



The impact of rural status on pediatric chronic kidney disease

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Abstract

Children and adolescents in rural areas with chronic kidney disease (CKD) face unique challenges related to accessing pediatric nephrology care. Challenges to obtaining care begin with living increased distances from pediatric health care centers. Recent trends of increasing centralization of pediatric care mean fewer locations have pediatric nephrology, inpatient, and intensive care services. In addition, access to care for rural populations expands beyond distance and encompasses domains of approachability, acceptability, availability and accommodation, affordability, and appropriateness. Furthermore, the current literature identifies additional barriers to care for rural patients that include limited resources, including finances, education, and community/neighborhood social resources. Rural pediatric kidney failure patients have barriers to kidney replacement therapy options that may be even more limited for rural pediatric kidney failure patients when compared to rural adults with kidney failure. This educational review identifies possible strategies to improve health systems for rural CKD patients and their families: (1) increasing rural patient and hospital/clinic representation and focus in research, (2) understanding and mediating gaps in the geographic distribution of the pediatric nephrology workforce, (3) introducing regionalization models for delivering pediatric nephrology care to geographic areas, and (4) employing telehealth to expand the geographic reach of services and reduce family time and travel burden.

Keywords Rural health · Rural populations · Pediatrics · Kidney failure · Health services accessibility

Introduction to rural populations

For children, adolescents, and young adults living with chronic kidney disease (CKD), residential status in a rural area (e.g., “rurality”) may impose unique challenges and barriers to accessing pediatric nephrology care. CKD is a burdensome and costly disease that necessitates significant personal and financial healthcare utilization costs across the lifespan. For example, in the USA, hospitalizations for pediatric CKD accounted for 400,000 days of hospitalizations and \$1.3 billion USD in 2016 alone, with over 85% of

care provided in urban teaching hospitals [1]. Delivering healthcare to children and adolescents with CKD in rural areas is additionally challenging because although there is substantial morbidity and healthcare utilization associated with CKD, it is also a relatively rare condition with the more severe disease, kidney failure with kidney replacement therapy, affecting an estimated 55 to 80 children per million of age-related population [2]. Unfortunately, access to primary, subspecialty, and hospital-based care for pediatric CKD patients may be severely limited or absent in some rural areas [3, 4] in parallel with perhaps even more striking health care disparities for indigenous and native populations living in rural areas across the globe [5, 6]. Recently, additional closures and transformation of pediatric inpatient beds to adult beds during the SARS-CoV-2 pandemic have been reported to acutely worsen healthcare access for children in rural areas [7].

In this educational review, we will (1) summarize current research exploring the relationship between rurality and pediatric CKD care utilization and outcomes, (2) discuss potential challenges and considerations unique to the care of CKD patients living in rural areas internationally, and (3)

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highlight opportunities to improve care and outcomes for the rural pediatric CKD population. As the effects of rurality can vary considerably by both setting and system, where available we will concentrate on work derived from national or multi-site data. In some cases, single-center experiences may be the only available data on a topic or in a region, and such data will be discussed in the context of generalizability and scientific rigor.

Defining rurality: geography and beyond

Definitions of rurality

When discussing rural populations, it is important to first consider how rurality is defined. There is no universal definition for rurality, and in some contexts, the definition chosen may be specific to the primary outcome — such as health research and policy. Despite the lack of a uniform definition, the complexity in terminology can confer flexibility to inform and understand different aspects of rurality across the globe.

The World Bank and World Health Organization define rural populations based on country-specific definitions. For example, the European Union uses a population density and geographic contiguity, while Australia uses an accessibility/remoteness index based on road distance to population areas. More universal standard rural–urban classifications may be more informative in comparing data across countries [8]. Most definitions of rurality encompass a variety of ecological factors, ranging from population density, distance to essential services or large populations/cities, commuting behaviors, and/or the number of persons not living within an

urban area (Table 1) [9]. These definitions may vary in the unit of measurement ranging from larger geographic units (i.e., from larger geographical units like states, provinces, and territories to smaller units such as postal/zip codes and neighborhoods) [9]. Unfortunately, variability in the definition of “rurality” lends the potential for large differences in both the size and characteristics of the “rural” population within a single country based on the definition utilized. For example, in one large US study using 2010 census data, the size of a national rural population varied from 6.9 to 75.5 million rural residents depending on the definition used [10].

