ORIGINAL ARTICLE

Overcoming the challenges in setting up a renal registry in a sub-Saharan African country: Preliminary report on the Kenya Haemodialysis Registry

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ABSTRACT

Introduction: Haemodialysis (HD) is the most common kidney replacement therapy (KRT), yet over 90% of KRT patients reside in high-income countries and HD registries exist in only 12 African countries. The Kenya Renal Association established the Kenya Haemodialysis Registry to document, analyse and improve national HD services. We report its implementation and a preliminary epidemiological analysis of the first four months of data.

Methods: The registry is a prospective record of prevalent and incident HD patients treated nationally. Using consecutive sampling, patient data were captured on a digital questionnaire, anonymised immediately, and uploaded to cloud-based storage.

Results: Over four months from September 2024, 130 HD units (49% of those in Kenya) were approached; 16% declined and 20% had closed. Of 2193 patients registered, 65% were male. Estimated prevalence was 130 per million population (pmp) — 170 pmp in males and 91 pmp in females; a ±10% sensitivity analysis gave 117–143 pmp. Median age was 54.0 years, with only 22% younger than 40. A tunnelled catheter was the commonest vascular access (57%); 27% had an arteriovenous fistula. Over 95% received twice-weekly HD and over 90% were treated for anaemia, though more than half had been transfused. HIV positivity was 4.6%, hepatitis B 1.5% and hepatitis C 0.3%. Most patients (60%) had been on HD for 1–5 years and 6.6% for over five years.

Conclusions: This interim report demonstrates the feasibility of renal registries in Africa despite logistical challenges such as technical and ethico-legal constraints.

Keywords: haemodialysis; renal registry; chronic kidney disease; end-stage kidney disease.

INTRODUCTION

The proportion of individuals living with chronic kidney disease (CKD) is estimated to be 10.4% among men and 11.8% among women [1]. Moreover, the proportion of deaths worldwide attributed to CKD rose by 41.5% between 1990 and 2017 [2]. Consequently, CKD has grown from the 25th to the 16th leading cause of years of life lost between 1990 and 2017 and is projected to reach fifth place by 2040 [3]. Of the 850 million people worldwide living with CKD, the majority are in low-income (LIC) or in low- and middle-income countries (LMICs) [4].

Haemodialysis (HD) is the most common kidney replacement therapy (KRT), accounting for 69% of all such cases and 89% of all dialysis therapies [5]. In 2010, over 90% of patients receiving KRT resided in high-income countries [6]. Kidney registries in Africa are few, with only 12 countries having established them, representing 31% of the countries surveyed, compared to a country coverage for dialysis registries of 100% in North and East Asia and 91% in Western Europe [7].

The availability and affordability of dialysis services are major constraints on the access of the treatment in

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Africa. Even where these services are available, the quality of dialysis is not known and patient outcomes are unavailable. The annual cost of in-centre HD in Africa has been estimated at approximately US$14,000 [7], placing a substantial economic burden on already over-stretched health budgets in countries such as Kenya.

Since 2010, the Government of Kenya has rapidly increased the access to haemodialysis services [8]. As a result, the number of patients on haemodialysis substantially increased and is currently estimated to be more than 4000 individuals.

The Kenya Haemodialysis Registry was established to document, analyse and improve the country's quality of haemodialysis services. Its specific objectives were to record all patients being treated by haemodialysis nationally and to monitor their demographic data, clinical aspects of their HD treatments, their specific corresponding laboratory parameters, and to correlate these with their clinical outcomes.

This paper serves a dual purpose: first, to report the implementation and early operation of the Kenya Haemodialysis Registry; and second, to present a preliminary descriptive epidemiological analysis derived from the first four months of registry data.

METHODS

We adopted a mixed implementation and descriptive epidemiological approach. The former describes the development, data architecture, and operationalisation of the registry, whereas the latter component comprises analysis of data collected during the first four months of registry operation, to characterise patient demographics, clinical features, treatment patterns and selected outcomes among individuals receiving HD.

