EDITORIAL

The challenges of rare kidney diseases in Iraq

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ABSTRACT

Rare kidney diseases (RKDs) significantly contribute to chronic kidney disease and failure, particularly among children and young adults. Collectively, they account for up to 60% of pediatric end-stage kidney disease. In Iraq and the Middle East, this burden is likely higher due to high rates of consanguinity, large family sizes, and limited data. RKDs are often underrecognized, with diagnostic delays of 6–8 years stemming from limited genetic testing, workforce shortages, fragmented care, and the effects of conflict.

Access to treatment is further constrained by high costs, limited availability of orphan drugs, and significant out-of-pocket expenses. The absence of registries and research impedes understanding and policy development, while low awareness and the lack of a national strategy exacerbate these challenges. Addressing RKDs requires a coordinated, multi-sectoral approach aligned with UN and SDG goals, focusing on improved diagnostics, registries, workforce development, access to therapies, integrated care, public health initiatives, and sustainable financing. Collaborative action is essential to improve outcomes and equity for RKD patients in Iraq.

Key words: Rare kidney disease, chronic kidney disease, Iraq.

INTRODUCTION

A rare disease is defined as a condition affecting a small proportion of the population, yet collectively, rare diseases affect more than 300 million people worldwide. Most are genetic, chronic, and often life-threatening, with many presenting in childhood and requiring lifelong care. Because of their rarity, limited research, limited funding, and the lack of effective treatments, these conditions are also called orphan diseases. Rare diseases account for approximately 3–8% of total healthcare expenditure in the US.[1,2]

According to the National Institutes of Health's Office of Rare Diseases Research, a rare disease is any condition affecting fewer than 200,000 people in the United States. By contrast, the European Union defines a disease as rare when it affects fewer than 5 per 10,000 people (1 per 2,000).[3]

Rare kidney diseases (RKDs) are a subset of rare diseases, comprising about 300–400 disorders, approximately 80% of which have a genetic basis. Their prevalence is 60–80 cases per 100,000 in Europe and the USA. RKDs are the fifth leading cause of end-stage kidney disease, with at least 10% of adults and nearly all children requiring kidney replacement therapy due to inherited kidney disease. RKDs are categorised as growth and structural abnormalities, glomerular diseases, tubular diseases, or metabolic diseases. Their diverse phenotypes, variable progression, and limited natural history data contribute to delayed diagnosis and management challenges.[1,4]

The socioeconomic burden of rare kidney disease includes direct healthcare costs, indirect costs such as lost education and productivity, and psychosocial impacts on patients and caregivers. Individuals with rare diseases have complex, lifelong needs, yet

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significant disparities persist in meeting them across populations. Disadvantaged groups and those in conflict regions, including displaced people and refugees, are disproportionately affected.[5]

The United Nations recognised rare diseases as a global priority through its 2021 resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families," emphasising that addressing these conditions is essential not only for health but also for achieving broader goals, including education, employment, poverty reduction, and social inclusion, under the Sustainable Development Goals.[6]

Direct epidemiologic data on rare kidney diseases in Iraq, the Arab region, and the Middle East are scarce. More than 1,000 genetic disorders have been identified in Arab populations, and approximately 2.8 million people in the Middle East and North Africa (MENA) are living with rare diseases. Rare diseases may affect ~5–6% of the population, consistent with global estimates.[7]

Rare kidney diseases in Iraq are still under recognised yet clinically significant, contributing to paediatric and early-onset kidney failure. These include, but are not limited to, congenital anomalies of the kidney and urinary tract (CAKUT), hereditary nephritides and nephrotic syndrome, complement-related diseases, nephropathic cystinosis, Fabry's disease, and primary hyperoxaluria.

