



Psychosocial considerations and recommendations for care of pediatric patients on dialysis

Michelle A. Clementi¹ · Cortney Taylor Zimmerman²

Received: 4 January 2019 / Revised: 22 February 2019 / Accepted: 5 March 2019 / Published online: 20 March 2019
© IPNA 2019

Abstract

Dialysis treatment has evolved to enable children to live longer and transition to adulthood. Thus, the focus of care shifts to a consideration of pediatric patients' quality of life and psychosocial functioning across childhood, adolescence, and young adulthood. Despite well-documented concerns in various domains (including depression/anxiety, self-esteem and social functioning, behavior problems, and academic and cognitive functioning), limited literature exists regarding psychosocial guidelines for children and adolescents undergoing dialysis. This article aims to address this gap by providing a review of the pediatric literature examining psychosocial functioning in patients treated with dialysis, as well as recommendations for specific psychosocial concerns. Overall recommendations for care include screening for anxiety and depression, referral to pediatric psychologists for evidence-based intervention, utilization of child life specialists, opportunities to promote social functioning, neuropsychological evaluation and school programming, ongoing support in preparing for transition to adult care, and periodic measure of quality of life. Together, these suggestions promote a holistic approach to patient-centered care by supporting both physical and psychosocial well-being.

Keywords Psychosocial · Quality of life · Dialysis · Chronic kidney disease · End-stage renal disease · Pediatric

Introduction

Chronic kidney disease (CKD) is marked by severely impaired quality of life for children and caregivers alike, with the chronicity of the disease often resulting in considerable distress regardless of disease stage or treatment modality [1, 2]. Significant medical advances, however, have allowed for dialysis to become a life-saving treatment option for patients with end-stage renal disease (ESRD) since its inception in 1943. Dialysis in children has greatly improved over the past 20 years, particularly with the introduction of guidelines for pediatric dialysis management [3]. Now that children are living longer with dialysis, the focus shifts to a question of whether

children are “living well” (i.e., quality of life), and how to assist patients and families contending with rigorous medical regimens associated with dialysis. A systematic review of qualitative studies examining lived experiences of children on dialysis identified five common themes, including *loss of control* (e.g., reliance on caregivers), *restricted life* (e.g., limited socialization opportunities, struggle with academic performance), *managing treatment* (e.g., adherence), *coping strategies* (e.g., social support, denial), and *feeling different* (e.g., abnormal physical appearance) [4]. Given these significant challenges in a range of psychosocial domains, a proactive approach in identifying and assisting patients and families in need of psychosocial support is essential. Pediatric patients experience worse emotional functioning the longer they are treated with dialysis [5], and adults treated with dialysis in childhood and/or adolescence indicate that psychosocial difficulties originating in childhood were maintained or escalated as they entered adulthood [6]. Thus, early identification of psychosocial concerns could potentially prevent later difficulties for this particularly vulnerable population.

Although previous reviews have explored psychosocial concerns in pediatric patients with ESRD in general [7], it is important to specifically address the unique experiences and

✉ Michelle A. Clementi
michelleaclementi@gmail.com

¹ Department of Psychiatry, Boston Children's Hospital/Harvard Medical School, 333 Longwood Ave, Boston, MA 02115, USA

² Department of Pediatrics, Psychology Section, Baylor College of Medicine/Texas Children's Hospital, 1102 Bates Ave., Ste. 245, Houston, TX 77030, USA

needs of pediatric patients on dialysis. Given that children on dialysis endure poorer quality of life, including lower psychosocial health and emotional functioning, compared with ESRD patients with renal transplant [8–10], it is imperative that psychosocial well-being is considered specifically within this population. Guidelines for psychological management of adult patients with CKD have been explored [11], but published guidelines for psychological care of children on dialysis are extremely limited. Thus, this article aims to review psychosocial research pertaining to children on dialysis, as well as highlight important considerations and provide suggestions for psychological management in this population.

Internalizing problems

Internalizing problems (i.e., anxiety and depression) are prevalent among pediatric patients undergoing dialysis, with studies suggesting high rates of depressive and anxious symptomatology [12–16]. Significantly greater depression and anxiety symptoms have been reported in pediatric patients on dialysis compared with healthy controls and children with pre-dialysis CKD [17–20]. Risk for clinical depression is especially high for female adolescents treated with dialysis [12]. In a study of pediatric patients on dialysis (ages 9–15) meeting criteria for a psychiatric disorder, nearly half were diagnosed with depression or adjustment disorder with depression [13]. Interestingly, though, one study found that children and adolescents on dialysis were less likely to be depressed than patients with earlier stages of CKD [21]. Nonetheless, risk for depression has become such a concern that beginning in 2016, the Centers for Medicare and Medicaid Services mandated depression screening for pediatric patients on dialysis as part of its Quality Incentive Program [22].

Pediatric patients treated with dialysis also experience increased worry and separation anxiety, particularly persistent avoidance of being alone [18, 23, 24]. Internalizing symptoms in this population may be attributable to disease- and treatment-related adjustment difficulties, health-related fears, and high reliance on caregivers and medical regimens. Interestingly, anxiety, but not depression, is higher in pediatric patients on dialysis compared with patients with a functioning renal transplant [23–25]. This may be partially attributable to continued worries/uncertainty regarding future transplantation among those dependent on dialysis.