To be enrolled into the study, a patient had to suffer kidney failure and be undergoing HD at an HD unit in Kenya. Non-resident patients on holiday HD were excluded. In addition, dialysis duration cut-off of 90 days was applied, and patients who had been on HD for less than this time were excluded to minimise the inclusion of acute kidney injury (AKI) cases. All patients were sampled consecutively; their data were captured via a digital questionnaire, quickly anonymised and uploaded for cloud-based storage in a central database that is run by the Kenya Renal Association, which is the sponsor of the registry. Data were codified according to the renal diagnosis codes of the, European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) [10]. All new patients will be entered into the registry subsequently.

Ethical approval was obtained from the Kenyatta University Ethics Review Committee (approval number PKU/29693/I2017) and a research licence from the National Commission for Science, Technology, and Innovation (NACOSTI) (licence no. NACOSTI/P/24/40002). Approval for data collection was obtained from individual hospital management boards. Scrupulous attention was paid to ethical aspects, patient privacy, and data protection. Informed consent was obtained from patients who were 18 years of age or older. For those younger than 18, assent from the person responsible or consent from their parent or legal guardian was obtained.

Patient confidentiality was maintained and compliance with good clinical practice was emphasised. The data are owned by the Kenya Renal Association on behalf of the Ministry of Health of the Government of Kenya. Individual HD units have access to the data for that facility's patients. The principal investigator ensured protocol fidelity.

The following patient details were collected: age, gender, dialysis unit involved, how dialysis is paid for, details of kidney disease and dialysis treatment, laboratory sourced and corresponding parameters recorded, and major clinical outcomes (death, transplantation, and hospitalisation).

Data were analysed using the Statistical Package for Social Sciences version 29. Continuous variables were summarised using appropriate measures of central tendency (such as mean or median) and variability (such as standard deviation (SD) or interquartile range (IQR)). Categorical variables were presented as frequencies and percentages to describe their distribution within the corresponding population. Crude registry-based period prevalence rate was defined as the number of all the patients receiving maintenance HD that were registered over the four-month period of registry set-up divided by the total estimated population of Kenya as of 30 June 2024.

RESULTS

This report summarises the data entered over the first four months of the registry's operation (between 3 September 2024, when it began enrolling patients, and 20 December 2024).

A total of 263 HD units were identified from data available from the licensing authority (the Kenya Medical Practitioners and Dentists Board) and from the insurance payer (the National Hospital Insurance Fund). A total of 130 of these units were approached, representing 49% of the total identified.

Of those accessed, 21 units (16%) declined or delayed providing approval to share their HD data, for reasons including the nephrologist in charge declining approval, the tedious process of securing approval from the hospital's

ethics review board, exaggerated approval fees, and failure to respond. From prior records taken four years previously, we found 26 HD units (20%) that subsequently ceased to offer dialysis services. To offset this, 24 new dialysis units have been registered over the past four years. Of the 83 dialysis units that are now enrolled in the national registry, the mean number of patients was 26.4, with a median of 24 and a range of 1–96 patients.

A total of 2193 patients with end-stage kidney disease (ESKD) have been enrolled, of whom 65% are male. Their mean age was 52.6 years (SD ± 15.8), and the median age was 54.0 (IQR 41–65) years with an age range of 13–99 years (Figure 1). The proportion of patients older than 60 was 40%, and 22% were younger than 40.

By crude extrapolation, the 263 units in the country are estimated to represent 6948 patients [11].

A sensitivity analysis showed that, under all plausible hypotheses, the national burden of haemodialysis has stayed constant. The estimated 6948 patients recorded by the country's HD units correspond to a crude national prevalence of 130 per million population (pmp), with 91 pmp for females and 170 pmp for males. A ±10% sensitivity adjustment was used to account for potential non-response bias, resulting in a range of 117–143 pmp. Period prevalence varied slightly after controlling for gender (154–188 pmp for males and 82–100 pmp for females).

Of the cases of patients recorded at CKD stage 5 on maintenance HD, 80% had hypertension labelled as the cause of the condition, with diabetes accounting for 17% (Figure 2).

Only 15% of these patients confirmed they have a potential kidney donor for kidney transplantation.

