Selected Primary Care Issues and Comorbidities in Children Who Are on Maintenance Dialysis: A Review for the Pediatric Nephrologist

Colin Thomas White, Peter Trnka, and Douglas George Matsell

Division of Nephrology, Department of Pediatrics, British Columbia Children’s Hospital, University of British Columbia, Faculty of Medicine, Vancouver, British Columbia, Canada

Ten-year survival of all children who initiate dialysis at any age now approaches 70%, and in the older child this number is closer to 80%. These children will live with chronic kidney disease and its myriad of associated comorbidities during and throughout their childhood. Their care is complex and requires both teamwork and careful attention paid to maintaining lines of communication among patient, family, and both the facility-based nephrology team and caregivers who are outside the hospital setting. Irrespective of their need for dialysis, children with ESRD deserve and require developmentally appropriate care and anticipatory guidance with respect to primary care issues of childhood. The child who is on dialysis often is cared for solely or in large part by a nephrology service, therefore this review discusses issues that are particularly important to pediatric nephrologists in relation to selected primary care issues and comorbidities for the child who is on dialysis, with an emphasis on medical and psychosocial issues, and with particular weight placed on issues that are pertinent to the adolescent dialysis patient.

Minimizing the impact on normal growth, development, and age-appropriate behaviors and on the well-being of the child, the family, and the community of caregivers should be the primary goals of the nephrologist who cares for a child who is on dialysis. Children who initiate dialysis at <1 yr of age have a 10-yr survival as high as 67%, increasing to 79% in children who initiate renal replacement therapy between the ages of 15 and 19 yr (1). Similar results from US Renal Data System data (2) and a Dutch cohort study (3), showed approximately 80% 10-yr survival in adolescents who initiated dialysis between 12 and 19 yr of age, highlighting that children who have ESRD and are on dialysis or receive a transplant will live with the consequences and comorbidities of these conditions for many years of their childhood.

Whereas most children use family physicians or pediatricians as primary care providers, the child who is on dialysis is often cared for in large part by the nephrology service. This review discusses primary care issues that we believe are of particular importance to the pediatric nephrologist and his or her team in caring for the child who is on dialysis, with a focus on recognition and prevention of important comorbidities and the medical and psychosocial issues that are related to requiring long-term life-sustaining therapy and its impact on both the patient and the family. Because the adolescent on dialysis faces unique challenges in terms of health and psychosocial needs, we touch on a number of issues that are of importance to the adolescent caregiver, including socialization, sexuality, autonomy, and transition to adult care.

Care Issues in Children Who Are on Dialysis: Team

Care of the child who is on dialysis is complex and requires and benefits from involvement of a team that might include clinic/dialysis/community nurse, social worker, psychologist, child life specialist, dietitian, pharmacist (hospital and/or community), teacher (hospital and/or school), and the family physician and/or pediatrician. Three points deserve to be highlighted here. First, although the nephrology team may provide support in the areas that have an impact on the care of their patient, it is unlikely—perhaps unwise—that they will be aware of all of the family medical, social, or economic stresses that occur outside the facility. Therefore, it should be an explicit goal to ensure that the community care providers, in particular the family physician or pediatrician, are kept abreast of all patient-specific developments to assist in their care of the family. This may be accomplished by ensuring that members of the team are copied on notes, that scheduled patient conferences are booked in advance and run on time and in accessible locations for those who work outside the hospital setting, and that regular telephone or e-mail contact occurs to provide updates between notes or meetings. This approach also reassures the family that their community caregivers are knowledgeable about the current situation, trusted by the hospital team, and participate fully within the team, helping to maintain their sense of connection and trust with those caregivers.

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Second, the medical complexity of these patients mandates the need for ongoing, timely, and accurate updates of medications, procedures, or changes in health status. Although strategies as outlined above will be of use, other methods, including patient log books, vaccination and updated medication passports, and preferably point-of-care electronic chart access, will be required to ensure the most effective care model.

Finally, in the era of increasing numbers and complexity of patient care, it is unlikely that the pediatric nephrology team will be able to manage all of the primary care needs for all of their patients, in particular those with complex medical, social, and/or developmental issues. Although the team may occupy a central role in the patient’s and family’s life by necessity (e.g., providing life-sustaining care), this does not mean that they are best suited to discuss issues such as smoking, acne, peer pressure, drug experimentation, sexuality, fear of pregnancy, or the like and in truth would in most situations likely do better to leave this to the “professionals” outside the nephrology setting.