Dialysis treatment modality and illness-related characteristics may also contribute to internalizing symptoms. Increased worry and depressive symptoms have been reported in patients receiving in-hospital hemodialysis more so than in patients receiving peritoneal dialysis at home [23, 25]. In terms of illness-related characteristics, increased functional impairment (e.g., fatigue, aches and pains, physical limitations) is associated with higher ratings of depression and anxiety

among pediatric and young adult patients on dialysis [15]. While functional impairment may impact poor adjustment in terms of depression and anxiety symptoms, it is also possible that depression and anxiety may result in poor treatment adherence and thus more functional impairment [15]. Limited research has examined the association between depression/anxiety and low treatment adherence in pediatric patients on dialysis [14, 26]. However, depressed mood is a well-established risk factor for noncompliance with medical treatment among adult patients on dialysis [27].

Recommendations for care

Given the extensive contact patients have with their medical teams, it is important that medical providers identify patients that may benefit from referrals for additional mental health services. Depression screening is an initial step in this direction, as it can help to identify children who are exhibiting clinically significant depressive symptoms and would benefit from treatment referrals. There are several validated depression screening measures for children and adolescents, such as the Pediatric Health Questionnaire-9 (PHQ-9) [28, 29] and the Children's Depression Inventory-2 (CDI-2) [30]. There are also measures for pediatric anxiety, including the Screen for Child Anxiety Related Emotional Disorders (SCARED) [31]. Even for providers not trained specifically in mental health, it is important that the entire medical team is educated and cognizant of the symptoms of depression and anxiety in children and adolescents (e.g., persistent sadness, inability to find pleasure in previously enjoyed activities) in order to be able to refer for treatment. This may be addressed by educational seminars built into team meetings by psychologists and/or social workers at the hospital to review signs and symptoms of clinically significant depression/anxiety and interpretation of psychological screening tools.

Management of “in the moment” coping strategies (e.g., procedural anxiety), normalization and validation, and psychoeducation are often appropriate in the context of a referral to a Child Life specialist on the medical team. More complex psychological management of symptoms of anxiety and depression in this population is quite challenging and best addressed by a pediatric psychologist. Evidence-based treatments for various internalizing disorders can also be utilized in this population: cognitive-behavioral therapy [32], acceptance and commitment therapy [33], and interpersonal therapy [34] are all potential applicable modalities. As with any patient with a chronic illness, often patients' distressing cognitions are rooted in actual potential outcomes (i.e., illness, end of life). Thus, the patient must be taught coping strategies within a context of knowing that there is a possibility of negative medical outcomes. Because few community mental health providers are trained in this area, it is often most appropriate that patients work with a pediatric health psychologist or

medical clinical social worker. If this is not possible, it is highly recommended that the community mental health provider consult with a member of the medical team, pending permission from the family, to gain a better understanding of the psychosocial concerns within the medical context.

Self-esteem and social functioning

Pediatric patients on dialysis report lower self-esteem compared with healthy youth [16]. Middle childhood and adolescence are developmental periods when children begin to be more self-focused and any differences or ways they “stand out” from others can be seen as negative. Children treated with dialysis often feel different from their peers due to physical differences associated with ESRD, such as growth retardation, skeletal deformities, and delayed development of secondary sex characteristics [4]. They may also feel self-conscious of visible scars or medical tubes protruding from their bodies. Female pediatric patients on dialysis report significantly more concerns about physical appearance, and endorse poorer emotional functioning than males [5].

In addition to the physical aspects related to self-esteem, impairments in a child’s social functioning may also contribute to feelings of low self-esteem. They may experience limitations to social activities, such as restricted sports participation, or missing events due to a demanding treatment regimen on dialysis [4]. Children on dialysis often report experiencing difficulties with their peers/friends (e.g., getting along with others, being teased, difficulty keeping up with peers), noting the negative impact their medical condition/treatment has on social events and hobbies [4, 16]. Notably, youth treated with dialysis report higher levels of social impairment compared with children with a functioning transplant [25], children with CKD treated conservatively [35], and healthy children [16, 36], and this social impairment may impact future quality of life in young adulthood [6]. For example, a longitudinal study indicated patients with onset of ESRD before age 15 had significantly delayed autonomy and social development (e.g., social contacts with peers, romantic relationships) as young adults [6]. Furthermore, those who achieved fewer social milestones while growing up experienced more emotional problems in young adulthood [6].

Recommendations for care

Providers can normalize patients’ experiences and decrease feelings of isolation by connecting families with any known support groups. Connecting with other families of children on dialysis can also highlight to patients that they are not isolated. Specifically, children may benefit from engagement in activities with peers experiencing similar medical complications (e.g., attending kidney camp) to feel less like the “odd one

out” and learn from their peers’ experiences. A peer-to-peer support camp for children with ESRD (including some dialysis patients) has been shown to increase self-confidence and self-efficacy [37]. Camp participants also reported feeling more capable of standing up for themselves and being open with their peers after attending camp [37]. Youth leadership and mentoring programs may also facilitate social development and promote pathways to positive adult outcomes by emphasizing autonomous life skills and developing confidence, compassion, and social connection [38]. Such programs require more rigorous evaluation to fully understand outcomes but have generally demonstrated increased self-efficacy, satisfaction, and well-being among youth with chronic medical conditions [38].