The mean time that patients had been on haemodialysis was 2.89 (SD ± 2.62) years, with a median of 2.11 (IQR 1.05–3.86) years. Most patients (60%) had been on HD for 1–5 years, and 17% for more than five years (Figure 3).

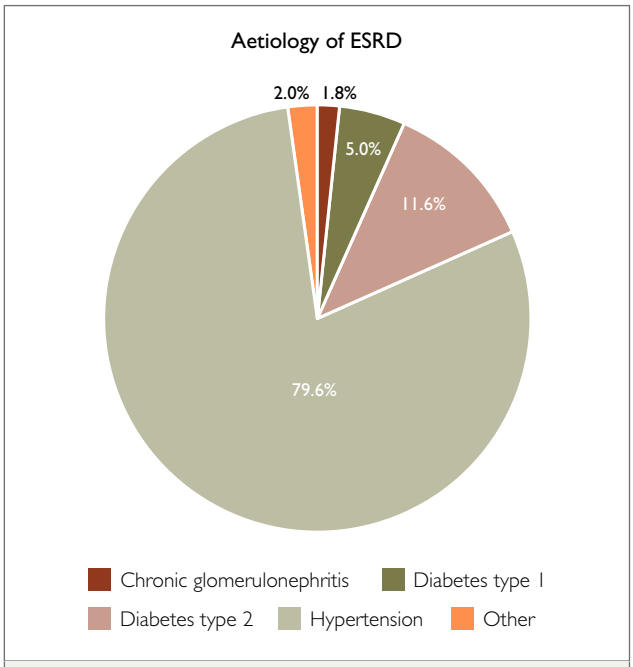

Figure 2. Aetiology of end-stage kidney disease.

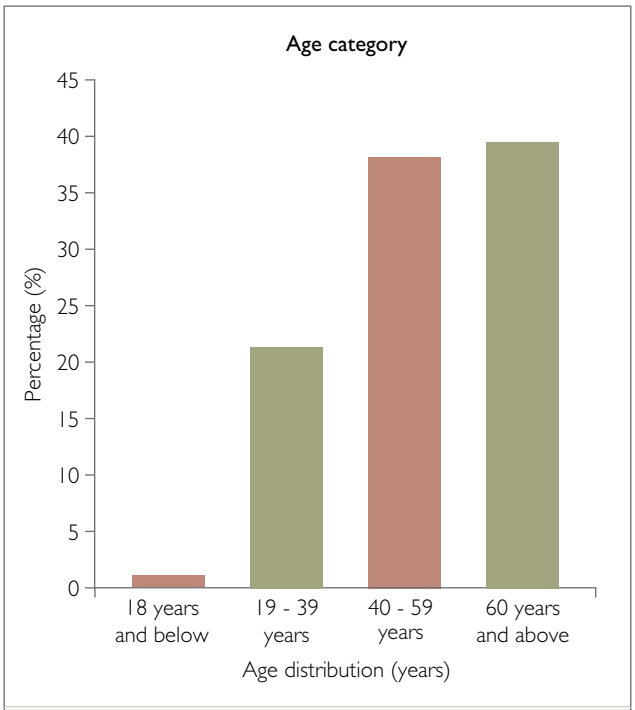

Figure 1. Distribution of patients on haemodialysis by age.

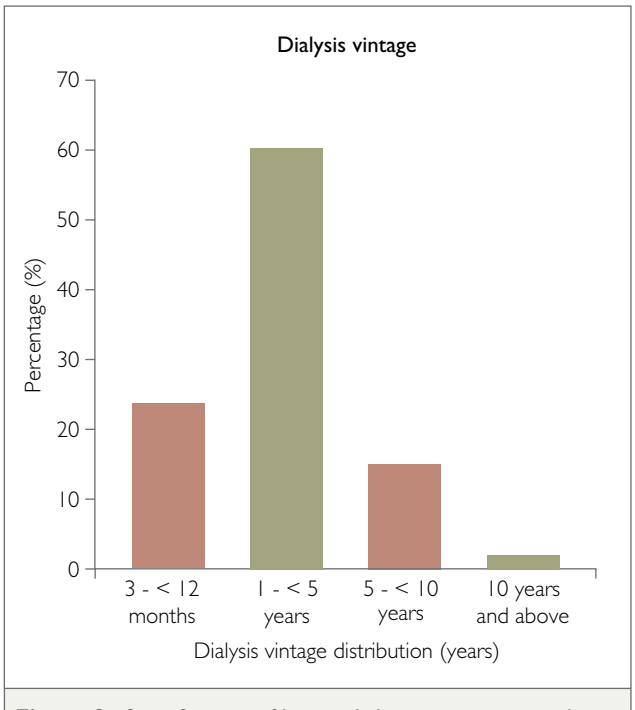

Figure 3. Stratification of haemodialysis patients according to duration on treatment.