The rural ecosystem

Approximately 43% of the worldwide population resides in rural areas, although significant variation exists by geographic area. For example, about 60% of people in South Asia and Sub-Saharan Africa live in a rural area, compared to 20–25% of people in North America, Latin America and the Caribbean, and the European Union [15, 16]. Changes in climate and environment could especially impact the health of rural populations, especially in areas of Africa, South Asia, and Central America, through drought, extreme temperatures, and livelihood collapse resulting in mass migration, increased poverty, and civil unrest [17]. This may increase the risk of rurality for children with chronic health conditions like CKD in the future.

Rurality confers a unique social context that impacts the household, community, and regional ecosystems across the lifecourse. Krieger’s “ecosocial approach” describes how a person *embodies* the lived environment as part of their biological health and wellbeing [18]. Rural populations face unique challenges in access and availability of resources,

Table 1 Examples of established and commonly used definitions of rurality, urbanicity, and remoteness

Concept	Description	Units/examples
Population and population density	Total population or population per land area per geographic unit (county, region, etc.)	Office of Management and Budget Metropolitan Designations (US), Degree of Urbanization (EU), population/km ² (multiple countries — e.g. OECD rural communities in CAN)
Distance to cities/metropolitan areas	Distance or drive time	Miles, minutes, kilometers (multiple countries)
Commuting population	Composite measure of the number of residents of a geographic unit that travel to a more urban/populated neighboring geographic unit for work	Rural urban commuting areas (US), census metropolitan area, and agglomeration influenced zones (CAN)
Distance to services	Composite score of distance to a given service (e.g. hospital, school, government service)	Accessibility/remoteness index of Australia (ARIA) + (AUS)
Largest populace in a geographic unit	A geographic unit’s rurality is determined by the largest population center/city within the unit (e.g. county)	Urban influence codes (US)
Lack of services	An area that does not receive a typical service	Rural postal codes (CAN)

Information adapted from Eurostat, US Department of Health and Human Services, Statistics Canada, and University of Adelaide Hugo Centre for Population and Migration Studies [11–14]

US United States, EU European Union, OECD Organization for Economic Co-operation and Development, CAN Canada, AUS Australia

including lower high-speed internet access, increased child poverty, lower educational attainment, and decreased employment opportunities in many sectors [19]. Likely in part due to these factors, there is a higher burden of chronic diseases, all-cause mortality, and infant mortality in rural America [20, 21]. In the USA, rural areas are more likely to remain persistently poor over multiple decades with higher proportions of racial and ethnic minority populations residing in persistently poor rural counties than in non-rural and non-persistently poor counties [19]. In the context of pediatric CKD and rurality, this may mean that the lived environment of rurality is limited not only to geographic access to care but potentially competing health priorities ranging from financial wellbeing, literacy and education, and social supports which may adversely contribute to their underserved healthcare needs.

Access to care is more than distance

Access to care encompasses multiple aspects of the ability to obtain health care. Levesque et al. describes a patient-centered framework of the multiple elements of access to care, including approachability, acceptability, availability and accommodation, affordability, and appropriateness

(Fig. 1) [22]. Pediatric CKD research examining “access to care” has focused largely on the dimensions of availability and accommodation, including geographic location (e.g., distance to care) and affordability (e.g. costs and missed work/school) [23, 24]. While these are important measures of access, they may represent only a fraction of the true limitations in access to care experienced by pediatric CKD patients/families. Levesque further describes an access to care framework by adding five dimensions of abilities to perceive (e.g., health literacy and beliefs), seek (e.g., values and autonomy), reach (e.g., mobility, support, transport), pay (e.g., insurance, finances), and engage (e.g., empowerment, caregiver support, information) [22]. This powerful conceptual model provides a framework for how differences in rural–urban living could influence the health system supports and care accessibility experienced by pediatric CKD patients/families. Another important distinction in this conceptual model is the need to distinguish between realized and potential access. Potential access describes the system *available* to the health care user, whereas realized access describes the care *utilized* [22, 25]. Health care utilization (e.g., dialysis visits, primary care visits, hospitalizations) is often studied as a proxy measure for healthcare access [22].

