Data Challenges in Addressing Chronic Kidney Disease in Low- and Lower-Middle -Income Countries

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The burden of chronic kidney disease (CKD) is growing globally, particularly in low- and lower-middle-income countries (LLMICs) where access to treatment is poor and the largest increases in disease burden will occur. The individual and societal costs of kidney disease are well recognized, especially in developed health care systems where treatments for the advanced stages of CKD are more readily available. The consequences of CKD are potentially more catastrophic in developing health care systems where such resources are often lacking. Central to addressing this challenge is the availability of data to understand disease burden and ensure that investments in treatments and health resources are effective at a local level. Use of routinely collected administrative data is helpful in this regard, however, the barriers to developing a more systematic focus on data collection should not be underestimated. This article reviews the current tools that have been used to measure the burden of CKD and considers limitations regarding their use in LLMICs. A review of the literature investigating the use of registries, disease specific databases and administrative data to identify populations with CKD in LLMICs, which indicate these to be underused resources, is included. Suggestions regarding the potential use of administrative data for measuring CKD burden in LLMICs are explored.

The burden of CKD is growing globally and presents challenges for health systems.[1,2] Although the exact pathophysiology is not always clear, even mild forms of CKD are associated with significant morbidity and mortality, with societal and individual impacts that are disproportionately experienced in disadvantaged communities.[3] Access to representative and regularly updated data is central to understanding the nature and burden of disease, track progress, and to ensure that investments are clinically and cost effective. Such data sources do not exist in many parts of the world, especially the LLMICs. As a result, the need to develop sustainable approaches to data measurement, particularly in LLMICs, has been emphasized as a crosscutting theme in the International Society of Nephrology (ISN) strategic plan for integrated care of patients with kidney failure.[4]

This article reviews the current tools that have been used to measure the burden of CKD and considers the challenges of their use in LLMICs. We include a review of the literature regarding the use of registries, databases, and administrative data in CKD in LLMICs which highlights their underuse. We provide suggestions for the potential use of administrative data as a cost-effective solution for measuring CKD burden in LLMICs, cognizant of these challenges, to improve health care systems into the future.

GROWING GLOBAL BURDEN OF CKD

The Global Burden of Disease study reported that the number of deaths attributable to CKD increased by 41.5% from 1990 to 2017,[5] with CKD ranked as the 10th leading cause of death by the World Health Organization in 2020.[6] These estimates mostly capture deaths due to the most severe stage of kidney failure, where kidney replacement therapy (KRT) is necessary

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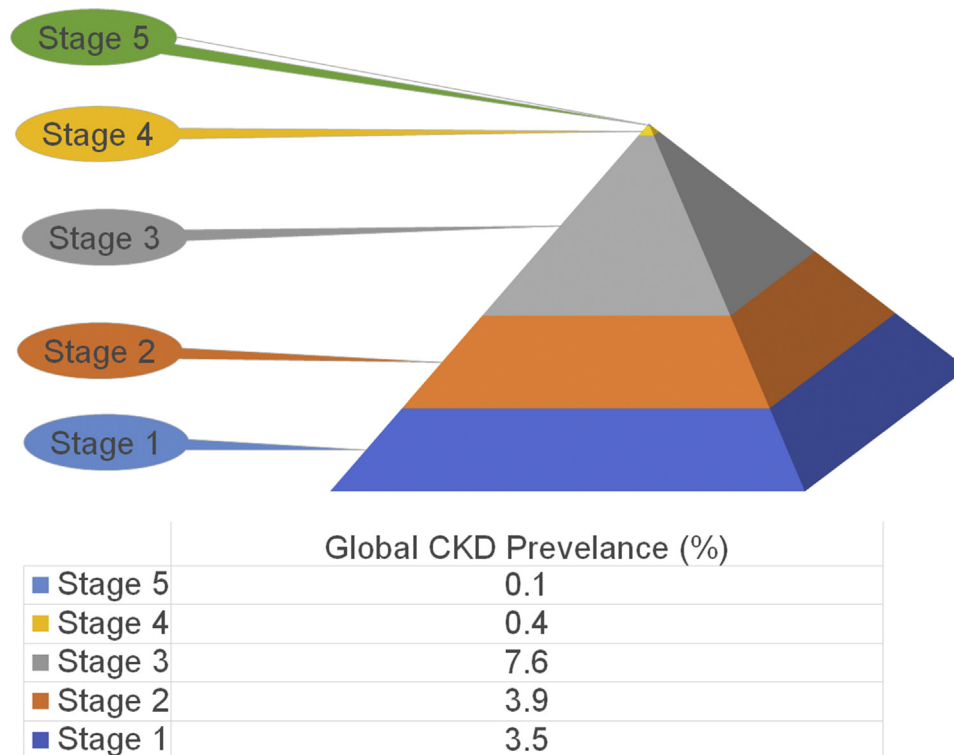
Figure 1. The distribution of global chronic kidney disease (CKD) prevalence by stage of CKD.
Stage 1 (glomerular filtration rate [GFR] > 90 ml/min/1.73 m^2 and albumin-to-creatinine ratio [ACR] > 30 mg/g).
Stage 2 (GFR 60 – 89 ml/min/1.73 m^2 and ACR > 30 mg/g).
Stage 3 (GFR 30 – 59 ml/min).
Stage 4 (GFR 15 – 29 ml/min/1.73 m^2).
Stage 5 (GFR < 15 ml/min/1.73 m^2)
Data presented as calculated by Hill et al.[20] in 2016.