The patients' most common vascular access type was a tunnelled haemodialysis catheter (57%), with only 27% having arteriovenous fistulas (Figure 4). Most patients (96%) were on twice-weekly HD, this being driven by the reimbursement policy of the main insurer [the Social Health Insurance Fund (SHIF)], which covers only two haemodialysis sessions a week; 2.5% of patients had dialysis three times a week whereas 1.2% had the treatment only once a week. The SHIF pays for 95% of the patients with only 3.5% being covered by out-of-pocket expenses (Figure 5).

Almost all patients received treatment for anaemia, with 95% receiving erythropoietin stimulating agents and 94% given intravenous iron. However, more than half of the patients (55%) reported having received blood transfusion at one time in their CKD treatment, with the median number of units received being two units of red blood cell transfusion (Figure 6).

The serological tests conducted on the patients identified the majority (94%) as being sero-negative for hepatitis B virus (HBV), hepatitis C virus (HCV) and human immunodeficiency virus (HIV) (non-HBV/HCV/HIV). Only 4.6% tested positive for HIV, 1.5% for HBV, and 0.3% for HCV. It was found that 45% of patients had completed four doses of hepatitis B vaccination, 5.4% had received fewer than four doses, and the majority (50%) had not received any hepatitis B vaccination.

The mean haemoglobin level was 9.34 g/dL (SD ± 1.9 g/dL), median 9.2 g/dL (IQR 8.1–10.5 g/dL) with a range from 2.90 g/dL to 16.4 g/dL. Only 8.6% recorded a haemoglobin level ≥ 12 g/dL; 26.5% had mild anaemia (Hb 10 to < 12 g/dL), whereas the majority (47%) had moderate anaemia (Figure 7).

Catheter-related bloodstream infection (CRBI) was experienced by 47% of the patients. A total of 917 patients (42%) reported having been hospitalised at one stage during dialysis, the most common cause of which was uncontrolled hypertension (44%), followed by hospitalisation from CRBI (18%) (Figure 8).

DISCUSSION

Renal registries provide essential real-world data regarding epidemiology, associations, management practices, cost and clinical outcomes of kidney diseases [12,13]. This

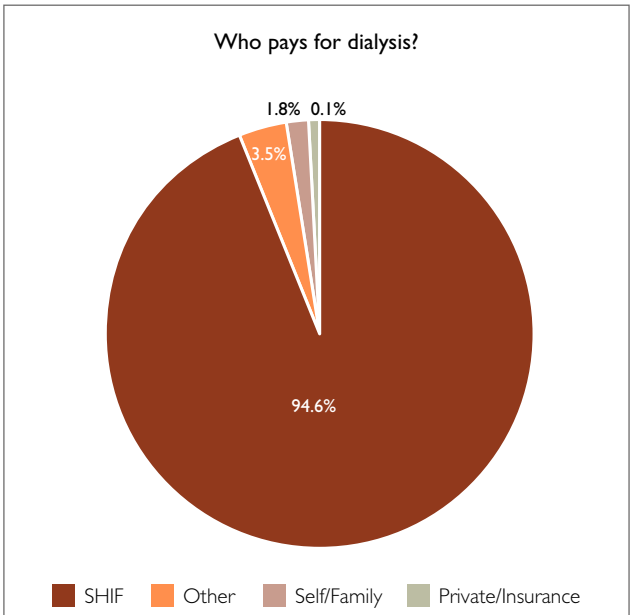

Figure 5. Funding of haemodialysis service (SHIF: Social Health Insurance Fund).