Care Issues in Children Who Are on Dialysis: Medical Immunization

Children who receive maintenance dialysis are prone to infections as a result of increased exposure to infective agents (e.g., blood products, sharing of dialysis equipment) and altered immune status (e.g., uremia, immunosuppressive medications, disruption of mucosal and cutaneous barriers). Many of these infections are preventable by immunizations. Current guidelines for immunization in children are derived from small studies (4) or represent expert opinion (5).

Recommendations for vaccination vary between countries, with most recommending immunization of a child who is on dialysis as per the schedule for the general population (6). In particular, all children who are on dialysis should be immunized against *Streptococcus pneumoniae*, varicella, and influenza (5), and all live virus vaccines (e.g., measles-mumps-rubella, varicella) with the exception of oral polio are safe, as are inactivated or component vaccines. Some programs provide standard rotavirus immunization of infants who are on dialysis since the licensing of live rotavirus vaccines and recommendations for their routine use (7).

The exception to the live vaccine recommendation is the dialysis patient who is on immunosuppressive medications, in whom live vaccines should not be given (8). Accelerated schedules for vaccination of transplant candidates starting from 6 mo of age are available (9,10).

Most children with chronic kidney disease (CKD) produce detectable and protective levels of antibodies to primary vaccinations. However, some on dialysis may not respond optimally, having lower seroconversion rates, antibody titers, and a rapid decline of antibody levels. Protective antibody titers in healthy children may not be adequate to prevent infections as in immunized peritoneal dialysis patients who develop peritonitis from *Haemophilus influenzae* and *Streptococcus pneumoniae* (11).

For poor response to vaccination, increasing the dose, in the case of hepatitis B vaccine repeating the course, or providing supplementary doses all are strategies to overcome inadequate seroconversion or low titers (12). Any child who is older than 1 yr should have titers drawn for measles, mumps, rubella, and varicella to ensure protective levels and should be revaccinated if required before transplantation occurs.

Contraindications to vaccination of the dialysis patient are as in the general population; specifically, temporarily hold vaccination after a moderate to severe illness, and delay live vaccines after blood or antibody-containing product administration and in children who are on high-dosage corticosteroid therapy. Finally, documented anaphylactic reaction to a previous dose of a vaccine or any vaccine component is an absolute contraindication to the use of that vaccine in any child (10). Tables 1 and 2 review worldwide schedules for the most common childhood vaccinations, with dialysis-specific recommendations, and highlight important details of vaccination in this group.

Cardiovascular Health

Cardiovascular mortality in children who are on dialysis has not changed significantly in the past three decades (13): 25% of deaths in this group are due to cardiovascular causes (14), of which cardiac arrest is the most common, followed by fatal arrhythmias and cardiomyopathy (15). Both traditional and nontraditional cardiovascular risk factors contribute to morbidity and mortality in any patient with ESRD. Recommendations for evaluation of cardiovascular abnormalities and treatment of modifiable risk factors in children are based mainly on clinical experience and adult data (16). Epidemiologic studies on the prevalence and risk factors of cardiovascular disease, development of guidelines for screening and treatment of at-risk children, and studies on effective treatment are vital to caring for this population, who would also benefit from some form of a cardiovascular disease checklist to ensure regular monitoring (14). Selected cardiovascular risk factors and current best practice recommendations are summarized in Table 3.

Obesity/Malnutrition

The global epidemic of childhood obesity is alarming. In the developed world, 20% of children are overweight or obese, and computer modeling predicts that approximately 50% of children in the Americas and up to 40% of children in Europe will be overweight or obese by 2020 (17).

Obesity in adults is associated with glomerular hyperperfusion and hyperfiltration as a result of afferent arteriolar dilation and initially produces an increase in GFR. The first sign of renal injury is microalbuminuria, followed by increasing proteinuria and, eventually, progressive decline in GFR. Progression to ESRD, if the process is not interrupted, becomes inevitable, and because obese children tend to become obese adults, this issue will continue to have a significant impact on population health.

Emerging data in children support these concerns, with long-term follow-up data from Filler et al. (18) confirming that the increase in childhood obesity in their region coincided with a significant increase in the prevalence of CKD and ESRD. Obesity in the pediatric patient with ESRD might also have an impact on selection of dialysis modality, achievement of adequacy, and potential negative impact on kidney allograft func-
Provision of optimal diet with sufficient energy and macro- and micronutrients is the most important factor in improving growth in children who are on dialysis. Protein-energy malnutrition, however, is common in this population and might be associated with increased risk for morbidity and mortality. The important negative impact of malnutrition has been demonstrated by a U-shaped mortality curve in children with ESRD at either end of the body mass index (23). Obligate protein loss through the peritoneal space in combination with decreased appetite, resulting in decreased protein and energy intake, play the major role in the development of protein-energy malnutrition in children who are on peritoneal dialysis (24).

