

Children with CKD Are Not Little Adults with CKD

Pediatric Considerations for the Advancing American Kidney Health Initiative

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The Executive Order on Advancing American Kidney Health (AAKH) focused overdue attention on the long-underserved needs of patients with CKD. Most notably, it called for broad changes in care delivery, especially the current approach to KRT in chronic pediatric kidney failure. Although a child featured prominently in the AAKH public announcement, children with CKD are not actually included in the AAKH. While a small proportion of the total CKD population, there are compelling reasons why children warrant special attention.

Pediatrics and the First Goal of the AAKH: Reducing the Risk of Kidney Failure

Nephrogenesis concludes in normal fetal development by 36 weeks gestation, when an average kidney has formed upward of 1 million nephrons. Thereafter, the nephron count can only fall, with a deleterious effect on kidney function if the rate of normal obsolescence is accelerated. Because a primary objective of the AAKH is to reduce the number of individuals with advanced CKD and kidney failure, ensuring all young adults reach maturity with a maximal complement of functioning nephrons is essential.

Most children who develop advanced CKD early in life suffer from congenital anomalies of the kidneys and urinary tract such as kidney hypoplasia, dysplasia, or urinary tract obstruction. As childhood advances, FSGS, acquired GN or vasculitis, and various cystic kidney diseases become more common. The genetic underpinnings of these processes are being increasingly elucidated and may enhance our understanding of their pathogenesis.

In addition to these primary kidney conditions, other conditions that may adversely affect childhood kidney reserves may result in a higher likelihood of CKD, as exemplified by the long-term clinical outcomes of premature infants. In these children, gestation and nephrogenesis cease well in advance of normal development. Many require neonatal intensive care that often includes nephrotoxic medication exposures and episodes of AKI. In terms of kidney health, the legacy of prematurity can be silent. Although most will manifest an apparently normal

GFR by serum creatinine measurements as children, adults who were born prematurely have higher rates of proteinuria, hypertension, and CKD (1).

Similarly, linked to the epidemic of pediatric obesity, an ever-increasing number of children are developing hypertension and diabetes. Ensuing metabolic complications affect kidney health earlier in life, subsequently swelling the ranks of adults with CKD and kidney failure (2). Additionally, with advances in pediatric intensive care and higher efficacy of therapies for life-threatening illnesses, more children are also surviving after complex medical courses marked by episodes of AKI. Longitudinal follow-up demonstrates that these children are more likely to manifest proteinuria, hypertension, and CKD over time (3).

Separate from this increasing population of children reaching adulthood with existing or evolving CKD, the genetic foundations of many risk factors for CKD in adults, such as obesity, hypertension, and diabetes, have been found to be modified by environmental factors early in life (4). Accordingly, a better understanding of these factors, and ways to temper the extent of their manifestation, is a potential preventative strategy to reduce adult CKD and kidney failure prevalence.

Ultimately, because children with CKD become adults with CKD, preventing the evolution of CKD in childhood and adolescence will only improve the kidney health of an individual when adulthood is reached. Concomitantly, resources to optimize the physical, cognitive, and social development of any pediatric patient with CKD from infancy to late adolescence will also result in healthier and more productive adults with CKD.

Pediatric Kidney Health: A Unique Subset for Consideration within the AAKH

The AAKH describes the burden of CKD and kidney failure on patients and the health care system, supports novel evidence-based therapies to reduce CKD incidence and progression, and emphasizes home-based dialysis therapies and higher rates of kidney transplantation. However, the needs and experiences of pediatric patients with CKD are

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without mention, and it is important to consider the pediatric experience within the overall context of optimizing complex kidney care with defined or limited resources to produce better outcomes.

Children with kidney failure in the United States are much more likely than adults to receive home-based dialysis therapies or a kidney transplant, the treatment modalities emphasized by the AAKAH. These higher rates are achieved despite a paucity of pediatric dialysis and transplant facilities where children can receive pediatric-specific care, and a very small national pediatric nephrology workforce. Currently, three states have no certified pediatric nephrologists, and in the others, their availability ranges from 1:30,000 children in Vermont to 1:500,000 children in Idaho (5). As with many other pediatric subspecialties, the workforce shortage is being exacerbated, with pediatric nephrology seeing a decline in the number of fellows in training recently from 123 in 2009 to 114 in 2018, all while overall clinical volumes are increasing in most institutions.