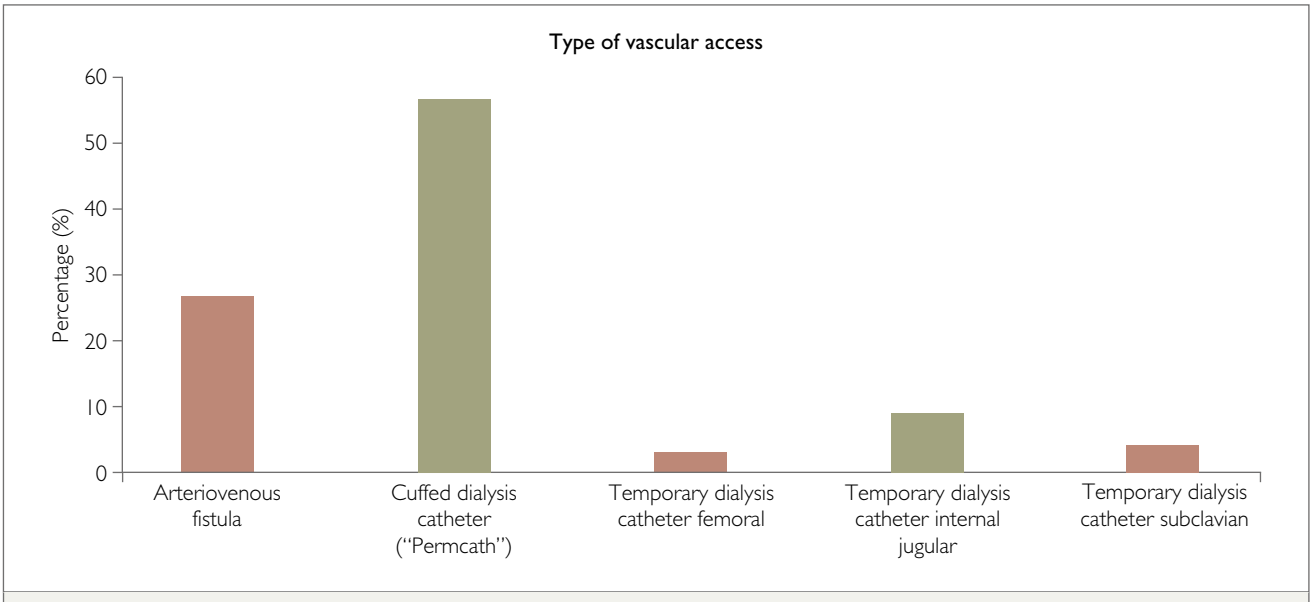

Figure 4. Types of vascular access used by HD patients.