Table 1. Recommended immunizations in children who are on maintenance dialysis

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>No. of Doses</th>
<th>Usual Schedule</th>
<th>Determination of Serologic Status</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>DTaP and IPV</td>
<td>Up to six doses of DTaP and four to five doses of IPV</td>
<td>2 mo onward; three doses, minimum monthly intervals; boosters from 12 mo; Td recommended every 10 yr in some countries</td>
<td>Not routinely done</td>
<td>Before travel to endemic areas of diphtheria, shorter booster intervals should be based on antipertussis toxin titers; booster dose recommendations vary among countries</td>
</tr>
<tr>
<td>HiB</td>
<td>Up to four doses</td>
<td>2 mo onward; three doses, minimum monthly intervals; &gt;2 yr age, one dose only; one booster from 12 mo</td>
<td>Not routinely done</td>
<td>In children &gt;5 yr of age only if IgG negative</td>
</tr>
<tr>
<td>HB</td>
<td>Three doses</td>
<td>Birth onward; first two doses at monthly interval, third dose 6 mo after the first dose</td>
<td>Regular measurement of anti-HB recommended</td>
<td>20-μg or higher doses suggested; additional doses are recommended when anti-HB levels fall to &lt;10 IU/L</td>
</tr>
<tr>
<td>MMR</td>
<td>Two doses</td>
<td>9 mo onward; second dose 4 to 6 wk after the first dose</td>
<td>Assessment of protective titers before transplantation recommended</td>
<td>Complete vaccination at least 4 wk before transplantation</td>
</tr>
<tr>
<td>Influenza</td>
<td>Annual dose</td>
<td>6 mo onward; two doses 4 to 6 wk apart if given for the first time before 8 yr of age</td>
<td>Not routinely done</td>
<td>Household contacts and caregivers should also be vaccinated</td>
</tr>
<tr>
<td>Varicella</td>
<td>One to two doses</td>
<td>9 to 12 mo onward; second dose 4 to 6 wk after the first dose if IgG negative after the first dose</td>
<td>Assessment of titers recommended before transplantation</td>
<td>For children with negative history of wild-type infection and negative IgG, complete vaccination at least 4 wk before transplantation</td>
</tr>
<tr>
<td>Hepatitis A</td>
<td>Two doses</td>
<td>6 mo onward; 6 mo between doses</td>
<td>Not routinely done</td>
<td>Consider for children in communities with high incidence of hepatitis A</td>
</tr>
<tr>
<td>MCV4 and MPSV4</td>
<td>One to three doses for at-risk children</td>
<td>2 mo onward (MCV4); number of doses depends on age; 2 yr onward (MPSV4); booster if still at risk 2 to 3 yr later; part of routine immunization in some countries</td>
<td>Not routinely done</td>
<td>MPSV4 not immunogenic at &lt;2 yr of age</td>
</tr>
<tr>
<td>PCV7 and PPV23</td>
<td>Four doses of PCV7, two doses of PPV23</td>
<td>2 mo onward to 2 yr: three doses at 6- to 8-wk intervals, fourth dose at 15 to 18 mo of age (all PCV7), followed by first dose of PPV23 6 to 8 wk after the last dose of PCV7; 2 yr onward: two doses of PCV7 at 6- to 8-wk interval, third dose with PPV23 6 to 8 wk after the last PCV7 dose; booster doses of PPV23 every 3 to 5 yr</td>
<td>Not routinely done</td>
<td>PPV23 not immunogenic at &lt;2 yr of age</td>
</tr>
<tr>
<td>Rotavirus</td>
<td>Three doses</td>
<td>2 mo onward with subsequent doses at 4 and 6 mo of age; three doses, minimum monthly intervals</td>
<td>Not routinely done</td>
<td>Immunization should not be initiated for infants &gt;12 wk of age (insufficient data on safety); vaccine should not be administered after 32 wk of age (insufficient data on safety and efficacy); simultaneous administration with other childhood vaccines safe and efficacious</td>
</tr>
</tbody>
</table>

aAdapted from references (5,7–10). DTaP, diphtheria-tetanus toxoid-acellular pertussis vaccine; HB, hepatitis B; HiB, Haemophilus influenzae type B conjugate vaccine; IPV, inactivated polio virus vaccine; MCV4, meningococcal conjugate vaccine; MMR, measles-mumps-rubella vaccine; MPSV4, meningococcal polysaccharide vaccine; PCV7, pneumococcal conjugate vaccine; PPV23, pneumococcal polysaccharide vaccine; Td, tetanus and low-doseage diphtheria toxoid vaccine.
Table 2. Vaccination for dialysis-dependent childrena