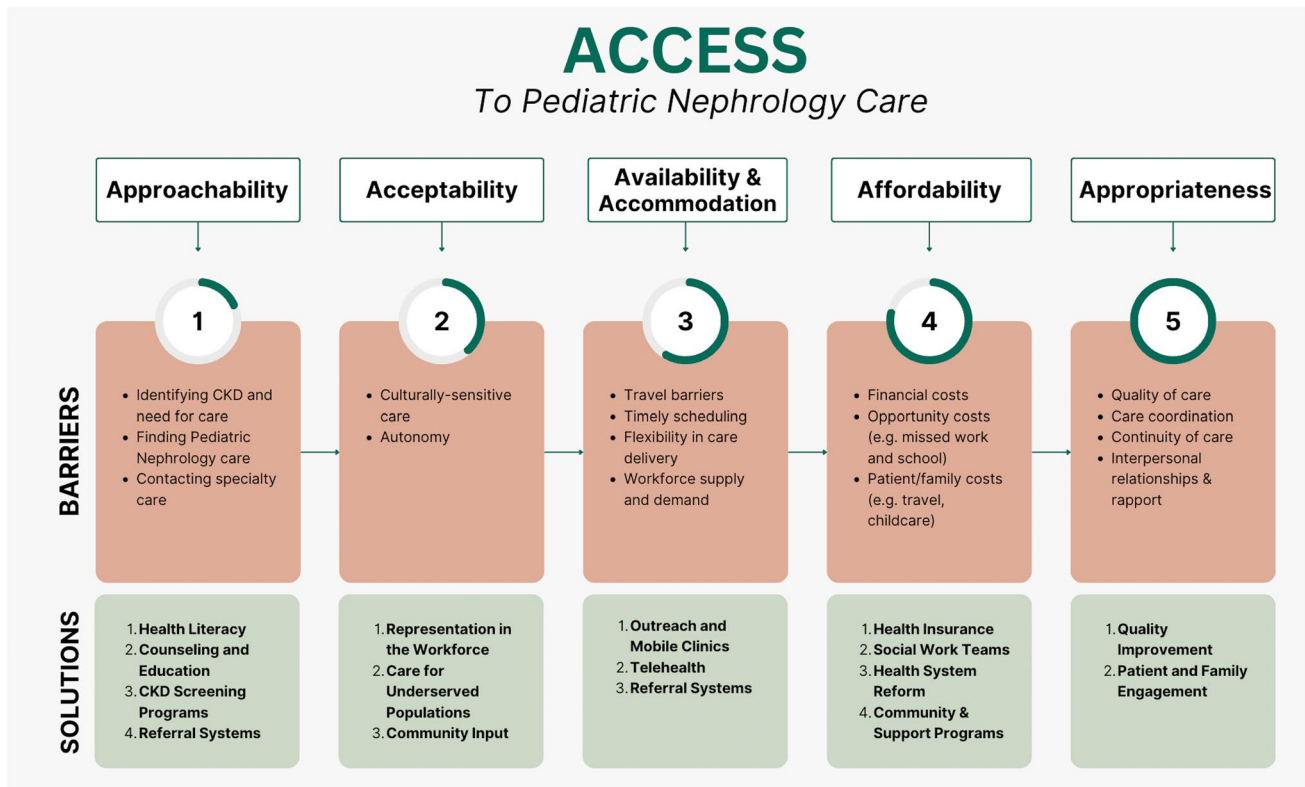


Fig. 1 A patient-centered framework of the multiple elements of access to care, including approachability, acceptability, availability and accommodation, affordability, and appropriateness. Adapted from Levesque et al.’s model of Access to Care [18]

“Driving distance” to care has been used to examine geographic proximity to care in pediatric CKD. The effects of distance to care and rurality are different for each region or country studied. In the USA, the average distance to a pediatric nephrologist is 30 miles and 25% of children live 36 or more miles from a pediatric nephrologist. However, this study may have over-estimated these percentages as it was based on the physician’s primary address (often located at a large urban children’s hospital) and not have included suburban or rural outreach clinics [3]. Certainly, geographic proximity to pediatric care — starting with the pivotal role of a primary care pediatrician — may confer a major barrier to both available and utilized care for pediatric nephrology patients living in rural areas. Presently in the USA, 61% of rural counties do not have a pediatrician [26]. This is further compounded by declining inpatient community-based hospital bed availability — for example, hospitals with inpatient pediatric services have decreased by 19% since 2008. Importantly, a disproportionate loss of access has been observed in rural areas which comprise 42% of the inpatient pediatric bed closures, thus necessitating transfer of pediatric CKD patients to tertiary medical centers potentially several hours from the patient/family’s home [27]. Recently, additional closures of pediatric inpatient units have accelerated during the SARS-CoV-2 pandemic with the repurposing of pediatric units to adult which has resulted in ongoing financial disincentives to return to a pediatric unit due to lower reimbursement rates [28]. These real and perceived gaps in proximity to care lead to higher utilization of acute and emergency care services among rural adults, including those with CKD, compared to non-rural peers [29, 30].