Furthermore, if patients endure low self-esteem due in part to significant teasing, or bullying, providers may strongly consider facilitation of discussion with the school and parents regarding how to navigate those circumstances, as well as a referral to a mental health provider. Psychologists and clinical social workers can utilize strengths-based approaches to improve self-esteem, as well as help patients build problem-solving skills and other strategies to manage bullying and teasing.

Behavior problems

A potential manifestation of poor adjustment to diagnosis and treatment is behavior problems in children and adolescents. Mixed findings exist regarding whether patients on dialysis exhibit significantly more behavior problems than pre-dialysis patients [19, 25]. Nonetheless, approximately one-quarter of pediatric patients on dialysis exhibit clinically significant externalizing problems [19]. These problems may differ based on the modality of dialysis treatment. For instance, one study found higher rates of behavior problems among children receiving hospital-based dialysis compared with dialysis in the home [25]. In an open dialysis unit with many chairs, a tantrum or other externalizing behavior can be quite challenging for a family and team to manage. Further, increased child behavior problems are associated with lack of social support for the family [15], highlighting the need for parental support in response to behavior problems associated with medical care.

Recommendations for care

There are multiple evidence-based strategies for management of behavior concerns. For young children especially, utilization of Child Life services can be helpful for addressing behavioral concerns occurring on the dialysis unit (e.g., by providing distraction and/or rewards for desired behavior). A psychologist trained to deliver evidence-based behavior

management interventions, such as Parent Management Training [39], can be utilized in hospital settings, although modifications will be required. In these settings, the medical staff are caregivers, as well as the parents. Thus, all providers need to be clear in setting boundaries in their expectations, limitations, and consequences. Behavior management strategies should be given to the family, as well as the medical providers, as many of the concerning behaviors are likely to manifest in the time spent on dialysis. Consistency among providers becomes paramount. Reward system utilization (e.g., checklist of steps for being accessed and beginning dialysis, with a reward such as tablet time contingent on completion of the required steps) is also recommended as appropriate. This requires education to parents and all members of the medical team involved in the child's care.

Of note, poor adherence to treatment regimens is often attributed to oppositional or defiant behavior, particularly in adolescents. Although this is often frustrating for providers, it is important to recognize that poor adherence may be a reflection of numerous challenges, including “burn out” of medical management, developmentally expected efforts to establish autonomy, depression, and even passive suicidal ideation [26, 27]. Involvement from a psychologist is important to help validate the patient's experiences and to collaborate with parents and the medical team in utilizing developmentally appropriate reward systems and behavior management strategies in conjunction with Motivational Interviewing to facilitate treatment adherence [40].

Academic and cognitive functioning

Children treated with dialysis and their parents consistently report impairments in school adjustment and functioning. Frequent absences from school and school-related events often occur due to dialysis treatments, unexpected health problems, hospitalizations, clinic appointments, and reluctance or refusal to go to school [4, 18, 24]. Pediatric patients on dialysis may lose up to 60% of their school contact time [7, 36]. Findings consistently demonstrate greater school maladjustment in patients treated with dialysis compared with healthy controls [10, 16, 24, 36]. Some evidence also suggests poorer school functioning in patients on dialysis compared with those with renal transplant [8].

Frequent school absenteeism and maladjustment (such as keeping up with schoolwork) may contribute to poor academic achievement and increased risk for grade retention [41]. Parents report that academic problems for pediatric patients on dialysis increase over time [5]. Strikingly, in a sample of patients on dialysis compared with those with renal transplants, all patients on dialysis performed below grade level, while all of those with transplants performed at or above grade level [42]. Notably, the two groups did not differ in terms of

days absent from school [42], thus suggesting that other aspects of dialysis treatment may impact school performance beyond simply falling behind in exposure to the material.

While some deficits may result from missed school, other deficits may be due to impaired neuropsychological and central nervous system development. Extensive research has documented high rates of cognitive impairments in children on dialysis [43] and greater intellectual deficits in children with CKD compared with healthy controls, including sibling controls [41, 44–46]. Additionally, deficits in memory have been identified among pediatric patients with CKD [44, 46, 47], particularly those with congenital ESRD compared with those with acquired ESRD [48]. Poorer renal function and longer duration of renal failure are associated with increased intellectual, academic, and memory impairment [41, 45, 49–53].

Limited work has examined cognitive outcomes for patients on dialysis, specifically. However, one study compared children on dialysis with children with pre-dialysis CKD and healthy controls and found that patients treated with dialysis had lower mean scores on Verbal, Performance, and Full Scale IQ [54]. Furthermore, higher documented rates of attention-deficit/hyperactivity disorder (ADHD) among pediatric patients on dialysis compared with healthy controls may imply impairments in executive functioning in patients on dialysis [55]. Among pediatric patients with ESRD, however, cognitive functioning did not differ based on treatment modality (i.e., transplant versus dialysis); this implies that factors associated with ESRD, not dialysis or transplant specifically, are associated with increased risk in cognitive functioning [45].

Recommendations for care

Providers should be cognizant of the general deficits in academic performance and cognitive functioning for pediatric patients on dialysis. Given the established academic impact and cognitive concerns for these patients, a referral for a neuropsychological evaluation is indicated in many, if not all, cases. Neuropsychological evaluation can provide an understanding of a patient's cognitive strengths and weaknesses, taking into consideration their medical diagnosis and treatment. This information can inform medical education and treatment, preparation for transition to adult care, and psychological intervention, in addition to providing guidance to foster the patient's strengths within the academic setting.