CHALLENGES

While rare kidney disease poses global care challenges, these issues are especially pronounced in low- and middle-income countries and developing regions. Consanguinity is prevalent in Iraq and the Middle East (about 60%), and a cultural preference for large families further increases the incidence and severity of inherited disorders. This genetic landscape makes RKDs more common and severe than in many Western populations.[8]

1. Health System Challenges:

- Limited Diagnostic Infrastructure: Genetic testing is scarce and costly, resulting in average diagnostic delays of about 9 years and missed opportunities for targeted therapies.[9]
- Workforce and Expertise Gaps: Iraq and the broader region have among the lowest nephrology workforce densities, with few subspecialists in glomerular and genetic nephrology, and shortages of trained renal pathologists and genetic counsellors. [10]
- Fragmented Health Systems: Major gaps include a lack of integrated referral pathways, poor transitions from paediatric to adult nephrology, and inconsistent access to multidisciplinary care. In conflict-affected areas, disrupted healthcare infrastructure further limits access to essential services, including kidney transplantation.

2. Therapeutic and Access Challenges:

- Difficult Access to Treatment: Patients in Iraq and other developing countries often cannot access necessary medications due to unavailability, inconsistent supply, and high costs.
- Financial Constraints: Limited health spending and the high cost of rare-disease therapies hinder kidney care, leading to substantial out-of-pocket expenses in many settings.

3. Data and Research Gaps:

- Lack of Registries: Iraq and other developing countries lack standardised data collection, resulting in the absence of kidney disease registries despite the high prevalence of kidney disease.
- Underrepresentation in Research: Due to limited data and registries, most RKD research originates in Europe and North America, leaving LMICs, including Iraq, underrepresented in clinical trials and genomic studies.

4. Policy and Governance Challenges:

- Low Awareness and Advocacy: RKDs are not prioritised in health agendas due to limited public, professional,

THE CHALLENGES OF RARE KIDNEY DISEASES IN IRAQ

Rare kidney diseases (RKDs) affect many lives, yet patients in Iraq face multiple barriers across the healthcare system, treatment access, data, research, and policy

1 HEALTH SYSTEM CHALLENGES

Limited Diagnostic Infrastructure

Genetic testing is scarce and costly, resulting in average diagnostic delays of about 9 years and missed opportunities for targeted therapies.

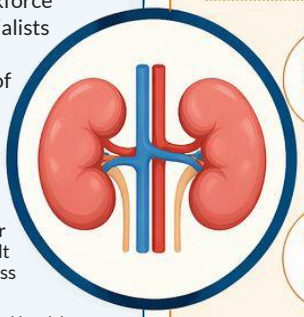
Workforce and Expertise Gaps

Iraq and the broader region have among the lowest nephrology workforce densities, with few subspecialists in glomerular and genetic nephrology, and shortages of trained renal pathologists and genetic counsellors

Fragmented Health Systems

Major gaps include a lack of integrated referral pathways, poor transitions from paediatric to adult nephrology, and inconsistent access to multidisciplinary care.

In conflict-affected areas, disrupted healthcare infrastructure further limits access to essential services, including kidney transplantation.



2 THERAPEUTIC AND ACCESS CHALLENGES

Difficult Access to Treatment

Patients in Iraq and other developing countries often cannot access necessary medications due to unavailability, inconsistent supply, and high costs.

Financial Constraints

Limited health spending and the high cost of rare-disease therapies hinder kidney care, leading to substantial out-of-pocket expenses in many settings.

Consequences

Delayed treatment initiation, suboptimal disease management, and poorer clinical outcomes.

3 DATA AND RESEARCH GAPS

Lack of Registries

Iraq and other developing countries lack standardised data collection, resulting in the absence of kidney disease registries despite the high prevalence of kidney disease.

Under-representation in Research

Due to limited data and registries, most RKD research originates in Europe and North America, leaving LMICs, including Iraq, under-represented in clinical trials and genomic studies.

4 POLICY AND GOVERNANCE CHALLENGES

Low Awareness and Advocacy

RKDs are not prioritised in health agendas due to limited public, professional, and policymaker awareness and weak patient advocacy networks.