Enabling factors and barriers to care in rural areas

In this section, we will discuss some of the primary barriers and enablers to health care utilization and access that may be differential across rurality. Many of these enabling factors and barriers to care are shared by rural communities across the globe. For example, Australian nephrologists report rural CKD patients face multiple barriers to care — including tyranny of distance, difficulty navigating the complex healthcare system, disrupted care, financial distress, and local variability in support and resources — which could be similarly reported by rural persons across the globe [31]. Similarly, qualitative work exploring the viewpoints of barriers to CKD care in rural India found barriers to care including inadequate human resources and CKD resources, supply shortages, poor knowledge and awareness, limited continuity of care, referral, follow-up and financial burden, and facilitators to care such as mobile health technology and system approach to care coordination — all of which should

be considered when providing services to rural CKD patient populations [32].

Financial resources

Financial resources are necessary for access to healthcare, including the ability to pay for healthcare, transportation, and caregiver/childcare support during times of health crisis. The impact of rurality on financial resources has been evaluated in adult and pediatric CKD populations. There is a higher incidence of poverty among rural children than their non-rural peers (47% of rural children vs. 39% of non-rural children with household income levels <200% of the federal poverty limit), and most of the counties in the USA with a child poverty rate of 50% or higher are in rural areas [19, 33]. Household income level is also associated with CKD severity, emergency department (ED) use, hospitalization, and progression in the USA [23, 34]. Additionally, food insecurity — a direct extension of household income — is commonly reported in rural regions and may also confer a potentially modifiable risk factor for pediatric CKD progression [35].

Conversely, while some data suggests a strong relationship between rurality and lower financial resources, this is not universally true. For example, in the UK, there is less neighborhood-level socioeconomic deprivation in rural areas and no association was observed between increased distance to care and late presentation of CKD [24].

Educational resources

Health care utilization and access are largely driven by the patient and/or caregiver’s understanding and actions regarding the health needs of the patient. Children with CKD are at risk for academic underachievement and chronic school absenteeism [36, 37]. Rurality may potentiate school absenteeism due to longer travel times and possible higher propensity to utilize acute care such as emergency department and unplanned hospital visits [38]. Rural children are more likely to attend school in small districts with conceivably fewer resources to help children with complex CKD care needs — such as school nurse support to assist with self-catheterization, medication administration during school hours or even routine blood pressure assessment [39].

Community/neighborhood social resources

Social support can be variable in rural communities. While some families report physical isolation and distance as a barrier to creating robust community support network, others have reported high social capital resulting from a rural community [31, 40]. For some families, the “tight-knit” nature of a rural community may enable high-quality

care for individuals with CKD, as they harness community resources and inter-personal relationships to overcome the distance gradient to tertiary care centers. However, in other settings, marginalized and socially isolated families may find the additional demands of CKD care to be insurmountable, especially in the setting of additional resources needed to access high-quality pediatric nephrology care in a distant hospital or clinic setting.

At-risk rural populations and communities

Among rural residents, certain populations are likely to have higher risks of experiencing inequitable access to kidney screening and care. Indigenous populations have higher rates of CKD and live in some of the most rural and isolated areas worldwide [41], and they may be some of the most at-risk rural populations due to multiple barriers to accessing kidney care (i.e., clean water, broadband internet access). Minority racial and ethnic groups may experience additional burden in rural areas due to current and historic resource allocation, devaluation, and disempowerment [42]. As one example of how structural racism affects health status in pediatric CKD, African American children with CKD have been shown to have increased socioeconomic disadvantages when compared with white children with CKD, and this has been shown to affect cardiovascular function [43]. Rurality may widen the disparities in access to healthcare, empowerment of patients and families, and allocation of healthcare resources for racial and ethnic minority groups.

There is a need to identify patients most at-risk of being unable to obtain or maintain pediatric nephrology care to minimize barriers to care in rural areas. After identification of at-risk patients, resources and coordinated programs to cocoon high-risk patients and families in care coordination and follow-up services could help families have the needed supports for CKD care. For example, in Australia, there is a focus on policy to provide “timely access to quality and safe health care services” to all people, rural and urban. Included in that focus is understanding the equity of policies designed to alleviate disparities in health and healthcare access for rural, underserved populations, like the Aboriginal people [44]. In other countries, similar work is important to understand how all rural patients, and especially those whom are most underserved, interface with the nephrology system.