Furthermore, most pediatric patients treated with dialysis benefit from having a formal school accommodation plan to ensure equal access to a learning environment that promotes academic success in the context of additional challenges that medically healthy students do not face. Providers and caregivers alike should be informed of the potential legal rights/protections for children with disabilities (including complex medical needs) within an educational setting. For example, in the USA, children treated with dialysis may be entitled to a

Section 504 plan and/or an Individualized Education Plan (IEP) depending on specific learning challenges and educational needs. A Section 504 plan is supported by a civil rights statute that provides services and/or changes to the learning environment to meet the needs of a child as adequately as other students. Additionally, an IEP in the USA is supported by a federal special education law that requires specialized instruction to meet the unique needs of a child who may not be able to learn/benefit from general education. Some Canadian provinces/territories (e.g., Ontario, British Columbia) also have legislation entitling children with certain special needs to an IEP. Information about special education systems in specific European countries is available through the European Agency for Special Needs and Inclusive Education, an independent organization that works to help countries improve their inclusive policy and practice in education [56]. Having an individual on the patient's care team who is familiar with the often complex laws, regulations, and systems associated with educational services in their home country is ideal for informing and empowering caregivers to advocate for their child's educational experience.

Specific potential accommodations for students treated with dialysis may include modified gym class, extra time between classes to avoid crowded hallways, reduced workload, additional tutoring, and permission to put their head on the desk if feeling fatigued. Caregivers may contact the school to request a meeting to discuss accommodations or modifications for the school setting. The results of neuropsychological testing can also be utilized to inform potential school accommodations and set the patient on a positive academic trajectory. Furthermore, medical teams and schools can work together to best arrange dialysis scheduling. Adolescent patients may prefer peritoneal dialysis so that they miss less school; for those on hemodialysis, shifts that can minimize school absences are ideal. Relatedly, adjusting daily school schedules to avoid missing core academic classes for dialysis treatment can promote opportunity for instruction in the classroom. Teamwork and collaboration across the medical and educational settings are paramount for improved patient outcomes and may be enhanced by on-site educators in the dialysis unit.

Transition to adult healthcare

Transition is a planned process that occurs over time to prepare for and initiate transfer of care from pediatric to adult health care. Negotiating this process is generally considered challenging given the complex cognitive, emotional, and social changes associated with late adolescence and early adulthood. Transfer of care in young adulthood is generally marked by lapses in medical care and poor disease outcomes for all chronic illness populations [57]. Indeed, compared with pediatric patients, young adults on dialysis are less likely to

achieve the Kidney Disease Dialysis Outcome Quality Initiative recommendations and target values established by the National Kidney Foundation [58]. This may be due in part to difficulty adjusting to aspects of independent adult life and/or psychological distress, both of which can impact medical adherence [57]. Studies have shown that adults with ESRD in childhood report decreased autonomy and vocational attainment compared with healthy controls [59]. Furthermore, compared with young adults with ESRD presenting in adulthood, those with ESRD presenting in childhood were less likely to be living independently or with a partner, less likely to have full or part-time paid work, and have lower educational attainment [51, 60]. Common concerns regarding transition of ESRD patients include patient fears about assuming more responsibility, the unknowns of the adult healthcare system, concerns regarding the competency of adult healthcare providers in dealing with congenital illness, and parent and pediatric providers' worries of relinquishing responsibility [61].

Limited research has systematically examined transition programs for patients with ESRD and of those that have, the vast majority have focused on renal transplant patients [61]. The only study that has examined transition programs specifically for pediatric patients on dialysis found that only one-third of pediatric dialysis centers across North American and Europe had a formal transition program [62]. Of note, however, this number has likely increased given the attention placed on the importance of transition planning since the time of the study.

Recommendations for care

Guidelines informing transition to adult care have been established by the International Society of Nephrology/International Pediatric Nephrology Association (ISN/IPNA), which deems it "essential" that transfer of care occurs only after efforts have been made to assess and prepare patients for transfer and is based as much as possible on individual educational, social, and psychological attainment [63]. Furthermore, transfer itself should take place in a period without crises and with appropriate social support [63].

Transition planning is particularly important for patients on dialysis since the time-consuming nature of dialysis often closely ties adolescents to their parents and hospital staff, which may hinder autonomy and self-advocacy. Transition programming is best delivered by a multidisciplinary team of providers, including pediatric and adult nephrologists, nurses, psychologists, social workers, dieticians, and other clinicians/staff. For some, transitioning to an adult dialysis clinic can be particularly difficult given the significant age discrepancy between the young adult and the majority of the other patients. Thus, the opportunity to informally visit adult clinics before official transfer of care may be helpful. Information about insurance and financial support is also paramount at this time, as

the ISN/IPNA guidelines specifically state that the transfer should not take place without adequate consideration and preparation of financial responsibilities [63].

Formal transition programs are resource intensive, but if established as a team priority, all providers can work together to facilitate adolescent/young adult patients' active engagement in their own care and help patients regularly set small, manageable goals toward self-management. For example, patients may be encouraged to have a portion of their appointments alone (without a parent present), fill their own prescriptions, schedule their own appointments, and independently contact the medical team when questions arise. Taking ownership of these responsibilities while still having their parent as a "back up" can help prepare for the eventual transfer to adult care.

