Report from the Caribbean Renal Registry, 2006

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ABSTRACT

Aim: *To develop a renal registry that will monitor renal epidemiology in the Caribbean and help determine the burden of disease.*

Methods: *Questionnaires were sent out to different Caribbean countries for distribution to the dialysis units. Data were obtained for patients with End Stage Renal Disease (ESRD) who were on long term renal replacement therapy in 2006. The demographic data, type of renal replacement therapy, laboratory data and causes of ESRD were obtained from the questionnaire. Data were analyzed using SPSS 11.0*

Results: *Data were reported from six English-speaking Caribbean countries: Bahamas (n = 211), Barbados (n = 185), British Virgin Islands (n = 27), Cayman Islands (n = 41), Jamaica (n = 366) and Trinidad and Tobago (n = 436). Haemodialysis was reported in all the countries; transplantation was not reported from the Cayman Islands. Only Bahamas, Jamaica and Trinidad and Tobago reported peritoneal dialysis. In Jamaica, male to female ratio was 1.5:1. The three commonest causes of end stage renal failure were hypertension (65.5%), diabetes mellitus (27.6%) and primary chronic glomerulonephritis (12.5%). The age range was 11–94 years (mean 47.7 years). Barbados had a male to female ratio of 1.8:1, age range of 19–81 years (mean age: 52.3 years). Hypertension (55.7%) and diabetes mellitus (27.0%) were the commonest causes. Trinidad and Tobago had a male to female ratio 1.3:1. The age range was 8–84 years (mean age 52.5 years). The four commonest causes of ESRD were diabetes mellitus (28.9%), hypertension (25.3%) and autosomal dominant polycystic kidney disease (3.9%) and chronic glomerulonephritis (3.9%). The British Virgin Islands, Tortola, had a male to female ratio 1.7:1.0. Age range was 26–86 years (mean, 57 years). Hypertension (67.9%) and diabetes mellitus (46.4%) were also the commonest causes. The Bahamas had a male to female ratio of 1:1.1 unlike the other countries. Hypertension (25.6%), diabetes mellitus (28.0%) and chronic glomerulonephritis (13.3%) were the commonest causes of ESRD. The Cayman Islands reported a male to female ratio of 1.2:1, with a mean age of 54.3 years. Hypertension (n = 27), diabetes mellitus (n = 12) and autosomal dominant polycystic kidney disease (n = 3) were the commonest causes of ESRD. Barbados and Jamaica had more than 50 per cent of its renal replacement therapy patients with serum albumin above the minimum of the normal range of 35–40 g/L. In regards to the calcium phosphate product, two-thirds of the patients in all countries reporting data had values below the recommendation of 4.4 $mmol^2/L^2$. The percentage of patients achieving haemoglobin concentration above 10.0 g/dL was: 16.9% for Jamaica, 75.6% for The Cayman Islands, 35.9% for Barbados and 68.6% for Tobago. Erythropoietin usage was not reported. The URR was only available for Jamaica and the Bahamas and 80.6% and 60.9% respectively had URR above the accepted value of 65%. For all reporting countries the range of patients coded for hypertension but who also had diabetes mellitus was 2.2% to 17.1%. Only Bahamas reported on vascular access with 51.7% of patients having native arteriovenous fistulae.*

Conclusion: *Hypertension, diabetes mellitus and chronic glomerulonephritis were the commonest causes of ESRD across most of the English-speaking Caribbean countries. Peritoneal dialysis was only offered in some of the islands and kidney transplantation was rarely reported. More males than females were on long term renal replacement therapy in most of the islands.*

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Reporte del Registro Renal del Caribe, 2006

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RESUMEN

Objetivo: *Desarrollar un registro renal que supervise la epidemiología renal en el Caribe y ayude a determinar la carga de la enfermedad.*