to prolong life, which represents only a small fraction of total CKD-related mortality. In 2017, CKD resulted in 2.6 million deaths worldwide; 1.2 million were a direct result of CKD, and a further 1.4 million were from the cardiovascular disease (CVD) attributable to impaired kidney function.[5] It is predicted that CKD will rise further to become the fifth leading cause of years of life lost by 2040.[7] Much of this growth in CKD burden will be in LLMICs, where treatment gaps for kidney disease are most stark.[8] Whereas consistent data regarding the cost of KRT in LLMICs is limited,[9] the experience from economically developed countries highlights the high cost of treatment, such that in 2010 the United Kingdom's annual cost of CKD was estimated at £1.44 to £1.45 billion, with more than 50% spent on those receiving KRT who constitute only 2% of the United Kingdom's diagnosed CKD population.[10]

Similarly, the bulk of current data collection efforts in CKD focus on patients receiving KRT, collected through dialysis and transplant registries. This is understandable, given the high cost of KRT and the high burden of complications and mortality. According to the ISN Global Kidney Health Atlas survey in 2017, dialysis and transplant registries were present in 75 (64%) and 68 (58%) of responding countries, respectively, compared with only 9 (8%) countries with a nondialysis CKD registry.[11] In the 2019 Global Kidney Health Atlas survey, chronic hemodialysis was available in 156 (98%) and transplantation in 114 (71%) of 160 responding countries, with information on the prevalence of treated kidney failure available in 91 (57%).[12]

A strong case for systematic measurement of CKD not requiring KRT also exists. Data from several large-scale studies including the Chronic Kidney Disease Prognosis Consortium (CKD-PC; more than 70 cohorts, including data on more than 11 million people worldwide)[13] show that subjects with milder degrees of CKD (Figure 1) are also at a high risk of mortality,[14] morbidity,[15] and reduction in quality of life.[16] Indeed, recent literature has highlighted the important role CKD plays in driving the number one cause of death globally, CVD, where CKD is a more powerful risk factor for incident coronary events than diabetes.[17] When the additional adverse impacts of CKD on cancer[18] and infection risk[19] are considered, the need for a systematic approach to measurement of CKD becomes even more compelling.

Table 1. Sources of Data Which Can Contribute to CKD Burden Measurement

Source of Data	Description	Examples of Use in CKD
Prospective cohort studies	Observational, often longitudinal studies, to measure the occurrence of a disease or outcome and its association to an exposure	CanPREDDICT study[30] The PSPA study[31]
Clinical trials	Interventional, prospective studies to evaluate the effects of an intervention on human health outcomes.	ADVANCE trial[21] ACCORD trial[33]
Registries	Systematic collections of observational data for specific groups of patients, which can be used to track prevalence, outcomes, and care for patients with chronic diseases	The Indian CKD registry[34] CKD registry of Queensland (Australia)[35]
Administrative datasets	Repositories of data, usually maintained through health care providers or other institutions, which may include a variety of demographic, diagnostic, and health service use information	GLOMMS-II study[36] Alberta Kidney Disease Network[37]

ACCORD, Action to Control Cardiovascular Risk in Diabetes; ADVANCE, Action in Diabetes and Vascular Disease: Preterax and Diamicron MR Controlled Evaluation; CanPREDDIRCT, Canadian study of prediction of death, dialysis and interim cardiovascular events; CKD, Chronic kidney disease; GLOMMS-II, The Grampian Laboratory Outcomes, Morbidity and Mortality Study-II; PSPA, Parcours de Soins des PersonnesAgées (characteristics and treatment course of patients older than 75 years, reaching end-stage renal failure in France).