Rurality confers barriers to kidney replacement therapy options

There are large variations globally in the resources available for pediatric nephrology care — in particular, access to kidney replacement therapy [45]. Due to the limited amount of work evaluating relationships between rurality and kidney

replacement therapy options in pediatric CKD patients, adult studies are also discussed in this section.

Dialysis options are limited for adults in rural areas. Only about 10–18% of all adult dialysis centers in the USA are located in rural areas [46, 47], and about one-third of pediatric kidney failure patients receive their dialysis care in an adult dialysis unit [48]. In the USA, travel distance to dialysis for adults was almost 4 times further for rural adults versus non-rural adults with CKD, but remained relatively short for most patients (median, 10.9 miles) [47]. In Australia, drive time for remote and rural patients were longer and there are large populations without access to nephrology care (i.e., dialysis units and other kidney management services) within 60 min of drive time [30]. Some adult patients also bypass a local, closer dialysis center to receive care at a further dialysis center, especially in the setting of complex medical comorbidities or if the more distant center has a greater quality rating [47]. Rural adult dialysis patients are less likely to start home dialysis, less likely to be listed for transplant, and have worse survival even when attending an urban dialysis center, despite rural dialysis facilities reporting higher outcome-based quality metrics on average than urban centers [46]. Unfortunately, the distance to care imposed by rurality is not ameliorated by transplantation. Temporary relocation for several weeks to months is often a prerequisite to facilitate kidney transplantation in the immediate post-operative period, thereby removing patients from their home communities, places of employment, and support systems during one of the most challenging transition periods, both physically and emotionally, for a patient with kidney failure [49].

Pediatric versus adult kidney replacement therapy: effect modification by age

Geographic access to kidney replacement therapy for the pediatric population is far worse than what is experienced by adults. Pediatric designated dialysis centers encompass less than 1% of all dialysis centers in the USA and most are located in urban children’s hospitals, and about one in three rural or semi-rural pediatric kidney failure patients receive dialysis at adult facilities [48, 50]. There are characteristics of dialysis centers that are distinct to facilitating pediatric care, including pediatric-specific care team members (i.e., pediatric nurse specialists, psychologists, dietitians, social workers, child life specialists, education specialist). Benefits of a pediatric multidisciplinary care team include pediatric-focused training and competencies to care for a pediatric patient including special attention to growth and nutrition parameters, flexibility to adjust nurse: patient ratios depending on the child’s needs, and potentially quicker transition to transplant from dialysis [51]. Scarcity of pediatric kidney replacement therapy in rural areas likely influences choice

of kidney replacement therapy. Peritoneal dialysis allows for in-home dialysis, which may be preferable for rural patients and families, yet peritoneal catheter complications are a potential risk; catheter failure rates approached nearly 25% in a study of children in a rural US center [52]. Australian and New Zealander children residing in remote areas were 35% less likely to have a pre-emptive kidney transplant but with no association between remoteness and acute transplant rejection or graft loss [53].

In many rural areas, especially in lower income countries, there are no options or extremely limited options for kidney replacement therapy (transplant or dialysis) due to availability of resources [54, 55]. Pediatric CKD patients may receive adult dialysis or no kidney replacement therapy at all, and children on dialysis in rural and semi-rural areas are about 25% less likely to be seen by a pediatric nephrologist [56]. An estimate of the true disparity in pediatric kidney replacement therapy rates by country income level is not available due to the dearth of data on the incidence of kidney disease and lack of national data in many countries. A study of international pediatric peritoneal dialysis centers found that during 3-year follow-up, there was a three-fold higher risk of death and patients were 50% less likely to receive transplant in low-income versus high-income countries [57]. This study included only pediatric patients able to access pediatric peritoneal dialysis centers for care, with many countries reporting an inability to provide chronic peritoneal dialysis (i.e., 36% of countries surveyed in Africa) or kidney transplantation capabilities (i.e., only 38% of all African countries) [55].

Strategies for health systems improvement for rural patients and families

Research with rural populations

Rural populations are traditionally underrepresented in clinical research [58]. This may be especially true in the field of pediatric nephrology, where funded research is traditionally conducted mostly at large urban children's hospitals. Travel and financial costs are known barriers to research participation for rural patients/families [58]. However, many patients/families note that adequate compensation and flexible recruitment and study visit methods can facilitate rural pediatric research participation [58, 59]. Virtual clinical trial enrollment, visits, and mobile laboratory collections are other novel options to increase recruitment and retention of research participants from rural areas [60].