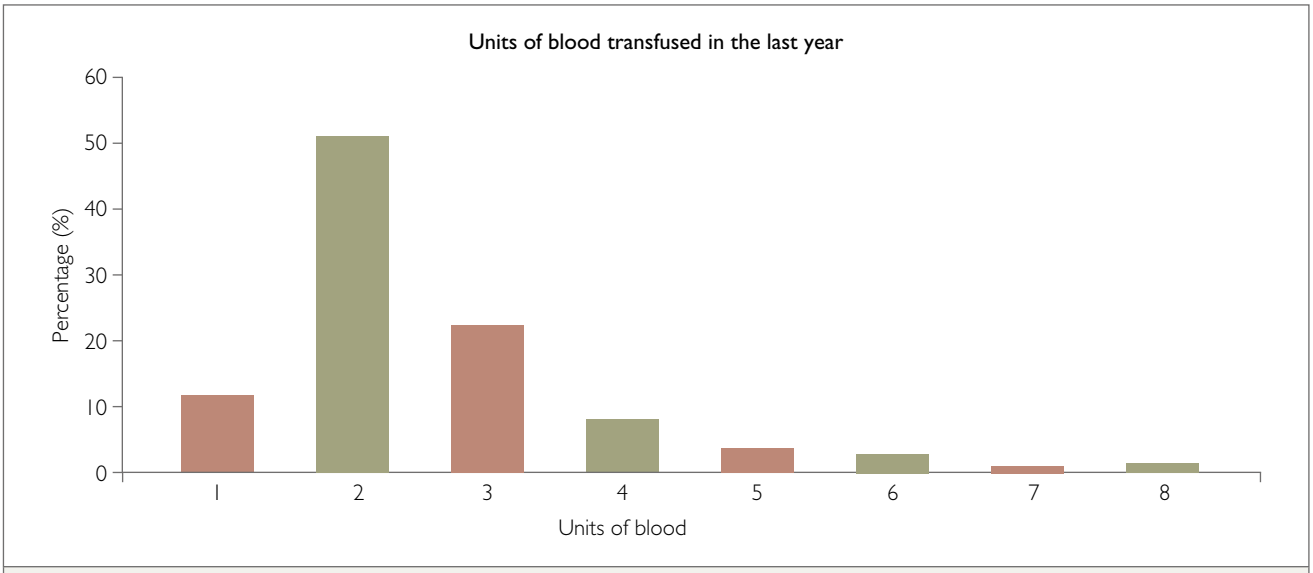

Figure 6. Number of units of red blood cell transfusions in the past year given as a percentage of the haemodialysis population.

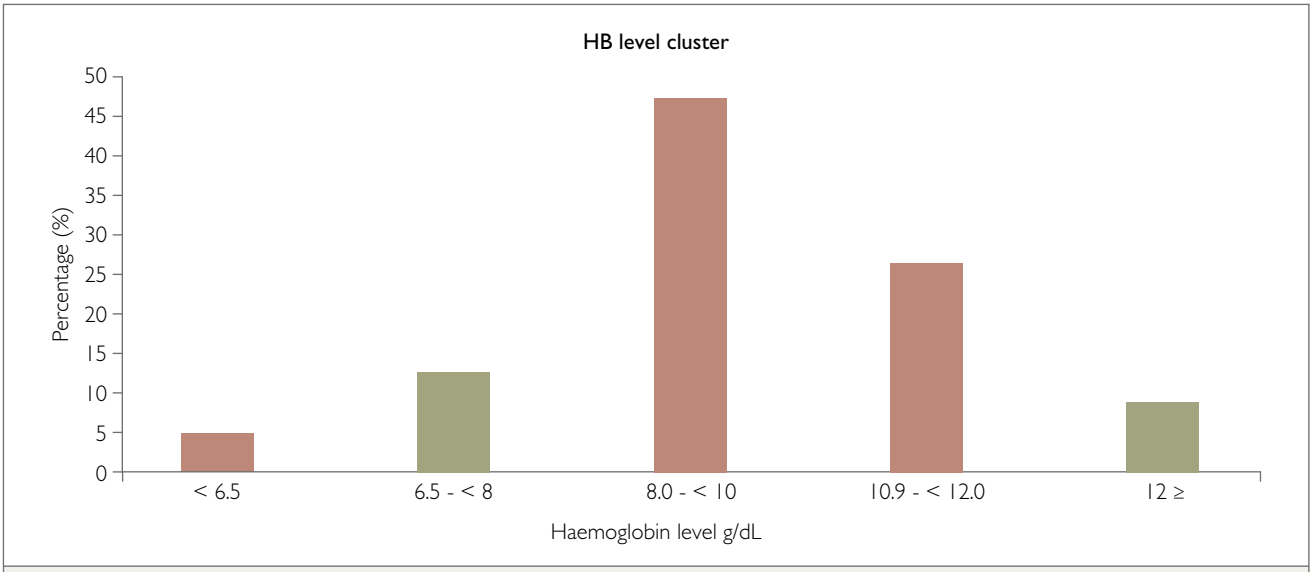

Figure 7. Haemoglobin level clusters as percentages.

preliminary report demonstrates the technical and ethico-legal challenges faced when establishing a functional national registry in Kenya, which evolved over a four-year period.