No Nation Kidney/ RKD Strategy

The absence of a dedicated national strategy for kidney diseases/PKDs results in fragmented efforts, inadequate funding, and missed opportunities to integrate kidney disease into national health plans.

TO IMPROVE OUTCOMES FOR PATIENTS WITH RARE KIDNEY DISEASES IN IRAQ:

- Strengthen diagnostic infrastructure and specialised workforce
- Improve access to affordable and reliable treatment
- Establish national registries and support local research
- Raise awareness and develop a national kidney/RKD strategy

Integrated action today can transform the future for patients with rare kidney diseases in Iraq


STRATEGIES TO IMPROVE THE SERVICES OF RARE KIDNEY DISEASES (RKDS)
A MULTI-PRONGED APPROACH FOR BETTER OUTCOMES
1 STRENGTHENING DIAGNOSTICS
Enhance early and accurate diagnosis by establishing regional genomic centres, expanding access to kidney diagnostics and pathology services, and developing diagnostic algorithms tailored to resource-limited settings.
2 BUILDING REGISTRIES AND DATA SYSTEMS
Prioritise developing national RKD registries, integrate them with regional and global databases, and implement standardised coding and reporting systems. These steps will generate evidence, measure service outcomes, and support evidence-based reimbursement.
3 EXPANDING WORKFORCE CAPACITY
Strengthen human resources through targeted training in glomerular diseases and genetic nephrology, and by increasing the overall nephrology workforce density.
4 IMPROVING ACCESS TO THERAPIES
Improve treatment availability through regional procurement of orphan drugs, inclusion of RKDs in universal health coverage, and partnerships with international organisations, including the World Health Organisation.
World Health Organization
5 IMPROVING SERVICE DELIVERY
This can be achieved by streamlining referral pathways and establishing centres of excellence. A hub-and-spoke model may help ensure geographical equity.
6 POLICY INTEGRATION
Integrate RKDs into national health priorities by including them in non-communicable disease strategies and rare disease frameworks, and by developing an Iraq-specific national kidney disease plan.
7 PUBLIC HEALTH AND PREVENTION
Promote prevention through genetic counselling programs, especially in high-consanguinity populations, and through awareness campaigns for early detection and screening in high-risk families.
8 FINANCIAL SUPPORT
Financing models for rare kidney diseases (RKD) are evolving to address the high treatment costs and small patient populations, often through collaborative, public-private, and value-based strategies.
9 PATIENT ENGAGEMENT AND ADVOCACY GROUPS
These groups are essential for empowering patients, driving research funding, and accelerating the development of therapies. They provide education, foster patient-led communities, and advocate for patients with policymakers to improve access to treatments.
THE NEXT CRITICAL STEP: ESTABLISH A NATIONAL SCREENING PROGRAM FOR RARE KIDNEY DISEASE
Early detection, timely intervention, and preventing disease progression - particularly in high -risk populations. In regions such as Iraq, where consanguinity is common, targeted screening strategies are especially important.
TARGETED SCREENING STRATEGIES
Family-based screening.
Newborn screening for selected genetic and metabolic disorders.
Screening of individuals with a family history of kidney disease or early-onset CKD.
INTEGRATED GENETIC COUNSELLING
Integrated screening with genetic counselling servics improves risk stratification and clinical decision-making.
REQUIREMENTS FOR EFFECTIVE IMPLEMENTATION
Accessible diagnostic infrastructure.
Trained personnel
Clear referral pathways to specialised care.
ALIGN WITH NATIONAL SYSTEMS AND WHO STRATEGIES
When incorporated into national health systems and aligned with the World Health Organisation's prevention strategies.....
ACHIEVE BETTER OUTCOMES
Reduced morbidity.
Reduced mortality.
Reduced cost.
Improve quality of life
A coordinated, sustainable, and patient-centred approach will transform the landscape of rare diseases in Iraq and improve the lives of patients and their families.

and policymaker awareness and weak patient advocacy networks.