<table>
<thead>
<tr>
<th>Vaccination for dialysis-dependent childrena</th>
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<tbody>
<tr>
<td>Monitor and update the immunization status of the patient and household contacts.</td>
</tr>
<tr>
<td>Administer full courses of live virus vaccines 4 wk or more before transplantation.</td>
</tr>
<tr>
<td>Monitor levels of protective antibodies after vaccination, and revaccinate those who remain nonimmune.</td>
</tr>
<tr>
<td>Review current recommendations and update local protocols for vaccine use in CKD/dialysis patients frequently.</td>
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</table>

aCKD, chronic kidney disease.

parenteral nutrition can be used to improve nutritional status of hemodialysis patients and has been shown to be effective (25). The interested reader is referred to an excellent review for further details on this topic (26).

Care Issues in Children Who Are on Dialysis: Psychosocial Quality of Life

Measurements of quality of life (QoL) attempt to quantify the net effects of both therapy and disease on the individual’s perception of his or her ability to lead a useful and fulfilling life (27). Fruitful discussion of QoL in pediatric dialysis patients is limited by (1) the absence of a validated dialysis-specific tool, currently in development (28); (2) the fact that many QoL reports come from parents or teachers and so vital subtext is lost because the child is not involved; and (3) as Koch reminds us, “Where surveys and questionnaires begin with the assumption of ‘disease burden’ and a medical model of life quality, the assumptions of those positions—not the individual’s state—is often what is typically measured” (29).

Two studies using the Pediatric Inventory of Quality of Life Core Scales (PedsQL version 4.0) demonstrated significantly lower physical health scores on both child self-report and parent proxy in the combined dialysis and transplant cohorts in comparison with healthy control subjects, with the dialysis patients scoring lower than the transplant cohort (28); similarly, in a CKD, dialysis, and transplant cohort, lower physical scores were again demonstrated compared with the normal control subjects (30). These data are supported by studies that demonstrated decline in physical scores using other QoL tools (e.g., Child Health Questionnaire Parent Form [31], RAND 36 Health Survey [32]).

School

Most children who are on dialysis attend school full time, 79 to 94% (30,33,34), although many miss almost 1 d in 6 (30). Studies that have examined children who initiated dialysis as infants or toddlers have demonstrated global developmental delay of mild to moderate severity in 20 to 25% (34–36), with evidence of improvement in the more recent dialysis cohorts (34). Older school-aged children with CKD generally show an IQ that is in the low average to average range (33,37,38), and approximately 15% of children with CKD receive specialized education supports (33,34), exclusive of those with hearing loss (approximately 18%) or visual abnormalities (33,39). A number of neuropsychological and neurobehavioral areas of concern may be inherent to a child who is on dialysis (see recent reviews by Gerson et al. [40] and Gipson et al. [41] for more details).

Tables 4 and 5 present practical and targeted educational strategies to assist the pediatric nephrologist and ESRD team in managing the school-aged pediatric dialysis patient with neurocognitive or behavioral concerns and an educational checklist to assess these children. Our program is now starting to use modifications of Table 4 when requesting from schools or teachers special consideration and or program modifications for our children who have progressive CKD or are on dialysis. Perhaps because it is written in their language (i.e., psychology/education, not medicine), all schools to date have responded with reduction in workload, increased time allowed for projects or exams, and/or further supports being offered.

Family

Families with children who have chronic diseases often experience financial burden as a result of their child’s illness (42) and have smaller groups of friends or relatives from who to draw support (43). Dialysis itself imposes a large burden of care on families (44), and the child’s chronic illness can have an affect on and be affected by their family.

The impact on siblings of children with ESRD is often forgotten in this population. A number of studies have reiterated the importance of maintaining parental contact and communication with the “well” children and treating the family as whole as opposed to focusing solely on the parents and ill child (45–47). This seems to be of particular importance for siblings in families with a child who is on dialysis (47).

