<td>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.</td>
</tr>
</tbody>
</table>

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; SCICA, Semi-structured 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; WASI, Wechsler Abbreviated Scales of Intelligence; 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; KIDSCREEN-52-HRQOL, KIDSCREEN-52 Health related quality of life questionnaire for children and adolescents.
<table>
<thead>
<tr>
<th>Tools</th>
<th>Purpose/ primary use</th>
<th>Number of items and administration time</th>
<th>Target population</th>
<th>Strengths and Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBCL/6-18 YSR/11-18, and TRF/6-18&lt;sup&gt;40)&lt;/sup&gt;</td>
<td>It measures internalizing behaviour problems, externalizing behaviour problems and social competence in children and adolescence based on the preceding six months.</td>
<td>113 behavioural items, scored as (0) not true, (1) somewhat true, (2) very true or often true.</td>
<td>CBCL/6-18- parents YSR/11-18-youths TRF/6-18-teachers familiar to the child.</td>
<td>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.</td>
</tr>
<tr>
<td>SDQ&lt;sup&gt;41)&lt;/sup&gt;</td>
<td>It screens children’s emotional problems, conduct disorder, hyperactivity, peer problems and prosocial behaviours over the last six months.</td>
<td>25 items, scored as 0 (not true) 1 (sometimes true) 2 (certainly true). 5 minutes.</td>
<td>Children between ages 4 to 17 years; Parent, teacher and self-report versions are available.</td>
<td>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.</td>
</tr>
<tr>
<td>RSE&lt;sup&gt;3&lt;/sup&gt;</td>
<td>It measures global self-esteem.</td>
<td>10 items rated on a 4-point scale as strongly agree, agree, disagree, and strongly disagree.</td>
<td>Children above 12 years.</td>
<td>Strengths: There is considerable evidence of its reliability and validity.</td>
</tr>
<tr>
<td>Test</td>
<td>Description</td>
<td>Forms</td>
<td>Age Range</td>
<td>Strengths</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
<td>-------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td>CFSEI</td>
<td>It is a self-report inventory to identify children who may require psychological evaluation and intervention. It is also applicable in research studies.</td>
<td>Primary form - 29 items, Intermediate form - 64 items, Adolescent form - 67 items.</td>
<td>Ages between 6-18.11 years.</td>
<td>It is a culture fair test that has good reliability and validity.</td>
</tr>
<tr>
<td>CDI-2</td>
<td>It assesses the cognitive, affective and behavioural signs of depression.</td>
<td>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</td>
<td>Parent, teacher and self-report (7-17 years) are available</td>
<td>Reliable and valid tool and can be used in settings such as schools and clinics.</td>
</tr>
<tr>
<td>Measure</td>
<td>Description</td>
<td>Age Group</td>
<td>Scale/Response Options</td>
<td>Strengths</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>-----------</td>
<td>------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>SCARED</td>
<td>It screens for childhood anxiety disorder and assesses panic/somatic, separation anxiety, generalized anxiety, and school phobia.</td>
<td>8-18 years</td>
<td>41 items rated on a 3-point scale (not at all) to 2 (very true).</td>
<td>Both child and parent versions are available.</td>
</tr>
<tr>
<td>STAI-CH</td>
<td>It evaluates the current state of anxiety and also measures the stable aspects of anxiety.</td>
<td>9-12 years</td>
<td>40-item and responses are rated on a 3-point scale.</td>
<td>Both parent and child versions are available.</td>
</tr>
<tr>
<td>PedsQL 4.0</td>
<td>It can be used across pediatric populations with chronic and acute health conditions,</td>
<td>Toddlers (2-4), Young children (5-7), Children (8-12), and Teens (13-18).</td>
<td>23 items; It has versions for toddlers (2-4), young children (5-7), children (8-12), and teens (13-18).</td>
<td>Child Quick completion and easy to score.</td>
</tr>
<tr>
<td>PedsQL ESRD Module</td>
<td>3.0</td>
<td>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.</td>
<td>34 items and seven subscales.</td>
<td>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.</td>
</tr>
</tbody>
</table>
| **ZBI**<sup>503</sup> | It is designed to reflect the caregiver’s stresses. | 22 items rated on a 5-point scale from 0 (never) to 4 (nearly always). 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**<sup>511</sup> | 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 three ways Real (Form R), Ideal form I) and Expected (Form E). The FES is composed of ten 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. Children 11 years and older | Strengths:  
Widely used tool  
Translated in other languages.  
Limitations:  
Low internal consistency for five subscales. |
CBCL/6-18, Child Behaviour 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**

- 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 behaviour. In this manner, the care provider may teach skills and alternative behaviours.
- 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).
- Relaxation skills training such as controlled breathing and muscle relaxation exercises as stressful events can increase physiological arousal and maintain or exacerbate symptoms.
- Cognitive coping strategies such as distraction techniques, positive self-talk (can use storybooks in young children) help children manage their pain and other problems.
- Cognitive restructuring to help children replace maladaptive thoughts with more adaptive and productive thoughts.
- 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.
- School readjustments
  - 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

- Connecting a parent with another parent who visits the medical team.
- Help support parents in balancing their responsibilities as a caregiver and in their personal lives.
- Parent training programme. Reduce dysfunctional parenting styles, improve communication patterns, increase parental self-efficacy and decrease parenting stress, promote parent-child support for autonomy, reinforce positive behaviours.
- Practical guidance and assistance regarding transport, financial management and child’s school reintegration.

Siblings

- Psycho-education about chronic diseases.
- Brief involvement in counselling sessions may assist a child in dealing with his or her feelings related to the troubles and pain his or her sibling is facing.
- Support groups for siblings may help them cope with grief and trauma related to a brother or sister’s illness.
Fig. 1. Bronfenbrenner’s ecological model.