- No National Kidney/RKD Strategy: Limited awareness prevents kidney disease from being included in national health strategies.

STRATEGIES TO IMPROVE THE SERVICES OF RARE KIDNEY DISEASES (RKDs):

1. Strengthening Diagnostics: Enhance early and accurate diagnosis by establishing regional genomic centres, expanding access to kidney diagnostics and pathology services, and developing diagnostic algorithms tailored to resource-limited settings.
2. Building Registries and Data Systems: Prioritise developing national RKD registries, integrate them with regional and global databases, and implement standardised coding and reporting systems. These steps will generate evidence, measure service outcomes, and support evidence-based reimbursement.
3. Expanding Workforce Capacity: Strengthen human resources through targeted training in glomerular diseases and genetic nephrology, and by increasing the overall nephrology workforce density.
4. Improving Access to Therapies: Improve treatment availability through regional procurement of orphan drugs, inclusion of RKDs in universal health coverage, and partnerships with international organisations, including the World Health Organisation.
5. Improving Service Delivery: This can be achieved by streamlining referral pathways and establishing centres of excellence. A hub-and-spoke model may help ensure geographical equity.
6. Policy Integration: Integrate RKDs into national health priorities by including them in non-communicable disease strategies and rare disease frameworks, and by developing an Iraq-specific national kidney disease plan.
7. Public Health and Prevention: Promote prevention through genetic counselling programs, especially in high-consanguinity populations, and through awareness campaigns for early detection and screening in high-risk families.
8. Financial Support: Financing models for rare kidney diseases (RKD) are evolving to address the high treatment costs and small patient populations, often through collaborative, public-private, and value-based strategies.
9. Patient Engagement and Advocacy Groups: These groups are essential for empowering patients, driving research funding, and accelerating the development of therapies. They provide education, foster patient-led communities, and advocate for patients with policymakers to improve access to treatments.

The next critical step is to establish a National Screening Program for rare kidney diseases, which will play a key role in early detection, timely intervention, and preventing disease progression, particularly in high-risk populations. In regions such as Iraq, where consanguinity is common, targeted screening strategies are especially important. These include family-based screening, newborn screening for selected genetic and metabolic disorders, and screening of individuals with a family history of kidney disease or early-onset CKD. Integrating screening with genetic counselling services further improves risk stratification and clinical decision-making. Effective implementation, however, requires accessible diagnostic infrastructure, trained personnel, and clear referral pathways to specialised care. When incorporated into national health systems and aligned with the World Health Organisation's prevention strategies, screening programs can significantly reduce morbidity, mortality, and costs. [11]

CONCLUSION

In conclusion, rare kidney diseases (RKDs) in Iraq pose a significant yet insufficiently recognised public health challenge. These

conditions predominantly affect children and young adults, often leading to premature renal failure and death, and they also burden families and caregivers. Contributing factors include genetic predispositions, limited diagnostic capabilities, fragmented healthcare systems, and inadequate access to therapies, which collectively lead to delayed diagnoses, suboptimal care, and socioeconomic repercussions. Additionally, gaps in data, research, and policy development further hinder effective planning and response. To address these issues, a coordinated approach is essential, one that enhances diagnostic infrastructure, data management systems, workforce competencies, and equitable healthcare access. Moreover, integrating RKDs into national health strategies, supported by sustainable funding and patient advocacy aligned with United Nations and World Health Organisation goals, is imperative. Targeted investment and unwavering policy commitment are crucial for improving outcomes for RKD patients in Iraq.

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Abbreviations list: Congenital anomalies of the kidney and urinary tract (CAKUT), Low-Middle Income Countries (LMICs), Middle East and North Africa (MENA), Rare kidney diseases (RKDs), United State of America (USA)**I**).

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