Métodos: *Se enviaron cuestionarios a diferentes países del Caribe, para ser distribuidos a las unidades de diálisis. Se obtuvieron datos sobre pacientes con Enfermedad Renal en Fase Terminal (ERFT) en proceso de terapia de reemplazo renal a largo plazo en 2006. Los datos demográficos, el tipo de terapia de reemplazo renal, los datos de laboratorio, y las causas de ERFT, se obtuvieron a partir de los cuestionarios. Los datos se analizaron usando SPSS 11.0.*

Resultados: *Se reportaron datos de seis países anglófonos del Caribe: Bahamas (n = 211), Barbados (n = 185), Islas Vírgenes Británicas (n = 27), Islas Caimán (n = 41), Jamaica (n = 366), Trinidad y Tobago (n = 436). Se reportó hemodiálisis en todos los países; no hubo reporte de trasplantes por parte de las Islas Caimán. Sólo Bahamas, Jamaica y Trinidad y Tobago informaron diálisis peritoneal. En Jamaica, la proporción varón/hembra fue 1.5:1. Las tres causas más comunes del fallo renal en fase terminal fueron: la hipertensión (65.5%), la diabetes mellitus (27.6%), y la glomerulonefritis crónica primaria (12.5%). El rango de edad fue de 11–94 años (edad promedio: 47.7). Barbados tuvo una proporción varón/hembra de 1.8:1, un rango de edad de 19–81 años (edad promedio: 52.3 años). La hipertensión (55.7%) y la diabetes mellitus (27.0%) fueron las causas más comunes. Trinidad y Tobago tuvieron una proporción varón/hembra de 1.3:1. El rango de edad fue de 8–84 años (edad promedio 52.5 años). Las cuatro causas más comunes fueron: la diabetes mellitus (28.9%), la hipertensión (25.3%) y la enfermedad renal poliquística autonómica dominante (3.9%) y la glomerulonefritis crónica (3.9%). Las Islas Vírgenes Británicas, Tortola, tuvieron una proporción varón/hembra de 1.7:1.0. El rango de edad fue de 26–86 años (edad promedio: 57 años). La hipertensión (67.9%) y la diabetes mellitus (46.4%) también fueron las causas más comunes. A diferencia de los otros países, Bahamas tuvo una proporción varón/hembra de 1:1.1. La hipertensión (25.6%), la diabetes mellitus (28.0%) y la glomerulonefritis crónico (13.3%) fueron las causas más comunes de la ERFT. Las Islas Caimán reportaron una proporción varón/hembra de 1.2:1, con una edad promedio de 54.3. La hipertensión (n = 27), la diabetes mellitus (n = 12) y la enfermedad renal poliquística autonómica dominante (n = 3) fueron las causas más comunes de ERFT. Barbados y Jamaica tuvieron más de 50 por ciento de sus pacientes de terapia de reemplazo renal con la albúmina de suero sobre el mínimo del rango normal de 35–40 g/L. Respecto al producto de fosfato de calcio, dos terceras partes de los pacientes en todos los países que reportaron datos, tuvieron valores por debajo de los 4.4 mmo/L recomendados. El porcentaje de pacientes que lograron concentraciones de hemoglobina por encima de 10.0 g/dL fue: 16.9% para Jamaica, 75.6% para Islas Caimán, 35.9% para Barbados y 68.6% para Tobago. No se reportó el uso de eritropoyetina. La La reducción porcentual de urea (URR) sólo estuvo disponible en Jamaica y Bahamas, y 80.6% y 60.9% respectivamente tuvieron URR por encima de 65%. Para todos los países del reporte, el rango de pacientes codificados para hipertensión pero que también tenían diabetes mellitus fue de 2.2% a 17.1%. Sólo Bahamas reportó acceso vascular con 51.7% pacientes con fístula arteriovenosa (FAV) nativa.*

Conclusión: *La hipertensión, la glomerulonefritis crónica y la diabetes mellitus fueron las causas más comunes de la ERFT para la mayoría de los países caribeños angloparlantes. La diálisis peritoneal sólo se ofreció en algunas de las islas y raramente se reportó trasplante del riñón. Más varones que las hembras estuvieron en terapia de reemplazo renal a largo plazo en la mayoría de las islas.*