Another powerful argument to support more accurate measurement of the burden of earlier stages of CKD is the strong evidence base suggesting that available treatments are effective at slowing the progression of CKD and preventing other complications including CVD.[21-24] Because CKD shares risks factors with many noncommunicable diseases, improved recognition of CKD will provide a synergistic opportunity to improve awareness and treatment of the other drivers of CVD. Additionally, an accurate estimation of burden will permit a better understanding of regional risk factors and support resource allocation decisions in deriving the greatest health gain.

The argument that is most likely to appeal to policy makers relates to health-economic analyses. Recent work sponsored by the Australian Commission of Safety and Quality in Health Care has highlighted that each $1 of expenditure on the Australia and New Zealand Dialysis and Transplant Registry has yielded $7 of benefits through improvements in clinical practice, with similar economic benefits seen from other Australian clinical registries.[25] These economic benefits, along with the clinical impacts that KRT registries have had on patient outcomes globally, make the case for setting up KRT registries compelling. Although the case for investment in systematic CKD measurement and reporting is powerful, better data are needed on the costs and cost-effectiveness of CKD monitoring before establishing CKD registries within discrete jurisdictions.

TOOLS USED TO MEASURE THE BURDEN OF CKD

The 2012 Kidney Disease Improving Global Outcomes guidelines[26] provide a structured way to identify and categorize patients with CKD, perform risk prediction, and plan treatment. These definitions have allowed standardized reporting internationally, including a recent meta-analysis (100 studies, 7 million people) that reported a global CKD prevalence of 11% to 13%.[20]

There are still significant gaps in CKD awareness, however, especially in low-income countries where robust primary care systems are lacking. Only 6% of low-income countries report the existence of CKD detection programs[11]; this has resulted in few high-quality studies and wide variations in reported CKD prevalence.[27] As a result, LLMICs are grossly underrepresented in large global CKD databases such as the CKD-Prognosis Consortium,[13] where 26 of 28 cohorts used to examine the role of differing risk factors on the prognosis of patients with severely decreased kidney function were from 12 high-income countries.[28]

DATA SOURCES

Various sources of data can be used to measure the burden of CKD (Table 1), including prospective cohort studies, clinical trials, medical registries, and administrative data.

Prospective Cohort Studies

Their observational nature and targeted data collection make prospective cohort studies a cornerstone of understanding chronic diseases, best shown by the Framingham Heart Study.[29] Many cohorts are providing similar insights in CKD,[30,31] including the International Network of Chronic Kidney Disease cohort studies (iNET-CKD) which was established in 2012 as a "virtual" collaborative network of CKD.[32] This global network, facilitated and endorsed by the ISN, includes 26 active member studies of patients with CKD not requiring KRT operating in Asia, Africa, Europe, Australia, and North and South America. Such prospective cohort studies, however, are expensive and time-consuming and may not offer the most cost-effective solution to the global CKD awareness gap.

Clinical Trials

Randomized controlled trials are vital in identifying treatments to improve disease progression and clinical outcomes but lend themselves poorly to address the burden of CKD. Patients are highly selected and often not representative of broader populations. Furthermore, historically, randomized clinical trials have either excluded patients with CKD or been few in number,

Table 2. The Strengths and Limitations of Potential Sources of Data to Estimate the Burden of CKD in LLMICs