Through the provision of additional resources and funding, the AAKH acknowledges that optimizing CKD and kidney failure care in adults will be expensive and labor-intensive. It is even more expensive and labor-intensive to provide equivalent best care to children. Just as there is a small pediatric nephrologist workforce, the number of nurses, social workers, and dietitians with pediatric-specific kidney failure expertise is limited. Moreover, because children with kidney failure are also growing and developing somatically, cognitively, and emotionally, the pediatric interdisciplinary team often needs to include resources such as child life specialists, teachers, behavioral specialists, and psychologists to attend to these developmental concerns concomitant with the usual focus on kidney health. Children with CKD and kidney failure also have different comorbidities than adults that confound their care, with issues like seizure disorder, neurocognitive delay, and congenital heart disease more frequently encountered and contributing to a heavy burden of care coordination. Moreover, as children, pediatric patients with CKD and kidney failure lack personal autonomy, and they are largely dependent on adults to ensure their access to care and to follow through with advised therapies. Providers for children with kidney failure often spend significant time either ensuring that there are reliable resources in place for children to receive prescribed care from their caregivers or facilitating such care provision.

Reimbursement Reform for Pediatric Nephrology Care

Current reimbursement for kidney failure care is largely on the basis of data derived from Medicare-insured patients. Because Medicare provides insurance for most adults with kidney failure, the cost data the Centers for Medicare Services obtains are relatively comprehensive for that population. Although children with kidney failure can qualify for Medicare, only about 40% of pediatric patients receiving dialysis opt for this coverage, with the majority insured either by state insurance programs (Medicaid) or private insurance.

As noted above, comprehensive kidney failure clinical care for children presents a different cognitive and time burden than adult care, and the supplies and resources also

vary. Because a minority of children have Medicare coverage and the information Medicare collects to understand care costs is adult-focused, there is suboptimal understanding of the costs involved in providing pediatric kidney failure care. Accordingly, setting appropriate reimbursement is a challenge.

With the AAKH's advent and the call to revisit kidney failure care delivery, an opportunity exists to augment pediatric dialysis reimbursement to the level that is needed to actually provide this specialized care. Incumbent on providing appropriate reimbursement would be acquiring cost data specific to delivering best pediatric care practices. Such an initiative would be consonant with the AAKH goal to improve the care provided to patients with CKD and kidney failure.

Research Collaboration

From a research standpoint, the opportunities furnished and goals established by the AAKH can be better realized by leveraging shared interests of the adult and pediatric nephrology communities. Notably, there should be better collaboration to understand the longitudinal course of CKD and kidney failure, and how pediatric factors may influence adult outcomes. Small steps along these lines could be readily implemented by collecting often ignored data elements in adult-focused studies such as birth weight and gestational age, childhood health history, and more detailed family histories.

Notwithstanding the need for closer collaboration, more funding for pediatric-specific research is also needed. Children are not "little adults"; the unique physiology of the developing child means more research is required to understand the causes of congenital anomalies and acquired kidney diseases in children, the factors influencing disease progression, and the appropriate pediatric therapeutic strategies. Resources are also needed to better understand how inherited predisposition to risk factors for kidney disease in adulthood, such as hypertension and diabetes, can be affected by interventions during childhood.

Conclusions

Pediatric nephrologists believe that their patients with CKD deserve a vibrant childhood: the joy of playing with friends, the ability to participate in and benefit from education, and the opportunity to build self-esteem and then achieve aspirations. As it stands currently, the reality of living with advanced pediatric kidney disease prevents too many children with CKD from realizing these ideals. As the AAKH opens up new opportunities to craft and implement policy to reduce the risk of kidney failure and to improve the quality of CKD care, this chance for broad-based improvements should not overlook the needs of children with kidney disease. Changes in policy need to consider the pediatric perspective, not only for clinical care benefits in children, but also for the potential insights into the foundations of adult CKD that are based in childhood.

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