Various tools are available for assessing transition readiness in adolescents with chronic illness [64]. Though no measures are specific for dialysis patients, the UNC TR(x)ANSITION scale [65] and the Transition Readiness Assessment Questionnaire (TRAQ) [66] are both well-validated measures for youth with chronic illness and may be appropriate for adolescent dialysis patients. Transition readiness should also be assessed with consideration of cognitive abilities. Collaboration with pediatric psychologists and other professionals familiar with the unique developmental, cognitive, and psychosocial needs of developmentally delayed young adults is imperative [67]. Ideally, patients would undergo neuropsychological evaluation to elucidate individual strengths and challenges to inform expectations for autonomy based on developmental level and to identify appropriate services. Without proper consultation, providers run the risk of overestimating or underestimating the patient's cognitive abilities—both of which would be detrimental to the patient's health and self-efficacy.

Review and conclusions

Dialysis treatment has evolved to enable children to live longer and transition to adulthood. However, the question of whether children are "living well" remains crucial and highlights the core of a patient-centered care model. This article reviews multiple domains that impacted children on dialysis and provides suggestions within each domain. Existing research has demonstrated that depression, anxiety, and behavior problems are prevalent among pediatric dialysis patients, and self-esteem and social functioning are lower compared with healthy counterparts. Pediatric dialysis patients also commonly experience numerous impairments in academic (e.g., school absences, poor grades) and cognitive (e.g., IQ, memory) functioning. Finally, adolescent and young adult patients face with unique challenges during the transition period.

Given the multiple areas of impacted functioning, it is crucial to consider the identification of patients who need

more intensive supports. Universal screening is a potential option for helping appropriately triage patients to the appropriate level of care. Quality of life (QOL) can be screened by various members of the medical team (psychologists, social workers). The Pediatric Quality of Life Inventory™ is a well-utilized tool for measuring and monitoring QOL and has a generic survey (PedsQL 4.0) [68], as well as an ESRD-specific module (PedsQL ESRD Module 3.0) [69] to be completed by patients and/or their primary caregivers. Currently, measurement of QOL is mandated in dialysis units due in part to research demonstrating that QOL is lower in children receiving long-term dialysis compared with most other chronic medical conditions [8]. Annual measurement of QOL can lead to identification of lower domains of QOL, as well as negative changes over time, and highlight areas for potential suggested intervention.

Prior to initiation of dialysis, ideally, every patient would undergo psychosocial screening, as well as neuropsychological testing to provide a baseline for later comparison, and highlight potential areas for intervention which could impact patient outcomes. Following this initial step, patients could then be triaged depending upon individual need. Patients with significant psychosocial concerns in any domain could be referred for psychological intervention. Evidence-based treatment modalities typically used for various psychological concerns are appropriate, but require modification given the complexities of the medical environment and increased number of caregivers (i.e., the medical team). For all school-aged and adolescent patients, periodic screening for depression and anxiety should be ongoing. With regard to school, families may utilize their child's neuropsychology report to inform appropriate school accommodations. Finally, adolescents and young adults should be encouraged by all medical team members to gradually increase independence in their care and have pointed discussions about planning for the transfer of care in young adulthood.

Understandably, not all dialysis units have access to resources to provide all of the services listed above. However, the current review calls for the importance of multidisciplinary care and may serve as support for providers to request additional resources to fully address the psychosocial functioning of their patients. This review also calls for additional research across many overlooked issues faced by children treated with dialysis. For example, studies examining the precise nature of cognitive impairments associated with CKD and prolonged dialysis is imperative for identifying potential prevention and/or treatment targets. As the field continues to systematically explore these issues, clinical providers are encouraged to be cognizant of patients' psychosocial well-being and regularly discuss the importance of this with patients, families, and other providers to promote optimal quality of life and psychological and medical outcomes for pediatric patients on dialysis.

Key summary points

1. Chronic kidney disease is marked by severely impaired quality of life for children and caregivers alike, and children on dialysis endure poor quality of life, including low psychosocial health and emotional functioning.
2. Pediatric patients on dialysis also face considerable psychosocial challenges, some of which are unique to the dialysis treatment modality (e.g., severely affected school functioning due to lengthy dialysis sessions) and others that more generally affect patients with CKD and/or other chronic conditions (e.g., poor emotional functioning, peer difficulties).
3. These challenges are crucial to address because in addition to poor psychosocial outcomes there is evidence that psychosocial issues can also negatively impact medical outcomes.
4. In order to comprehensively address the needs of pediatric patients treated with dialysis, patient care teams are encouraged to regularly screen for psychological concerns, enlist support from psychosocial providers (psychologists, social workers, child life specialists), closely attend to cognitive/academic and social concerns, and incorporate transition planning efforts throughout adolescence and young adulthood.
5. This review calls for the need for additional resources for patient care teams to address the psychosocial needs of patients and families, in addition to further research dedicated to psychosocial issues faced by pediatric dialysis patients.