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INTRODUCTION

Dialysis and transplantation commenced in Jamaica in 1970 and 1971 respectively. Since then, Jamaica and the Caribbean have had a growing number of persons developing chronic renal failure eventually leading to End Stage Renal Disease (ESRD). There has been no published data reporting the incidence, prevalence and causes of Chronic Kidney Disease (CKD) and ESRD in the Caribbean region, except in Jamaica (1, 2). It is important to have a registry in order to define the causes of CKD and ESRD and to be able to

perform (inter)national comparisons in renal epidemiology. Such a registry will monitor the causes, incidence and prevalence of CKD and any emerging trend.

The number of patients with ESRD continues to grow at a rapid rate with no signs of slowing globally. It exceeds the yearly world population growth rate. Worldwide at the end of 2001, over one million patients were receiving renal replacement therapy (RRT): 1 015 000 patients on haemodialysis (HD) and 126 000 patients on peritoneal dialysis (PD) (3). The highest prevalence rate for treated ESRD was reported in Japan (1730/million population), followed by Taiwan (> 1400/million population) and the United States of America (USA) (1030/million population). Fifty-eight per cent of the world's ESRD population lived in just five countries (USA, Japan, Germany, Brazil and Italy) that total less than 12% of the world's human population (3).

There are three main types of RRT available for persons with CKD/ESRD. These are haemodialysis, peritoneal dialysis and kidney transplantation (cadaver and live donors). There are data available about the most suitable type for any patient population (4–7) although transplant has been widely accepted as the best modality of RRT. There are suggestions about the modality best suited based on patient characteristics such as age, cause of CKD and the availability of resources for such treatment plan (4–6). Therefore, it is useful to know the type of renal replacement modality available for each country and then the best options can be assessed based on the patient characteristics, social belief and economic feasibility for that country. A renal registry will allow for the determination of the burden of disease as well as planning and policy formulation in the healthcare sector.

The registry will present information about incidence, prevalence, causes, distribution, type of RRT and patient outcome for each individual Caribbean country. This will allow for comparison and peculiarity. As the registry develops, data will become available for patients with different stages of CKD (8) rather than just those with ESRD on RRT alone, as is reported here.

The database needed for storage of information is not fully developed as yet. The database will have a secure network for information transfer and online registry for each individual country to access information by selected individuals. The accuracy and completeness of data will be verified before transfer to the database and reminders will be sent on a monthly basis to update new patients. Reports will be sent from the local renal unit to the national registry which will send its report to the Caribbean centre for the registry. The information will be a source of epidemiological data for research and it will help both national and regional health planning.

Data will be released once a written consent form is filled out for data release and approved by the consultant member of the particular country and by the administrative board of the registry.

The team steering the registry will be comprised of a nephrologists, a senior public health nurse, dietician, epidemiologist, programme and software designer, senior laboratory scientist and a consultant in public health medicine. There would be an annual meeting for the Caribbean delegates and a quarterly meeting at the national level. There would be an administrative team responsible for operation of the Caribbean renal registry office. The collection and collation of data for each member country would be carried out under the supervision of the consultant member.

METHOD

A questionnaire was created, based on international guidelines (9–10) and it included patient identification number for cross-reference and back reference, demographic data, vital statistics, income, ethnicity and cause of CKD. Risk factor for cardiovascular disease, family history of CKD and also other chronic diseases were included (Appendix 1). It also included RRT modality and any switches made from one long-term treatment modality to another, including the reason(s). In the revised questionnaire, diseases will be coded to allow for uniformity and negate ambiguity in relation to causes and other co-morbid conditions. Also, it will include drug history (including immunosuppressives).

The questionnaire was sent out to different Caribbean countries for distribution to the dialysis units. Data were obtained for patients with ESRD who are on long term renal replacement therapy for 2006. Patients with ESRD without renal replacement and those who received acute dialysis and died shortly afterwards were not included in the data. The demographic data, type of renal replacement therapy, access type, laboratory data and causes of ESRD were obtained from the questionnaire. The name of the dialysis centre was included to determine the number of dialysis centres available for each country, private or public. The date of first dialysis was included in order to calculate duration on dialysis and each year after to calculate both prevalence and incidence for each year.