Data Source	Strengths	Limitations
Level of care		
Primary	Access to, and represents, general population Ongoing patient-health worker relationship Understands community context of patient	"Cases" diluted in large "well" population Lack of electronic databases Limited access to CKD detection tools (*e.g.*, laboratory testing)
Secondary	Better resourced for CKD detection and reporting Patients presenting to secondary care likely higher risk for CKD Hospital administrative data systems better developed	Only opportunistic patient capture/detection Less likely to capture rural and remote patients Not structurally suitable for follow-up and intervention
Tertiary	Opportunity to achieve specialist input to data recording	Limited availability in, and not representative of, many regions Often focus upon treatment of kidney failure rather than prevention
Clinical research		
Prospective cohort studies	Usually robust disease estimates, allowing regional comparisons Allow detailed data on CKD, treatment, and outcomes	Need large numbers of participants to capture less common diseases Expensive and time-consuming, especially in resource-poor settings
Randomized controlled trials	Able to identify the effect of treatments of CKD, including regional differences Usually follow patients over time, showing rates of disease progression	Patients are often highly selected Expensive and rarely recruit in resource-poor settings
Registries	Systematic and focused data collection Allow detailed estimates regarding CKD prevalence, treatments, and outcomes	Can be costly and require a long-term commitment of resources Rely on high-quality data entry to be a valuable resource
Electronic health technologies		
Administrative data	Large repositories of data can be created across all levels of health care Minimal additional costs to interrogate data once established	Requires specific skills to analyze and report, especially in CKD Little experience of use in LLMICs Data accuracy dependent upon data entry and coding structures
Linked data	Leverages the value of existing data sources through data aggregation Can strengthen reliability and policy value of administrative data	Challenging where cohort and trial data are sparse Can be complex to administer, needs clear processes and data ownership Requires the necessary infrastructure to perform data linkage
EMR	Allows a combination of clinical, sociodemographic, laboratory, and other data types to be combined Data collected in real time and reflects extant clinical understanding	Often heterogenous data format and structure Requires advanced IT systems, which may be lacking in resource-poor settings Limited experience of use and reliability in LLMICs

CKD. chronic kidney disease; EMR, electronic medical record; IT, information technology; LLMICs, low- and lower-middle-income countries.

small in scale, and have rarely recruited from LLMICs. Notwithstanding the emergence of more pragmatic trial designs and broader inclusion, randomized clinical trial data is unlikely to form the basis of meaningful CKD measurement and prevention initiatives in LLMICs.

Medical Registries

Medical registries, which by their nature systematically collect clearly defined health and demographic data for patients with specific health conditions,[38] can be used for understanding the burden of CKD. Such registries have been central to measuring KRT and improving the outcomes for those patients. However, registries require a long-term commitment of resources and their value strongly depends on the quality of data recorded,[39] which has implications when considering their effectiveness in monitoring the less-severe stages of CKD. Unlike KRT which is managed primarily in renal units and nephrology practices, CKD is largely a slowly progressive, insidious disease that is spread across all levels of the health system, which may explain why few such registries currently exist.[11]

Administrative Data

Administrative data, originally developed as part of electronic health records or for billing purposes,

include a variety of demographic, diagnostic, and health service use information.[40,41] The use of administrative data in kidney disease is complex because the diagnostic accuracy is dependent on good information flow between different levels of the health care system and standardized coding of care episodes.[42] For identifying patients receiving KRT, administrative data are largely comparable to purpose-designed disease registers.[43] The diagnosis of CKD in administrative data has historically been less sensitive,[44-47] but improves with advancing CKD stage and in high-risk populations,[48] suggesting greater utility in identifying patients with more advanced kidney disease.

An important advantage of administrative data is the ability to link to clinical, pathology, or pharmaceutical datasets with the prospect of a better understanding of treatments and their influence upon outcomes. The technique of linking datasets brings together data held by different entities (*e.g.*, electronic health records, pathology systems, hospital administrative data, and pharmaceutical data) regarding a single individual using a common identifier or probabilistic techniques.[41] Examples include a linked population-based cohort of all patients with renal impairment in Grampian, a region of north-east Scotland, served by a single biochemistry service, who