Three strategies that we use locally to offer family support and that have been published on by others include (1) a monthly parental support group run by our social worker with varied medical, nursing, and dietary topics and at which child care is provided and parents may also “attend” by telephone; (2) a week-long summer camp experience providing care for children at all stages of CKD and ESRD, including hemodialysis and peritoneal dialysis patients; and (3) provision of training for community nursing to provide respite care for families who are at home with a child who is on peritoneal dialysis 1 to 2 nights per week (48–50).

Growth

Growth failure remains a major problem for children who are on maintenance dialysis (51). Even modest gains in height are associated with demonstrable gains in physical functioning scores (31). Although associations between final body height and a low achieved educational levels (52) are likely confounded by time spent on dialysis, they do reinforce the need to follow growth as an important predictor of children who are at risk for poorer outcomes in adult life.

A more complete discussion on this important topic is beyond the scope of this article, but the reader is directed to the following recently published articles. Rees and Shaw (26) reviewed the impact of nutrition on growth and stressed the need for careful nutritional evaluation and frequent dietary support to support growth in children with CKD, in particular those...
### Table 3: Selected cardiovascular risk factors and their management in children who are on dialysis

<table>
<thead>
<tr>
<th>Traditional risk factors</th>
<th>What to Look for</th>
<th>Type and Frequency of Monitoring</th>
<th>Management and Targets</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Elevation of BP</td>
<td>BP measurement during each HD session and during monthly PD outpatient visits</td>
<td>Antihypertensives (preferably ACEI, ARB) with target BP &lt;90th percentile for age, gender, height or &lt;120/80, whichever is lower (74)</td>
<td>Use of ABPM in difficult-to-control hypertension might be helpful</td>
</tr>
<tr>
<td>Dyslipidemia</td>
<td>Abnormal fasting lipid profile with high TG and high HDL, VLDL, and low HDL cholesterol; total cholesterol might be elevated especially in PD patients</td>
<td>Fasting lipid profile upon presentation; 2 to 3 mo after the change in treatment or other conditions that are known to cause dyslipidemia; at least annually thereafter</td>
<td>TLC if TG ≥500 mg/dl; statins should be considered when LDL ≥130 mg/dl and non-HDL (total cholesterol minus HDL) ≥160 mg/dl in adolescents with CKD stage 5 (75)</td>
<td>Only atorvastatin currently approved for the use in children; benefit must outweigh the potential risk for myopathy and hepatic dysfunction</td>
</tr>
<tr>
<td>Sedentary lifestyle, obesity</td>
<td>Presence of overweight/obesity/ malnutrition</td>
<td>Monthly 4-monthly nutritional and growth assessment (depending on the parameter) in HD and PD patients by dietician (74)</td>
<td>TLC, dietary modification; weight loss if overweight/obese</td>
<td>Definition of overweight/obesity depends on the criteria chosen (e.g., BMI percentiles, weight ideal height) (17); both obesity and malnutrition have negative impact on survival of dialysis patients and need to be treated aggressively (23)</td>
</tr>
<tr>
<td>LVH</td>
<td>LVH, cardiomyopathy, valvular disease</td>
<td>ECHO within 3 mo of the initiation of dialysis (77), probably yearly thereafter</td>
<td>Control of volume status and hypertension with minimization of fluid overload, adequate ultrafiltration, and antihypertensives</td>
<td>Adequate dialysis treatment improves LVH via reduction of extracellular volume and normalization of BP (79)</td>
</tr>
</tbody>
</table>