Further research examining the effects of rurality on CKD-associated health outcomes and health care utilization is critical given the current information gaps in this vulnerable and underserved population. The current body of

work suggests that the effect of rurality on CKD outcomes varies across geographies and health systems. This is well-illustrated in the context of the more recently and vastly understudied entity CKDu (“CKD-unspecified”) which is characteristically seen only in rural/agrarian populations in Sri Lanka, India, southeast Europe, and Central America [61]. Although the underlying etiology of this fascinating disease remains unknown, it has reached epidemic proportions in some communities, seems to be associated with rapid progression, and is often fatal in these communities due to their inability to provide dialysis and transplantation. Interestingly, this phenotype is not classically observed in the rural populations of the USA, Canada, or western Europe, highlighting the importance of evaluating the burden of CKD among rural persons on a global perspective that accounts for environmental and cultural differences that may impact kidney care in rural settings.

In addition to clinical and basic science research, qualitative research is needed to understand the patient perspectives among this unique population. While small sample sizes can create some limitations in studying rural pediatric CKD, focusing on work that is both pediatric-specific and considers that rural populations are not homogenous entities may provide critical insight for how to improve health care delivery. Prioritizing and uplifting the viewpoints of underserved rural patient groups and their caretakers is critical to re-designing effective health care delivery interventions that are effectively tailored to optimizing health care access among rural settings/populations. Furthermore, intentionally considering indigenous and First Nation populations, migrant and marginalized workers, other racial and ethnic minorities, and those with the least economic resources when studying healthcare delivery for CKD in rural areas may help overcome barriers to access for rural populations that can be masked in traditional dichotomous rural vs. non-rural research.

Pediatric nephrology workforce and geographic distribution

Access to quality medical care is influenced by the geographic distribution, availability, and future workforce of pediatric nephrologists. Pediatric nephrology services are largely centralized in urban settings with the average distance to a pediatric nephrologist being about 25 miles (40 km) in the USA (Fig. 2) [3, 62]. This has been reported to increase barriers to subspecialty care for rural pediatric patients [63]. The potential for geographic barriers to care is further potentiated by concerns about the pediatric nephrology workforce across most regions worldwide — including pediatric subspecialist workforce shortages in rural areas and comparatively lower compensation of pediatric nephrologists compared to other pediatric subspecialties and