Table 3. Summary of Articles Meeting Eligibility Criteria

Study	Study Type	Region/ Country	Year Published	Population	Data Sources	n	Primary Outcome Reported
Aatif et al.[50]	Retrospective observational study	Morocco	2012	Patients undergoing native renal biopsy 2000–2007	Single-center renal biopsy database	161	Frequency of glomerular disease
Agarwal and Srivastava[51]	Review article	India	2009	Patients with CKD	Indian CKD Registry /published articles	>30,000	Prevalence and cause of CKD
Bamgboye[52]	Cross-sectional observational study and questionnaire	Multinational	2016	Patients treated with KRT	Published (South Africa) and unpublished (Nigeria) renal registry reports / questionnaire	Unable to determine	Incidence, prevalence, and challenges of managing KRT
Counil et al.[53]	Retrospective observational study	Tunisia	2008	Patients treated with KRT 1992–2001	Tunisian dialysis registry	6937	Incidence rates of patients commencing KRT
Davids et al.[54]	Review article	Multinational	2016	Patients treated with KRT	African renal registries	Unable to determine	Registry output not reported
Davids et al.[55]	Review article	Multinational	2017	Patients with CKD and those treated with KRT	African renal registries	Unable to determine	Registry output not reported
Edefonti et al.[56]	Review article	Nicaragua	2010	Children with CKD 2000–2009	Nicaraguan CKD database	>2000	Registry output not reported
Ene-Iordache et al.[57]	Cross-sectional observational study	Multinational	2016	Patients with CKD	Kidney Disease Data Centre database	75,058	Prevalence and awareness of CKD and risk of cardiovascular disease
Ghods et al.[58]	Review article	Multinational	2015	Organ donation and transplantation for patients within 57 member states of Islamic Cooperation	Organ donation and transplantation registries/ published articles	Unable to determine	Rates of organ donation and transplantation
Jain et al.[59]	Review article	Multinational	2012	Patients treated with PD 1997–2008	Renal registries/ nephrology societies/ health ministries/ academic centers	195,555	Trends in PD use
Lim et al.[60]	Review article	Multinational	2008	Patients treated with KRT	Renal registry data	Unable to determine	Review the uses of renal registry data in health and dialysis care
Liyanage et al.[8]	Systematic review	Multinational	2015	Patients treated with KRT	Renal registries/ published articles/ national experts	2,618,000	Prevalence and worldwide use of KRT
MacGregor et al.[61]	Cross-sectional observational study	Multinational	2006	Patients treated with home HD	Renal registries	Unable to determine	Prevalence of home HD
Rajapurkar and Dabhi[62]	Review article	India	2010	Patients with CKD	Indian CKD Registry/ published articles	38,193	Prevalence and cause of CKD
Rajapurkar et al.[34]	Cross-sectional study	India	2012	Patients with CKD	Indian CKD Registry	52273	Prevalence and cause of CKD
Schaefer et al.[63]	Prospective observational study	Multinational	2012	Children and adolescents (0 to 19 years old) receiving chronic PD	International Paediatric Peritoneal Dialysis Network Registry	1773	Relationship between economic wealth and PD practices and outcomes
Shaikh et al.[64]	Retrospective observational study	India	2018	Patients treated with HD	The Rajiv Aarogyasri Community Health Insurance Scheme	13,118	Clinical outcome and cost of care
Thin[65]	Retrospective observational study	Myanmar	2004	All kidney transplant recipients and donors in the Myanmar renal transplantation program	Patient databases	22	Donor and recipient outcomes
Zafar et al.[66]	Prospective observational study	Pakistan	2018	Living-donor kidney transplant recipients 1993–2009	Single-center database	2283	Risk model predicting long-term patient and allograft outcomes

CKD, chronic kidney disease; KRT, kidney replacement therapy (including hemodialysis, peritoneal dialysis, and kidney transplantation); HD, hemodialysis; PD, peritoneal dialysis.

have been linked to national hospital episode diagnosis data.[36] The Alberta Kidney Disease Network in Canada is another example, linking laboratory results, population registries, clinical claims, hospital encounters, and medication data to provide important insights in to the impact of CKD.[37]

BARRIERS TO COLLECTING DATA ON CKD BURDEN IN LLMIC

Unique barriers to data collection in LLMICs may contribute to their under-representation in the types of studies described. The strengths and limitations of

potential sources of data to estimate CKD burden in LLMICs are presented in Table 2.

LITERATURE REVIEW OF THE USE OF REGISTRIES OR ADMINISTRATIVE DATA IN CKD IN LLMICS

We conducted a review of the literature using a predefined search strategy of MEDLINE, EMBASE, and PubMed from inception until July 2019. Broad search terms for registries, administrative data, CKD, and LLMICs were developed using the Cochrane Kidney and Transplant glossary of kidney disease terms, the

Cochrane Effective Practice and Organisation of Care Lower-Middle-Income Country Databases 2013, and assistance from the University of New South Wales Library (Supplementary File S1). Additional studies identified through reference list review and peer discussions were included. Two authors (BT and AA) independently reviewed all titles and abstracts and conducted full-text review of eligible papers. Any disagreement was resolved by consultation. A flow diagram of the search strategy, presented according to the Preferred Reporting in Systematic Reviews and Meta-Analysis guidelines, is included in the Supplementary Material (Supplementary Figure S2).