| Nontraditional risk factors | Adequacy of dialysis | spKt/V urea measured within the first month of initiation of dialysis and at least 6-monthly thereafter on PD; monthly spKt/V and nPCR on HD; calculation of RKF every 3 mo (79) | Adequate dialysis treatment with minimal total (peritoneal and kidney) spKt/V urea of at least 1.8/wk for PD; target spKt/V of 1.4 per dialysis not including RKF, or URR of 70% for HD given 3 times per week (79) | Monitoring and preservation of RKF is very important; prescription of higher dialysis dosages and higher protein intake at 1.8 to 2.0 g/kg/day is indicated in younger dialysis patients may be important (79) |
| Proteinuria             | Presence of proteinuria | 24-h urinary protein excretion as part of RKF measurement | Reduction of proteinuria with ACEI, ARB | Caution at Hb levels >12.5 g/dl would seem warranted in the dialysis population in light of recently published CREATE (83) and CHOIR (85) trials |
| Anemia                  | Presence of anemia, iron deficiency, hyposensitivity to ESA | Assessment of red blood cell indices (Hb) monthly and iron status (TSAT, ferritin) every 1 to 3 mo or after significant clinical change (78) | Treatment with ESA and iron supplementation to target Hb 11 to 13 g/dl, TSAT 20 to 50%, and ferritin 100 to 500 ng/ml (80) | No comparable randomized trials conducted yet, is there an indication for ESA use? (74) |
| Impaired calcium-phosphorus metabolism | Hypercalcemia, hyperphosphatemia, elevated calcium-phosphorus product, secondary hyperparathyroidism | Measurement of serum levels of calcium, phosphorus, ALP, and iPTH and calculation of calcium-phosphorus product as part of regular monthly blood work | Maintenance of normal levels of calcium and phosphate and their product of ≤55 mg²/dl² and prevention/treatment of secondary hyperparathyroidism with judicious use of phosphate binders and vitamin D (27) | Introduction of non-calcium-containing phosphate binders might decrease the burden of vascular calcification |
| Impaired glucose metabolism | Presence of hyperglycemia, development of diabetes | Fasting blood glucose measurement as part of regular monthly blood work; OGTT, HbA1c, if fasting glucose suggests impaired glucose metabolism | Minimizing exposure to glucose through PD and medications that are known to cause impaired glucose metabolism (glucocorticoids) to achieve normoglycemia | Small adult studies suggest beneficial affect of vitamin E supplementation (82) and vitamin E–modified dialyzers (83); no similar studies have been conducted in pediatric dialysis patients |
| Chronic inflammation     | Elevated levels of CRP; anemia of chronic disease; hyposensitivity to ESA | Consider CRP measurement as part of monthly blood work | Serum CRP levels ≤1 mg/L are considered low risk for cardiovascular disease; treatment with anti-inflammatory medications (aspirin) remains experimental | Normal homocysteine levels for general pediatric population are available (81); supplemental folate reduces but does not normalize homocysteine levels; RCT of folate use in pediatric dialysis patients have not been conducted |

| Hyperhomocysteinemia | Elevated levels of homocysteine; clinical evidence of thrombosis | Homocysteine and folate levels in serum; frequency of measurements uncertain | Folate supplementation, although still unproven in large studies, might be beneficial (86) | Folate supplementation, although still unproven in large studies, might be beneficial (86) |

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*ABPM, ambulatory BP monitoring; ACEI, angiotensin-converting enzyme inhibitor; ALP, alkaline phosphatase; ARB, angiotensin-receptor blocker; BMI, body mass index; CHOIR, Correction of Hemoglobin and Outcomes in Renal Insufficiency; CREATE, Cardiovascular Risk Reduction by Early Anemia Treatment with Epoetin β; CRP, C-reactive protein; ECHO, echocardiography; ESA, erythropoiesis-stimulating agent; Hb, hemoglobin; HbA1c, glycosylated hemoglobin; HD, hemodialysis; iPTH, intact parathyroid hormone; LVH, left ventricular hypertrophy; nPCR, normalized protein catabolic rate; OGTT, oral glucose tolerance test; PD, peritoneal dialysis; RCT, randomized, controlled trial; RKF, residual kidney function; RNI, recommended nutrient intake; spKt/V, single pool Kt/V; TG, triglycerides; TLC, therapeutic lifestyle changes; TSAT, transferring saturation; URR, urea reduction ratio.*
Table 4. Educational strategies for children who are on dialysis