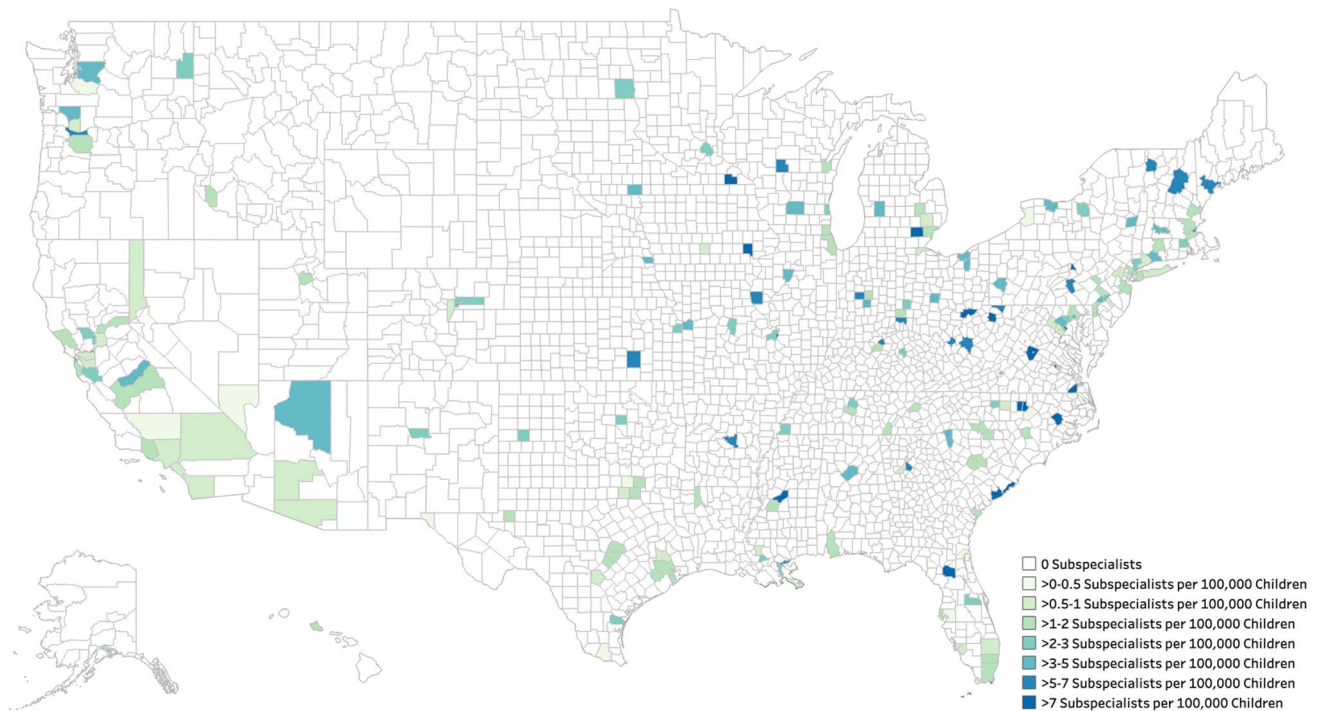


Fig. 2 Distribution of pediatric nephrology by pediatricians per 100,000 children (0–17). Source: <https://www.abp.org/dashboards/pediatric-subspecialty-us-state-and-county-maps>

adult nephrology [64, 65]. Worldwide, there is also much variation in the availability of pediatric nephrologists with concern for inequitable distribution of pediatric nephrologists in under-resourced/rural areas [66]. Overall, 95% of low-income countries report shortages in nephrologists with 0.3 nephrologists per million population compared to 53% of high-income countries (not pediatric-specific) with 26.5 nephrologists per million [67]. In a pediatric-specific survey, the most severe shortages were reported in Africa [64]. Rural populations may also experience worsening workforce shortages in the future as pediatric nephrologists currently working in small, more isolated rural practices reach retirement age, experience the deleterious effects of burnout, or migrate to larger urban practices due to a desire for a lessened call burden. To provide high-quality pediatric nephrology care in rural areas, it is important to have intentionally designed health care delivery systems that are geographically accessible to rural populations and sensitive to the needs, challenges, and cultural vision of rural communities.

Regionalization models for delivering pediatric nephrology care

Pediatric nephrology, dialysis, and transplant care are centralized primarily in large, non-rural children’s hospitals. For example, many states in the USA have a single children’s hospital or no children’s hospitals, meaning about

10% of children live over 80 miles (about 130 km) from pediatric nephrology care [3]. In emergency care conditions, such as pediatric trauma, regionalization of care works “to deliver the right resources to the right patient in the right place at the right time” by creating a system of healthcare resources with intentional transfer and treatment agreements [68]. Through adaptation of regionalization care metrics, pediatric nephrology care delivery could conceivably be reimagined to care for patient cohorts developed from geographic regions, rather than only patient panels that start when patients are able to physically see a subspecialty physician. This, in combination with telemedicine, could help to geographically extend pediatric nephrology expertise, to minimize the physical trips required to the larger distanced hospitals. Other technology-based innovations like home urine testing for monitoring proteinuria and mHealth family-self management for post-transplant care have been described in the literature and have high patient and caregiver satisfaction rates [69, 70]. Use of novel technologies could allow for hybrid follow-up models for rural CKD patients reducing the frequency of needed trips to local laboratories and distanced medical centers. However, currently in the USA, there are many policy barriers to using telehealth services, such as uncertain payment and lack of parity with in-person visits — all of which may disincentivize the implementation and use of telehealth [71].

Mobile outreach and screening programs can help to expand identification of kidney disease in rural areas among populations with high risk of kidney disease that have not traditionally had adequate access to kidney care. Among the First Nations people in Manitoba, Canada, there was a recognized high-risk population for CKD that also was geographically distanced from care — for example, in some cases, communities were accessible only by air flight [72]. A multi-disciplinary team worked closely with the community to develop a mobile screening program using vital signs and screening laboratory values to risk-stratify and connect pediatric participants (10 years and older) with counseling and appropriate referrals; 100% of patients referred to nephrology care were successfully seen by a nephrologist [72]. This program identified that 19% of participating children and adolescents had at least one risk for kidney disease, and 17% had pre-hypertension or hypertension [73]. An adult CKD screening program in the rural Guatemalan highlands, an area with increasing prevalence of CKDu, found over 50% of participants had laboratory findings suggestive of CKD [74]. This identified areas to improve screening programs, tailor patient education, and expand population-based research to improve kidney care for high-risk communities in rural areas of Guatemala [74].