For articles to be included there needed to be specific reference to the use of administrative data, such as International Classification of Disease, version 10 codes, or to a registry or database to define populations with CKD in LLMICs. Studies could include all stages of CKD, including those on KRT and participants of any age. Income status of countries within each article was determined using The World Bank income classification.[49] Only 19 full-text articles (8 review articles, 4 retrospective observational studies, 2 prospective observational studies, 4 cross-sectional studies, and 1 systematic review), shown in Table 3, were eligible for inclusion from more than 2000 titles and abstracts screened. Because of the heterogeneous nature of the studies, the varying outcomes and inconsistencies in data presented, a standardized quality assessment tool could not be applied.

Summary of Articles Meeting Eligibility Criteria

Eight review articles were identified. Two considered the incidence and prevalence of CKD in different regions of India including CKD registry data[51,62] and two used African renal registries to describe the lack of currently available data on CKD and KRT in Africa.[54,55] One article described an international collaborative project as a sustainable model for funding CKD health care in Nicaragua, including the establishment of a database of renal and urological diseases.[56] One article described how registries may improve health and KRT care using renal registries from the Asia Pacific region as an example.[60] The two remaining review articles described global trends in organ transplantation[58] and peritoneal dialysis[59] across numerous countries using registry data.

Of the retrospective observational studies, two were based in Africa. One reported registry data on the changing incidence of KRT in Tunisia,[53] and the other reported the incidence of glomerular disease from a renal biopsy database in Morocco.[50] In India, one study used claim reports from a community health insurance scheme to report clinical outcomes and the cost of care

for patients receiving maintenance hemodialysis[64] and one article from Myanmar in 2004 described the details of all 22 renal transplantations that have occurred there since the first transplantation in 1997.[65]

Of the two prospective observational studies, one used a large urology and transplantation database to develop a risk prediction model for long-term patient and allograft outcomes following living-kidney donor transplantation in Pakistan.[66] The second study used prospectively collected data from the International Pediatric Peritoneal Dialysis Network registry to describe the relationship between economic wealth and chronic peritoneal dialysis practices and outcomes in children.[63]

Of the four cross-sectional studies, one derived data from an international registry rather than a dedicated local renal registry to report the difference in prevalence of home hemodialysis between countries.[61] The second reported baseline data from the Indian CKD Registry,[34] allowing characterization of the demographics and etiologies of CKD in this population. The third described KRT prevalence and resource limitations in sub-Saharan African countries using data from renal registry reports and a questionnaire of nephrologists.[52] The last cross-sectional study compiled a database from screening programs in 12 countries across six world regions to describe the high prevalence and low awareness of CKD in these populations.[57]

The single systematic review addressed global access to KRT, including data from published observational studies, renal registries, and national experts.[8]

The heterogeneous collection of studies identified shows the varied ways in which registries and administrative data can be used within developing health care systems to report CKD related data. However, the small number of eligible articles and the small numbers of records analyzed in some of the publications indicates that this remains an underused resource for most LLMICs.

There are several limitations to our review. The search was restricted to articles published in the English language and in indexed journals which may have excluded some relevant articles. Income status was determined at the time of review rather than at the time of article publication which may have excluded articles from countries migrating between income categories.

FUTURE MEANS OF MEASURING CKD BURDEN

Logistical challenges have prevented the development and widespread implementation of data collection tools in less advanced countries.[67] In 2017, serum creatinine

testing was available in primary care settings in fewer than 50% of LLMICs, whereas qualitative urinalysis could be performed in primary care in only 41% of low-income countries and 56% of lower-middle-income countries.[11] Although reliable testing may be available within secondary care, this is often not the case in rural communities,[68] such that there remains a substantial challenge in strengthening laboratory services in LLMICs. Point-of-care tools such as salivary urea[69] and creatinine testing[70] have shown promise, and with further research and development may have wider applicability.