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Potential Impact as Demonstrated at School</th>
<th>Suggested Remedial Strategies</th>
</tr>
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<tbody>
<tr>
<td>Neurobehavioral symptoms (fatigue, lethargy, confusion, agitation, sleep disturbance, depression, decreased mental alertness)</td>
<td>Unable to complete full school day and/or heavy homework assignments; poorer results with test taking as evaluation method</td>
<td>Modified school day (e.g., fewer classes, shorter day, reduced work load) Alternative evaluation methods (e.g., summaries, projects, open-book) Behavioral strategies (e.g., teacher-parent log, behavioral incentives, multisensory teaching strategies, breaks when fatigued) Structured class environment, with reduced distractions, to facilitate attention (e.g., consistent routines/guidelines, quiet space, establish eye contact and physical proximity before giving instructions, ask child to repeat instructions) Increase social involvement with peers Support from school counselor (see Psychosocial section for more information) Psychoeducational or neuropsychological assessment to identify the disorder Development of an IEP focused on developing numeracy and literacy skills, daily living skills, and other identified deficits</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>Deficits in overall cognitive functioning (e.g., development of numeracy and literacy skills)</td>
<td>Development of an IEP focused on providing remedial education in reading, spelling, and/or mathematics (e.g., assistance with phonemic awareness and decoding; writing mechanics and planning skills; learning number facts and procedures)</td>
</tr>
<tr>
<td>Academic achievement reading</td>
<td>Deficits in adaptive functioning (e.g., daily living skills)</td>
<td>Read interesting, age-appropriate text; instruction in active reading and comprehension strategies (e.g., recognize main ideas, cause and effect, story telling)</td>
</tr>
<tr>
<td>Writing</td>
<td>Difficulty decoding; poor proficiency</td>
<td>Direct instruction; modeling and practice in spelling, grammar, writing mechanics, and planning; provide outlines, completed work as examples; clear and reasonable expectations Psychoeducational or neuropsychological assessment to identify specific cognitive deficits and impact on achievement Development of an IEP, focused on providing remedial education in reading, spelling, and/or mathematics (e.g., assistance with phonemic awareness and decoding; writing mechanics and planning skills; learning number facts and procedures)</td>
</tr>
<tr>
<td>Visual-spatial and visual-motor ability</td>
<td>Manipulating and perceiving spatial relationships; interpreting part-to-whole relationships; understanding concepts of time, space, quantity, and directionality Using vision to reproduce and coordinate movements (e.g., eye-hand coordination, clumsy, slow movements)</td>
<td>Instructions should be short, concrete, repetitive, structured, and multisensory Visual information should be combined with verbal explanations (e.g., verbal recipe cards, modeling, concrete manipulatives) Assistance with visual learning (e.g., part-whole relationships, visual recognition tasks, visual categorization) De-emphasize hand-written work (i.e., adjustments in rate, volume, complexity, tools, and format for writing assignments) Assistance with visual-motor tasks (e.g., folding, cutting) Visual-motor exercises; occupational therapy (e.g., tracing, matching) IEP includes accommodations and remedial assistance in mathematics and writing.</td>
</tr>
<tr>
<td>Visual, verbal, and working memory</td>
<td>Difficulty with the learning and acquisition of new skills Problems holding information in memory (e.g., remembering telephone number, following multi-step instructions) May appear inattentive and exhibit poor self-monitoring skills</td>
<td>Learning should be broken down into small, manageable chunks Overlearning (e.g., repetitively review, practice) of newly developed skills to assist with consolidation and storage of information Use mnemonic strategies (e.g., repetition, imagery, patterns) and visual outlining techniques (e.g., graphs, charts, word maps) to aid retention Use concrete aids to assist with learning (e.g., lists, open-book assignments) Emphasize structure/routine in the classroom; use visual and cognitive cues (e.g., daily schedule, mnemonics); teach time/space management and organization (e.g., lists, alarmed watch, study space, managing materials) Teach step-by-step problem solving for completing schoolwork (e.g., models of completed projects, plan ahead, develop schedules and to-do lists, chunk large projects into smaller tasks, use an organizer) Teach study and test-taking skills (e.g., organizing time during a test) Promote self-monitoring and positive coping strategies (e.g., gauging progress, reevaluating goals, providing feedback and verbal encouragement, coping with setbacks)</td>
</tr>
</tbody>
</table>

*IEP, Individualized Education Program.*
who are on dialysis. Stefanidis and Klaus (53) discussed the issue of growth in prepubertal children who are on dialysis, and a recent Cochrane Review by Vimalachandra et al. (54) reviewed the current evidence in support of growth hormone use for improvement in final height in the pediatric CKD population.

Socialization and Sexuality
Adolescence is a period in life when sense of self is formed (55), both individually and through time spent with and from support offered by peers (56). Chronic illness seems to be a limiting factor in childhood activity and socialization and within the school setting (57). Many children who are on dialysis enter puberty later than age peers (58). This along with decreased participation in peer and school activities as a result of cognitive limitations (41), illness (30), and potentially a sense of vulnerability regarding their own health may discourage the “normal” risk-taking behavior of adolescence (59) and in turn lead to being labeled as “different” and contribute to a sense of isolation from their peer group (60). Fewer friends along with lower self-esteem (described in hemodialysis patients) (61) are a negative impact on their psychosexual development as evidenced by data showing a later age at having a first girlfriend/boyfriend, falling in love, and sexual intimacy or intercourse when compared with a reference group (59).

Transition to Adult Care
In the past 25 yr, care for children with CKD, in particular for those who require dialysis and kidney transplantation, has dramatically changed. Children who have CKD and are on dialysis and those who receive kidney transplants are reaching adulthood and graduating from their pediatric care programs. This transition into the “adult world” brings with it many issues, barriers, and difficulties.