Our first registry report was in 2016 as an account of kidney transplants, based on a single centre. The logistical difficulties in setting up a transplant registry — chiefly the difficulty of reaching transplant recipients, who were scattered across different clinics and attended review at varying time points — informed the decision by the Kenya Renal Association to set up a haemodialysis registry. This decision rested on the ease of accessing HD patients as they had a definite location and fixed time schedules. Other renal registries are also largely based on kidney replacement therapy, with most being predominantly HD registries [13] including the world's oldest renal registry, the European Renal Association (ERA) registry, which started in 1964 as a chronic dialysis registry [14]. The South African Renal Registry, the only registry in Africa that publishes its reports regularly, collects data on patients undergoing all three modes of kidney replacement therapy [15].

The current results of the registry described here provide a snapshot of the status of HD services in Kenya. Challenges were encountered in setting up this registry. The design of the questionnaire required engagement with nephrologists to arrive at a consensus as to what should be included. While some considered the questionnaire was trimmed

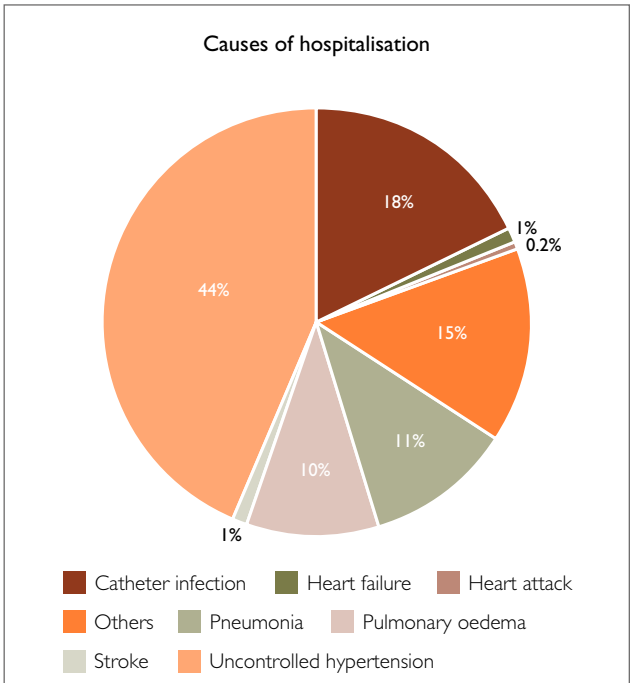

Figure 8. Causes of hospitalisation in HD patients.

too much and should have had more spread of the questions (for example, additional patient-reported and clinical measures such as symptom burden, quality of life, and comorbidity data), the administration of the questionnaire proved laborious for the data entry clerks and lengthy for some patients to complete. This also highlights a gap in stakeholder engagement, as the study did not include patients, nurses, healthcare managers, the national insurer, or the Ministry of Health in the planning process. There is an increasing shift to adopt more patient-centred outcomes in renal registries such as fatigue, pruritus and other symptoms, as well as quality of life [12].

Granting ethical approval went relatively smoothly. However, clarification had to be given to explain how different a registry is from a sample-based observational study, to justify why no sample size was calculated, and to explain the continuous, prospective, non-time-bound method of data collection of the registry. We contemplated requesting a waiver from the requirement of informed consent. However, we forfeited this request in order not to delay the ethical approval process. While ethical approval was confirmed by the national body, the National Commission for Science, Technology and Innovation, we still had delays and outright denials for data collection when we approached individual dialysis providers, both privately owned and public. In addition, some of these providers requested a separate ethical review process, while others demanded a research fee to be paid.

The digitisation of data collection was useful for administering the questionnaire. Other registries have well-established digital registries, often linked to a digitised health management information system, that allows automated data extraction [13]. Registries that are paper-based are rare; in Latin America, only four of the 19 countries with renal registries use a paper-based data collection method [16]. The software platform that we used was malleable, allowing us to create our own questionnaires. However, this system was designed in 2018 and, with the passage of time, became increasingly obsolete, such that we were unable to perform certain functions. For instance, logical data entry — the use of built-in validation checks that automatically flag implausible values — was not possible, and data could not be saved for later completion or editing but instead needed to be uploaded immediately. Its security features were also wanting and left us vulnerable to attacks. A previous system had suffered a ransomware attack in 2017 and had to be abandoned (no patient data had been entered).