The feasibility of screening individuals for CKD using a common protocol in under-resourced countries, particularly in individuals with traditional risk factors for CKD, has been examined by the ISN Kidney Disease Data Center.[57] Assessment for kidney disease has also been incorporated into pre-existing World Health Organization CVD guidance tools for lower-middle-income countries, such as the Package of Essential Noncommunicable Disease Interventions for Primary Health Care in Low-resource Settings[71] and HEARTS technical package[72]; a practical set of interventions to support primary care CVD risk factor management. Strengthening of monitoring systems that are integrated into existing health information systems should support such programs.[73] It is, however, important to emphasize that the risk factors for CKD in LLMICs are less well clearly delineated than in high-income countries and awareness of even the traditional risk factors is low.[57] Complex interactions between traditional and nontraditional risk factors including communicable and noncommunicable disease and environmental exposures also exist,[74] and the heterogeneity regarding presentation, management, and clinical setting of such contributory factors can undermine their recognition. Given this and the lack of evidence regarding cost-effectiveness of screening in developing countries, determining local high-risk populations is important before implementing a community screening program.[75]

Patients who present to secondary care for any reason are at increased risk for CKD and should be routinely screened for kidney disease as part of, and alongside, a more comprehensive CVD risk assessment. Screening such patients for CKD and the other, often concomitant, risk factors for CVD offers another opportunity to mitigate the burden of CVD in LLMICs through earlier detection, intervention, and surveillance of patients at risk of future CVD. Through the development of hospital administrative data systems improved monitoring offers an alternative approach to setting up de novo CVD or CKD registries. Many countries are creating unique identifiers for their citizens, using this mechanism for linkage of medical, insurance, and demographic datasets would allow system level monitoring of trends as well as tracking of individual patients. Many hospitals in lower-middle-income countries contract out laboratory services, with the resultant data able to be interrogated and linked to hospital data systems. Opportunities to improve understanding of CKD prevalence in some regions may further allow extrapolation to matched populations.[74]

The use of administrative data may be limited by poor quality and limited capacity for data extraction, analysis, and interpretation.[76] Investment will be required to build a workforce knowledgeable in health care and information technology to improve accuracy and develop a reliable method of disease surveillance. Such investments will improve understanding of the burden of other diseases as well, potentially offering a more sustainable and cost-effective alternative to single-disease registries.

Many health care providers are developing electronic medical record (EMR) systems, which offer access to a spectrum of information including clinical, administrative, and biochemical data without the need for data linkage. Data are collected in real time for provision of direct medical care rather than for reimbursement or monitoring of health service usage, as is often the case with administrative data. Using EMR to develop a nondialysis CKD registry has already been validated,[77] but several challenges continue to exist for EMRs, including heterogeneous data with differing formats and structures, and the lack of protocols to handle incomplete or inconsistent data.

Health care systems in LLMICs are increasingly adopting technology with improvement in quality of care[78] and user satisfaction.[79] Challenges include inconsistent impacts on workflow, integration with the existing health care systems with consequent impacts on sustainability,[78,79] local budgetary control, and in-country information technology.[79]

Ethical considerations exist regarding both administrative data and EMR technology, including data privacy, security, ownership, and informed consent. These must be properly contextualized and require open and transparent discussion of societal values and preferences, appreciating the increased sensitivity of some data for vulnerable populations within fragile political or cultural environments.[80] Digital health technologies should be developed under the oversight of ministries of health, responsible for data ownership and health resource allocation, and within the framework of the World Health Organization Global Strategy on Digital Health.[81]

CONCLUSIONS

Dramatic increases in the prevalence of CKD are projected for the future, particularly in developing

countries. Measurement is critical to mitigating this burden, but existing measurement tools such as dialysis registries are unlikely to be viable. Leveraging existing data collection tools, including administrative data sources to derive measures of CKD, is likely to be a more feasible approach, although our literature review suggests that the use of administrative data is very low in LLMICs.

DISCLOSURE

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AUTHOR CONTRIBUTIONS

BT and AA were responsible for research conception, literature search, study evaluation, manuscript writing, and revision. VJ and MG were responsible for research conception, manuscript writing, and revision.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Supplementary File S1. Database search strategy for MEDLINE, EMBASE and PubMed

Supplementary Figure S2. Flow diagram of search strategy and article identification

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