Multiple choice questions (answers follow references)

1. Which of these statements regarding depression is most accurate?
 - a. Greater depression and anxiety has been documented for patients on dialysis compared with those with pre-dialysis CKD and healthy controls.
 - b. Adolescent males are at greater risk of developing depression than females.
 - c. The Centers for Medicare and Medicaid Services (CMS) mandates depression screening for pediatric patients on dialysis.
 - d. Dialysis has not been associated with an increased risk for depression.
 - e. Both A and C
2. Which of these statements regarding academic performance and cognitive functioning is FALSE?
 - a. Patients on dialysis often experience absences due to dialysis treatment, hospitalizations, and health problems.
 - b. Parents report that academic problems for pediatric dialysis patients increase over time.
 - c. Patients on dialysis tend to perform well above transplant patients on all academic tasks.
 - d. Children with CKD often have higher intellectual and memory deficits than healthy controls.
 - e. Rates of ADHD are higher for pediatric dialysis patients compared with healthy controls.

3. A neuropsychological evaluation can inform:
 - a. Transition planning
 - b. Medical education approach
 - c. School accommodations
 - d. Psychological intervention
 - e. All of the above
4. Transfer to adult care is associated with:
 - a. Assurance that all adult providers are competent in working with patients with congenital issues.
 - b. Poor disease outcomes
 - c. Continued medical coverage with no lapses
 - d. Improved disease outcomes
 - e. No insurance concerns
5. Ideal recommendations for psychosocial care of pediatric patients on dialysis include:
 - a. Psychosocial screening and triage of all patients
 - b. Neuropsychological testing
 - c. Annual depression screening
 - d. Regular QOL assessment
 - e. All of the above

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Funding No funding to report.

References

1. Splinter A, Tjaden LA, Hayerman L, Adams B, Collard L, Cransberg K, van Dyck M, Van Hoeck KJ, Hoppe B, Koster-Kamphuis L, Lilien MR, Raes A, Taylan C, Grootenhuis MA, Groothoff JW (2018) Children on dialysis as well as renal transplanted children report severely impaired health-related quality of life. *Qual Life Res* 27:1445–1454
2. Wiedebusch S, Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, Muthny F (2010) Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. *Pediatr Nephrol* 25:1477–1485