This demonstrates that data safety is paramount when collecting patient data. We ensured data protection by cloud-based storage of data, password protection, tiered access to data, and anonymisation of patient identifiers from the data, staff at each dialysis unit were granted access only to view and manage patient records from their respective facility. We intend to upgrade the software to meet international standards as well as the stringent conditions set in Kenyan law by the Data Protection Act [17].

The past decade has seen several attempts made to establish a renal registry in Kenya. The success of the current attempt is attributed to the availability of its funding, allocated by the Kenya Renal Association. Five data collection officers were recruited but they managed to cover only 32% of the 263 HD units in the country after a period of four months, at a cost of US$12,450. Evidently this is not sustainable. Other registries have been funded by their governments (43%) or by the corresponding national society (38%), ensuring sustainability in running the registry [13]. In resource-limited countries such as Kenya, therefore, innovative ways must be found to guarantee the longevity of the facility. Measures we intend to implement to reduce the cost further include more user friendly, cellphone-based data collection software, involving HD unit nurses to enter data, requesting a policy change to make data entry mandatory or reimbursable, and having a standard renal patient digital file that allows data mining.

The Kenyan population is relatively young (median age 54 years), which is comparable to that in South Africa (median age 53.3 years) [15] but much younger than those of other continents (median age in Europe 68.0 years) [18]. Gender

distribution is like that of other registries, with our 65% male distribution reflecting the 62% male predominance in Europe [18].

The estimated HD prevalence of 130 per million population, while slightly lower than the ESKD prevalence of 151 pmp in South Africa, is substantially below the 2393 pmp ESKD prevalence in the United States [19] and 1034 pmp in Europe [18]. This low prevalence likely reflects access to health care, the underdiagnosis of kidney failure and unavailability or inaccessibility of kidney replacement services. As with other patient populations, this prevalence is higher in males (170 pmp) than in females (91 pmp), reflecting an 87% higher prevalence of HD in males than females. In the United States, the prevalence of ESKD is 61% higher in men than in women [19] whereas this male predominance is 63% higher in Europe [18].

The median dialysis vintage of 2.11 years suggests a shortened survival period on HD with most patients in our study receiving only twice weekly dialysis when compared to 5.8 years in South Africa [15]. Since only 14.6% of the HD patients have potential kidney donors and kidney transplantation is less than 300 cases per year in Kenya, these statistics imply an increased mortality rate of our population. More longitudinal data collection should confirm this extrapolation.

The most common co-existing illness in our HD population was hypertension followed by diabetes. While confirmation of these as being the primary renal disease in these patients was not possible, these figures are comparable to those in the US population in which 59% had diabetes and 25% had heart failure [19]. The primary cause of kidney failure in South Africa is hypertension (39%) followed by diabetes (12.8%) [15], while in Europe, miscellaneous causes are the most prevalent cause of kidney failure (18%) followed by diabetes (15%) and hypertension (9%) [18].

The mean haemoglobin level in our patients of 9.34 g/dL compares well with that of the US population of 9.3 g/dL [19], keeping in mind that this reflects cumulative prevalence-period data rather than a directly comparable incidence measure.

This data summary represents cumulative exposures over a period in a prevalent cohort. Therefore, although these data provide useful national estimates, they should be interpreted with caution given this limitation that raises the possibility of survivorship bias, as well as the possibilities of incomplete reporting and selection bias. Other limitations include the short duration of data capture and potential ascertainment bias stemming from missing records and variable documentation practices across different facilities.

CONCLUSIONS

This interim report on the Kenya Haemodialysis Registry demonstrates the feasibility of establishing renal registries in Africa despite the logistical challenges encountered. More robust efforts can be made to expanding the scope of renal registries by digitisation of healthcare records and establishment of standard renal patient files.

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Author contribution statement

JW conceived and designed the study, reviewed and approved the final version of the manuscript. EO conducted statistical analysis and contributed to data collection, drafted the initial manuscript. JO reviewed the manuscript and approved the final version. MK conceived and supervised the study, reviewed the manuscript, and approved the final version. JB reviewed the manuscript and approved the final version.

Use of AI in manuscript preparation

No AI tools were used in the preparation of this manuscript.

Conflict of interest

The authors have no conflicts of interest to declare.

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