Telehealth to expand geographic reach of services

Pre-pandemic, telehealth was considered a key strategy to improve access to pediatric subspecialty care for rural populations [75]. During the SARS-CoV-2 pandemic, there was a need for rapid expansion and innovation of telehealth services in the care of pediatric nephrology patients, as the pandemic triggered novel care delivery models and temporary easing of regulations allowed for rapid implementation of telehealth delivery. Yet despite this need, telehealth adoption remained variable. In a survey of European pediatric nephrology centers, telemedicine was only used in about half of centers during March to May 2020 [76]. In the USA and Canada, about 75% of physicians reported using video visits during the pandemic; however, single-state data demonstrated lower use of telehealth among pediatric nephrology (25% of visits) during the pandemic as compared to other pediatric subspecialties (e.g., neurology 55%, gastroenterology 50%) [77, 78].

Clinician perceptions of telemedicine clinical encounters are mixed; some remain uncomfortable with or do not desire to continue managing chronic pediatric nephrology conditions, like hypertension, CKD, and transplant by telehealth [79, 80]. Conversely, patients/families report mostly favorable views of telehealth, including ease of use without reductions in quality of care and financial savings; however, patients with more complex conditions report

favoring in-person care despite longer travel times [78, 81, 82].

Prior to 2020, challenges to utilizing telehealth included state-level variation in regulations, licensure differences preventing many out-of-state encounters, and payer-level variation in reimbursement for telehealth visits [83]. When regulations were temporarily eased to allow for telehealth expansion in the USA during the pandemic, clinicians were more able to receive payment for telehealth services (e.g., telehealth across state lines and telehealth for new and returning patients) [84]. However, some of these restrictions may be re-enacted after the pandemic public health emergency declaration is lifted without further policy changes, which could reimpose barriers to using telehealth as a tool to increase access to care for rural patients and families.

Conclusion

Rurality confers a unique social context that may impact healthcare access and outcomes for pediatric patients with CKD. Current research on the epidemiology, patient and family perspectives, health care utilization, and outcomes of rural pediatric nephrology patients is somewhat limited. Notably, rurality may confer barriers to kidney replacement therapy options for pediatric patients worldwide. Barriers to kidney replacement therapy are likely worsened by the worldwide variation in the availability of pediatric nephrologists with concern for inequitable distribution of pediatric nephrologists in under-resourced/rural areas. Innovative approaches to care — including mobile outreach/screening programs and expansion of telehealth services, as well as sustainable efforts to revitalize the pediatric nephrologist workforce pipeline — are crucial to meet the needs of pediatric CKD patients across the globe.

Key summary points

- Rural children and adolescents with chronic kidney disease have distinct challenges for obtaining and accessing pediatric nephrology care.
- Incorporating rurality and rural populations in CKD research is important to fully understand the impact of rurality and design rural-focused interventions to improve access to care.
- Telehealth, care regionalization, and other changes in care delivery models may help to better connect rural patients and families with pediatric nephrology care while lessening the burdens of accessing care.

Multiple choice questions

Answers appear following the References

1. What is the universal definition of rurality?
 - a) Living outside of a city
 - b) There is no universal definition of rurality
 - c) Residing more than 30 km from a town
 - d) Areas with less than 10,000 people per square mile

2. Which of the following domains of care from Levesque et al.'s model of access to care would best encompass issues with having very few pediatric nephrologists in a rural state?
 - a) Acceptability
 - b) Appropriateness
 - c) Availability and accommodation
 - d) Affordability

3. How is the current pediatric care capacity in the United States changing?
 - a) Fewer hospitals that provide pediatric inpatient care
 - b) Rural hospitals are admitting more pediatric patients
 - c) Creation of regionalized tiered systems of pediatric inpatient care based on acuity
 - d) Development of long-term telemedicine programs to deliver pediatric inpatient care in rural hospitals

4. What was unique about the screening programs presented in Guatemala and Canada?
 - a) Use of a novel technique to measure blood pressure and estimate GFR
 - b) Implementation of population-based screening programs in high-risk rural communities
 - c) Employing telehealth strategies to connect with rural populations from existing medical centers
 - d) Integration of CKD care into a primary care clinic visit

5. What is a strategy that could be used in research and quality improvement initiatives to better serve rural populations?
 - a) In-person enrollment at large, academic hospitals with multiple in-person follow-up visits
 - b) Recruitment from study populations of existing cohorts and clinical trials
 - c) Ensuring each participant has the same care coordination and study incentives

- d) Designing a study protocol with flexible follow-up modalities to allow study participants to conduct visits over video call and at local laboratories

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Declarations

Conflict of interest The authors declare no competing interests.

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Answers: 1. b; 2. c; 3. a; 4. b; 5. d

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