3. Fischbach M, Edefonti A, Schröder C, Watson A, European Pediatric Dialysis Working Group (2005) Hemodialysis in children: general practical guidelines. *Pediatr Nephrol* 20:1054–1066
4. Tjaden L, Tong A, Henning P, Groothoff J, Craig JC (2012) Children's experiences of dialysis: a systematic review of qualitative studies. *Arch Dis Child* 97:395–402
5. Neul SK, Minard CG, Currier H, Goldstein SL (2013) Health-related quality of life functioning over a 2-year period in children with end-stage renal disease. *Pediatr Nephrol* 28:285–293
6. Grootenhuys MA, Stam H, Last BF, Groothoff JW (2006) The impact of delayed development on the quality of life of adults with end-stage renal disease since childhood. *Pediatr Nephrol* 21:538–544
7. Watson AR (2014) Psychosocial support for children and families requiring renal replacement therapy. *Pediatr Nephrol* 29:1169–1174
8. Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW (2006) Health-related quality of life in pediatric patients with ESRD. *Pediatr Nephrol* 21:846–850
9. Goldstein SL, Rosburg NM, Warady BA, Seikaly M, McDonald R, Limbers C, Varni JW (2009) Pediatric end stage renal disease health-related quality of life differs by modality: a PedsQL ESRD analysis. *Pediatr Nephrol* 24:1553–1560
10. McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF (2006) Quality of life in children with chronic kidney disease—patient and caregiver assessments. *Nephrol Dial Transplant* 21:1899–1905
11. Indian Journal of Nephrology (2005) Guidelines for the psychological management of chronic kidney disease patients (for the psychologist). *Indian J Nephrol* 15:S103–S108
12. Hernandez EG, Loza R, Vargas H, Jara MF (2011) Depressive symptomatology in children and adolescents with chronic renal insufficiency undergoing chronic dialysis. *Int J Nephrol* 2011:1–7
13. Bakr A, Amr M, Sarhan A, Hammad A, Ragab M, El-Refaey A, El-Mougy A (2007) Psychiatric disorders in children with chronic renal failure. *Pediatr Nephrol* 22:128–131
14. Simoni JM, Asarnow JR, Munford PR, Koprowski CM, Belin TR, Salusky IB (1997) Psychological distress and treatment adherence among children on dialysis. *Pediatr Nephrol* 11:604–606
15. Fielding D, Brownbridge G (1999) Factors related to psychosocial adjustment in children with end-stage renal failure. *Pediatr Nephrol* 13:766–770
16. Buyan N, Türkmen MA, Bilge I, Baskin E, Haberal M, Bilginer Y, Mir S, Emre S, Akman S, Ozkaya O (2010) Quality of life in children with chronic kidney disease (with child and parent assessments). *Pediatr Nephrol* 25:1487–1496
17. Salam MMA, Abdo MA, Yousef UM, Mohamed SA (2014) Assessment of depression and anxiety in children on regular hemodialysis. *Egypt J Psychiatry* 35:100–104
18. Fukunishi I, Honda M, Kamiyama Y, Ito H (1993) Anxiety disorders and pediatric continuous ambulatory peritoneal dialysis. *Child Psychiatry Hum Dev* 24:59–64
19. Amr M, Bakr A, El Gilany AH, Hammad A, El-Refaey A, El-Mougy A (2009) Multi-method assessment of behavior adjustment in children with chronic kidney disease. *Pediatr Nephrol* 24:341–347
20. Garralda M, Jameson R, Reynolds J, Postlethwaite R (1988) Psychiatric adjustment in children with chronic renal failure. *J Child Psychol Psychiatry* 29:79–90
21. Kogon AJ, Vander Stoep A, Weiss NS, Smith J, Flynn JT, McCauley E (2013) Depression and its associated factors in pediatric chronic kidney disease. *Pediatr Nephrol* 28:1855–1861
22. Centers for Medicare & Medicaid Services (CMS), HHS (2015) Medicare program; end-stage renal disease prospective payment system, and quality incentive program. final rule. *Fed Regist* 80:68967–69077
23. Park K-S, Hwang YJ, Cho MH, Ko CW, Ha IS, Kang HG, Cheong HI, Park YS, Lee YJ, Lee JH (2012) Quality of life in children with end-stage renal disease based on a PedsQL ESRD module. *Pediatr Nephrol* 27:2293–2300
24. Fukunishi I, Kudo H (1995) Psychiatric problems of pediatric end-stage renal failure. *Gen Hosp Psychiatry* 17:32–36
25. Brownbridge G, Fielding DM (1991) Psychosocial adjustment to end-stage renal failure: comparing haemodialysis, continuous ambulatory peritoneal dialysis and transplantation. *Pediatr Nephrol* 5:612–616
26. Brownbridge G, Fielding DM (1994) Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatr Nephrol* 8:744–749
27. Clark S, Farrington K, Chilcot J (2014) Nonadherence in dialysis patients: prevalence, measurement, outcome, and psychological determinants. *Semin Dial* 27:42–49
28. Kroenke K, Spitzer RL, Williams JB (2001) The PHQ-9: validity of a brief depression severity measure. *Gen Intern Med* 16:606–613
29. Richardson LP, McCauley E, Grossman DC, McCarty CA, Richards J, Russo JE, Rockhill C, Katon W (2010) Evaluation of the patient health Questionnaire-9 item for detecting major depression among adolescents. *Pediatrics* 126:1117–1123
30. Kovacs M (2010) Children's depression inventory, 2nd edn. Multi-Health Systems, Inc., Toronto
31. Birmaher B, Brent DA, Chiappetta L, Bridge J, Monga S, Baugher M (1999) Psychometric properties of the screen for child anxiety related emotional disorders (SCARED): a replication study. *J Am Acad Child Adolesc Psychiatry* 38:1230–1236
32. Kendall PC (2012) Child and adolescent therapy: cognitive-behavioral procedures, 4th edn. Guilford Press, New York
33. Greco LA, Hayes SC (eds) (2008) Acceptance and mindfulness treatments for children and adolescents: A practitioner's guide. New Harbinger Publications, Oakland
34. Mufson L, Dorta KP, Moreau D, Weissman MM (2004) Interpersonal psychotherapy for depressed adolescents, 2nd edn. Guilford Press, New York
35. Kiliś-Pstrusińska K, Medyńska A, Chmielewska IB, Grenda R, Kluska-Jóźwiak A, Leszczyńska B, Niedomagała J, Olszak-Szot I, Miklaszewska M, Szczepańska M (2013) Perception of health-related quality of life in children with chronic kidney disease by the patients and their caregivers: multicentre national study results. *Qual Life Res* 22:2889–2897
36. Fukunishi I, Honda M, Kamiyama Y, Ito H (1993) Influence of mothers on school adjustment of continuous ambulatory peritoneal dialysis children. *Perit Dial Int* 13:232–235
37. Sattoe JN, Jedeloo S, van Staa A (2013) Effective peer-to-peer support for young people with end-stage renal disease: a mixed methods evaluation of camp COOL. *BMC Nephrol* 14:1–14
38. Maslow GR, Chung RJ (2013) Systematic review of positive youth development programs for adolescents with chronic illness. *Pediatrics* 131:1605–1618
39. Kazdin AE (2005) Parent management training: treatment for oppositional, aggressive, and antisocial behavior in children and adolescents. Oxford University Press, New York
40. Erickson SJ, Gerstle M, Feldstein SW (2005) Brief interventions and motivational interviewing with children, adolescents, and their parents in pediatric health care settings: a review. *Arch Pediatr Adolesc Med* 159:1173–1180
41. Duquette PJ, Hooper SR, Wetherington CE, Icard PF, Gipson DS (2007) Brief report: intellectual and academic functioning in pediatric chronic kidney disease. *J Pediatr Psychol* 32:1011–1017
42. Lawry KW, Brouhard BH, Cunningham RJ (1994) Cognitive functioning and school performance in children with renal failure. *Pediatr Nephrol* 8:326–329
43. Neu AM, Sander A, Borzych-Dużałka D, Watson AR, Vallés PG, Ha IS, Patel H, Askenazi D, Balasz-Chmielewska I, Lauronen J (2012) Comorbidities in chronic pediatric peritoneal dialysis