Children with special health care needs, including CKD, are defined by being at increased risk for a chronic physical, developmental, behavioral, or emotional condition and requiring health and related services of a type or amount beyond that required by children generally (62). They currently represent approximately 9 million children in the United States and so constitute an important focus for health care provision (63). It is estimated that 500,000 of them will require transition to adult care per year in the United States and 50,000 per year in Canada (64,65).

Although the need is apparent, very little published research is available on pediatric renal transition to adult care programs. The fundamental guiding principles of an effective transition program must include comprehensive, coordinated, and uninterrupted health care that is age and developmentally appropriate along with promotion of skills in communication, decision making, assertiveness, and self-care and fostering a sense of control and independence of health care.

That this is not being achieved in children with CKD is evidenced by a number of reports. Between 2000 and 2003, the National Health Survey of Children with Special Health Care Needs determined that among 5500 adolescents and young adults who were identified as being in need of transition, only half had discussed the issue of changing health care needs with their physician, a little more than half had a plan to address these needs, and fewer than half of this last group had discussed these plans with their doctor (63). Similarly, in a cohort of 360 patients who were aged 19 to 21 and had a history of congenital heart disease, only 47% had successfully made the transition to appropriate specialist care in an adult program, despite recognition of the medical need (61).

Stam et al. (38) administered a Course of Life Questionnaire to more than 1100 adults who were aged 18 to 30 and were classified as having had a chronic childhood disease, including survivors of childhood cancer, gastrointestinal surgery, and ESRD. The validated questionnaire retrospectively assessed the achievement of developmental milestones, including autonomy, psychosexual and social development, and risk behavior, compared with age-matched control subjects. The young adults with chronic childhood disease either achieved significantly fewer milestones or achieved them at an older age than their peers in all course-of-life domains. Alarmingly, young adults with childhood ESRD were the most delayed, compared even with survivors of childhood cancer. Other investigators have illustrated similar compromised psychosocial outcomes of young adults who transferred to adult care programs, including delayed independence and autonomy (37,66), compromised education and employment (66), and debilitating medical outcomes such as accelerated renal allograft loss within 36 mo of transfer (67) seemingly as a result of nonadherence (68).

Although a number of well-designed transition curricula have been developed and published, such as the On-Trac program at the British Columbia Children’s Hospital (Figure 1) (69), a recurring obstacle to the development and implementation of such programs seems to be health care funding constraints. Given their issues around neurocognitive development, dependence, autonomy, and multiple and complex medical needs, among others, the youth who has CKD or is on dialysis requires a stepwise transition clinic that begins sufficiently early (i.e., young age) to enable success. Success itself must be documented by objective evidence of mastery of age- and developmentally appropriate goals as is done with the On-Trac program (69). Clearly, any such clinic needs experienced health care providers from multiple disciplines, including pediatric nursing, nephrology, social work, psychology, clinical pharmacy, and adolescent health.

Although potentially beneficial for such a youth, this model is resource-intensive and not immediately cost-efficient, at least

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**Table 5. Educational checklist for children who are on dialysis**

1. Ensure normal hearing and vision.
2. Consider IQ testing.
3. Psychoeducational evaluation; if not available, then consider screening assessment.
4. Target learning strengths and weaknesses based on points 1 to 3.
5. Ensure that adequacy targets are being met; treat anemia, hypertension, and malnutrition aggressively because all can have an impact on school functioning.

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not during the years when the patient is enrolled in the pediatric program. Solutions for the implementation of such programs start with increasing awareness among caregivers, nephrologists, families, and hospital and health policy administrators that such programs of transition for the youth with CKD are beneficial and potentially cost-effective in the long term. Standardized and well-staffed transition clinics for youths with CKD or ESRD should be viewed as interventions, and their effects on long-term outcomes, both patient and economic, should be studied as proof-of-principle initiatives.

Economic and Vocational Status

Unemployment and poor-paying jobs as a result of poor educational achievement are common in adults who survived childhood dialysis or transplantation (66,70). Although unemployment rates have varied across studies and among countries, most are in the realm of 15 to 25% (22,71,72), although one report placed it as high as 65%, depending on dialysis status and comorbidities (73). Children with ESRD are less likely to have a paid job during high school (59), and if on dialysis for >8 yr, then they have a 10-fold higher likelihood of being in a low-paying vocational job as an adult when compared with the normal population (32).

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Disclosures

None.

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