There were some confounding factors that made data unavailable for some patients. Also data submitted by each country differed, and hence comparison was not possible between the countries for certain aspect of the registry.

A death form (Appendix 2) was not available for all the countries at the time of collection for 2006, but will be made available for subsequent years. This will facilitate documentation of cause of mortality.

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 11.0.

RESULT

Data were reported from six (6) English-speaking Caribbean countries: Bahamas (n = 211), Barbados (n = 185), British Virgin Islands (n = 27), Cayman Islands (n = 41), Jamaica (n = 366) and Trinidad and Tobago (n = 436) (Table 1), but data

Table 1: Total number reported for each country

Country	Haemo	Peritoneal	Transplant	Total
Bahamas	164	37	1	211
Barbados	184	0	1	185
British Virgin Islands	26	–	1	27
Cayman Islands	41	–	–	41
Jamaica	320	30	18	366
Trinidad and Tobago	363	73	–	436
	1089	140	21	1266

were only available for 358 from Trinidad and Tobago. Haemodialysis was reported in all the countries, transplant was not reported from the Cayman Islands and only Jamaica, Trinidad and Tobago and Bahamas reported peritoneal dialysis.

The gender distribution of patients with ESRD reported from each country is given in Figure 1.

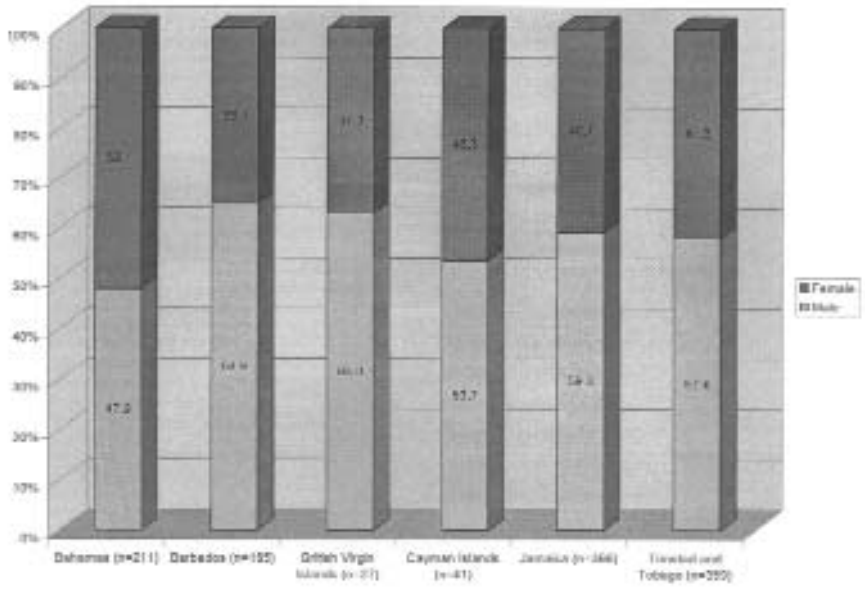

Fig.1: Gender distribution of patients with ESRD reported from each country.

