

## Responsive Designed Interventions Are Needed to Support Positive Outcomes of Children and Adolescents with CKD

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This review was of great interest to me, because I have had kidney disease since the age of 2 years old. I experienced effects of the disease throughout childhood and correspondingly, multiple periods of interrupted schooling. My experiences confirm conclusion from the recent study by Dr. Chen and colleagues that “children on dialysis may be at greatest risk compared to children with mild-to-moderate CKD and transplant recipients” (1).

I also affirm the authors’ conclusion that existing studies do not provide longitudinal data on the cognitive and educational progress of children and adolescents with CKD (1). I suggest that future studies focus on identifying interventions that help young people succeed in cognitive and educational attainment while undergoing treatment (not just pre- and post-transplant).

The cause of my kidney failure was hemolytic uremic syndrome. Luckily, my kidneys began functioning again after a short time on dialysis, and doctors were able to manage my high BP with medications that were mainly used on adults. My kidneys provided adequate clearance until I reached the age of 12 years old, when I experienced congestive heart failure and needed emergency dialysis. From ages 12 to 24 years old, I was on a combination of hemodialysis and peritoneal dialysis and went through two unsuccessful transplant attempts.

I recall occasions while on hemodialysis experiencing poor cognition and difficulty retaining information. It is not surprising that children and adolescents on dialysis are at greater risk of such effects. Studies have shown a decline in cognitive function that has been associated with fluid and solute shifts while undergoing hemodialysis. Anemia, hypotension, uremia, malnutrition, and diabetes are also known factors contributing to poor cognition. Helpful follow-on studies should be designed to identify successful interventions that health care teams and educators can use to counter the relevant effects of these conditions.

Because of my illness, I had to continue primary education on a home-schooling basis from tenth grade on. Different school systems have various approaches to educating chronically ill patients. The best fit should be the one that encourages the patient. On several occasions,

I sensed that home teachers and school administrators did not have very high expectations of my survival, and therefore, they had low motivation to help me succeed. I have also witnessed these attitudes among health care professionals and in some of the parents of youth who I have worked with over the years.

Depression is prevalent in the adult population of those with CKD and should be researched further in the CKD pediatric population. Children and adolescents with CKD need help embracing positive mental pursuits. I was very lucky to have a family that enjoyed making crafts and playing card games, such as Canasta, Pinochle, and Cribbage. The games required math and strategic thinking, and they helped me with my studies. Having a child life specialist and art therapy available when I was in the hospital as a child lessened my sense of worry, and I looked forward to learning and making a new craft. Loneliness is also a very big factor for this population; it can be hard to relate to your peers when dealing with diet restrictions, medication, treatment, body image issues, and prolonged absences from school.

I fully agree with the authors’ statement: “Identification of the bio-psycho-social factors associated with improved neurocognitive and educational outcomes, and the involvement of relevant expert teams, may inform the development of a comprehensive post-transplant rehabilitation service for children and adolescents with CKD” (1). However, I suggest that research needs to identify interventions countering poor neurocognitive and educational prospects for the full range of CKD stages, because not all patients have prognoses that suggest ideal transplant outcomes.

The effect of disease severity, the duration of CKD, and the age of disease onset were considered in four of the studies in the review, but the age of disease onset did not seem to have an effect. However, these were not longitudinal studies, and the authors state that “we could not assess the longitudinal change in cognitive function with advancing CKD stage” (1).

Because limited longitudinal evidence is available on children on dialysis and their cognitive ability, I support the idea of researching best practices for health care professionals to help these patients achieve optimal

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neurocognitive and educational outcomes. A few suggestions for study: art therapy, educating the school system on patients' needs, designing less stressful dialysis treatment regimens, and educating health care teams and families about projecting positive expectations for outcomes.

There are some closing questions to consider for study. Are patients involved in more passive types of activities, such as watching movies, or engaged in interactive activities that can help them? Are adolescents involved in taking their own BP and managing their medications and treatment schedule? (I managed my own peritoneal dialysis supplies from ages 16 to 23 years old, which led to a skill set that I now use in my company: inventory management.) How can the health care environment be enhanced to contribute to patients' learning and ensure that they have the cognitive ability to become productive adults that are able to care for themselves, pursue higher education, manage their health care, and enter the workforce with ease?

This is a valuable review of several existing studies; a serious reminder that children and adolescents with CKD face medical, psychologic, and social barriers to learning;

and a clear indication that interventions designed to be responsive to patient needs are necessary.

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Lori Hartwell is the Founder of Renal Support Network (RSN). Additional information about Ms. Hartwell and RSN is available at <http://www.rsnhope.org/about/about-lori-hartwell/>.

#### Disclosures

None.

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See related article, "Neurocognitive and Educational Outcomes in Children and Adolescents with CKD: A Systematic Review and Meta-Analysis," on pages 387–397.