- patients: a report of the International Pediatric Peritoneal Dialysis Network. *Perit Dial Int* 32:410–418
44. Bawden H, Acott P, Carter J, Lirenman D, MacDonald G, McAllister M, McDonnell M, Shea S, Crocker J (2004) Neuropsychological functioning in end-stage renal disease. *Arch Dis Child* 89:644–647
 45. Brouhard BH, Donaldson LA, Lawry KW, McGowan KR, Drotar D, Davis I, Rose S, Tejani A (2000) Cognitive functioning in children on dialysis and post-transplantation. *Pediatr Transplant* 4:261–267
 46. Gipson DS, Hooper SR, Duquette PJ, Wetherington CE, Stellwagen KK, Jenkins TL, Ferris ME (2006) Memory and executive functions in pediatric chronic kidney disease. *Child Neuropsychol* 12:391–405
 47. Fennell RS, Fennell EB, Carter RL, Mings EL, Klausner AB, Hurst JR (1990) A longitudinal study of the cognitive function of children with renal failure. *Pediatr Nephrol* 4:11–15
 48. Crocker JF, Acott PD, Carter JE, Lirenman DS, MacDonald WG, McAllister M, McDonnell M, Shea S, Bawden HN (2002) Neuropsychological outcome in children with acquired or congenital renal disease. *Pediatr Nephrol* 17:908–912
 49. Fennell RS, Fennell EB, Carter RL, Mings EL, Klausner AB, Hurst JR (1990) Association between renal function and cognition in childhood chronic renal failure. *Pediatr Nephrol* 4:16–20
 50. Geary DF, Haka-Ikse K (1989) Neurodevelopmental progress of young children with chronic renal disease. *Pediatrics* 84:68–72
 51. Groothoff J, Grootenhuys M, Dommerholt A, Gruppen M, Offringa M, Heymans H (2002) Impaired cognition and schooling in adults with end stage renal disease since childhood. *Arch Dis Child* 87:380–385
 52. Hartung EA, Kim JY, Laney N, Hooper SR, Radcliffe J, Port AM, Gur RC, Furth SL (2016) Evaluation of neurocognition in youth with CKD using a novel computerized neurocognitive battery. *Clin J Am Soc Nephrol* 11:39–46
 53. Slickers J, Duquette P, Hooper S, Gipson D (2007) Clinical predictors of neurocognitive deficits in children with chronic kidney disease. *Pediatr Nephrol* 22:565–572
 54. Amr M, El-Gilany AH, Bakr A, El Sheshtawy E (2013) Assessing the intelligence of children with chronic kidney diseases. *Saudi J Kidney Dis Transpl* 24:67–71
 55. Yousefichaijan P, Sharafkhan M, Vazirian S, Seyedzadeh A, Rafei M, Salehi B, Amiri M, Ebrahimonfared M (2015) Attention-deficit/hyperactivity disorder in children undergoing peritoneal dialysis. *Nephrourol Mon* 7:e24427
 56. European Agency for Special Needs and Inclusive Education (2019). <https://www.european-agency.org>. Accessed 1 March 2019
 57. Pai AL, Ostendorf HM (2011) Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: a literature review. *J Child Health Care* 40:16–33
 58. Atkinson MA, Lestz RM, Fivush BA, Silverstein DM (2011) Comparative clinical outcomes between pediatric and young adult dialysis patients. *Pediatr Nephrol* 26:2219–2226
 59. Stam H, Hartman EE, Deurloo JA, Groothoff J, Grootenhuys MA (2006) Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. *J Adolesc Health* 39:4–13
 60. Lewis H, Marks SD (2014) Differences between paediatric and adult presentation of ESKD in attainment of adult social goals. *Pediatr Nephrol* 29:2379–2385
 61. Francis A, Johnson DW, Craig JC, Wong G (2018) Moving on: transitioning young people with chronic kidney disease to adult care. *Pediatr Nephrol* 33:973–983
 62. Bell L (2007) Adolescent dialysis patient transition to adult care: a cross-sectional survey. *Pediatr Nephrol* 22:720–726
 63. Watson AR, Harden P, Ferris M, Kerr PG, Mahan J, Ramzy MF (2011) Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Neph Association (IPNA). *Pediatr Nephrol* 26:1753–1757
 64. Zhang LF, Ho JS, Kennedy SE (2014) A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatr* 14:4–14
 65. Ferris ME, Harward DH, Bickford K, Layton JB, Ferris MT, Hogan SL, Gipson DS, McCoy LP, Hooper SR (2012) A clinical tool to measure the components of health-care transition from pediatric care to adult care: the UNC TRxANSITION scale. *Ren Fail* 34:744–753
 66. Sawicki GS, Lukens-Bull K, Yin X, Demars N, Huang I-C, Livingood W, Reiss J, Wood D (2009) Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ—Transition Readiness Assessment Questionnaire. *J Pediatr Psychol* 36:160–171
 67. Herzer M, Goebel J, Cortina S (2010) Transitioning cognitively impaired young patients with special health needs to adult-oriented care: collaboration between medical providers and pediatric psychologists. *Curr Opin Pediatr* 22:668–672
 68. Varni JW, Seid M, Kurtin PS (2001) PedsQL™ 4.0: reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. *Med Care* 39:800–812
 69. Goldstein SL, Graham N, Warady BA, Seikaly M, McDonald R, Burwinkle TM, Limbers CA, Varni JW (2008) Measuring health-related quality of life in children with ESRD: performance of the generic and ESRD-specific instrument of the Pediatric Quality of Life Inventory (PedsQL). *Am J Kidney Dis* 51:285–297

Answers:

1. E; 2. C; 3. E; 4. B; 5. E

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.