In Jamaica, the male to female ratio was 1.5:1. The three commonest causes were hypertension (50.0%), diabetes mellitus (21.0%) and primary chronic glomerulonephritis (9.6%). The age range was 11–94 years of age (mean 47.7 years). Barbados had a male to female ratio of 1.8:1, age range of 19–81 years (mean age: 52.3 years). Hypertension (55.7%) and diabetes mellitus (27.0%) were the commonest causes of ESRD. Trinidad and Tobago had a male to female ratio 1.3:1. Age range was 8–78 years (mean age 52.5 years). The three commonest causes were diabetes mellitus (28.9%), hypertension (25.3%) and autosomal dominant polycystic kidney disease (3.9%) and chronic glomerulonephritis (3.9%). A cause was not defined for another 18.9% and there was one report of Alport's Syndrome. The British Virgin Island, Tortola, had a male to female ratio 1.7:1. Age range was 26–86 years (mean 57 years). Hypertension (70.4%) and diabetes mellitus (25.9%) were also the commonest cause. The Bahamas had a male to female ratio of 1:1.1. Hypertension (25.6%), diabetes mellitus (28.0%) and chronic glomerulonephritis (13.3%) were the commonest causes of ESRD. Recreational drug induced nephritis (0.9%) was also reported. The Cayman Islands reported male to female ratio of 1.2:1, with a mean age of 54.3 years. Hypertension (42.5%), diabetes mellitus (29.3%) and autosomal dominant polycystic kidney disease (7.3%) were the commonest causes of ESRD.

The average haemoglobin concentration (g/dL) for each country was reported as: Jamaica 8.17 g/dL (SD 2.52), Barbados 9.14 g/dL (SD 1.96), Tobago 11.2 g/dL (SD, 1.96), British Virgin Islands 12.1 g/dL (SD 1.76), Cayman Islands 11.3 g/dL (SD 1.57) and Bahamas 8.60 g/dL (2.72). Haemoglobin level was divided into four groups and the percentage of patients in each group calculated for comparison (Fig. 2).

Average serum albumin concentration (g/dL) for Jamaica was 39.5 (SD 6.22), Barbados was 40.8 (SD 3.32), British Virgin Islands was 39.4 (4.10), Cayman Islands was 34.6 (SD 4.90) and Bahamas was 29.4 (SD 11.4). The serum albumin concentration was divided into groups for comparison and evaluation of nutritional state (Fig. 3). There was no report of serum albumin from Trinidad and Tobago.

Serum calcium and phosphate levels were also divided into groups using recommended target value. The percentage of patients within the recommended range was calculated (Fig. 4, 5). The calculated serum calcium phosphate product

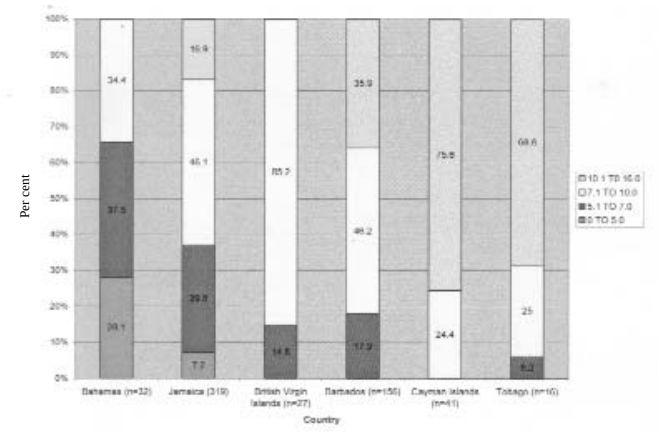

Fig. 2: Haemoglobin concentration for the countries (g/dL).

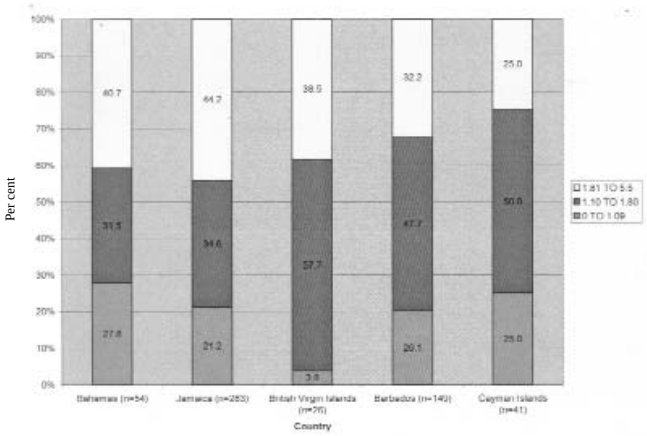

Fig. 5: Serum phosphate concentration for the countries (mmol/L).

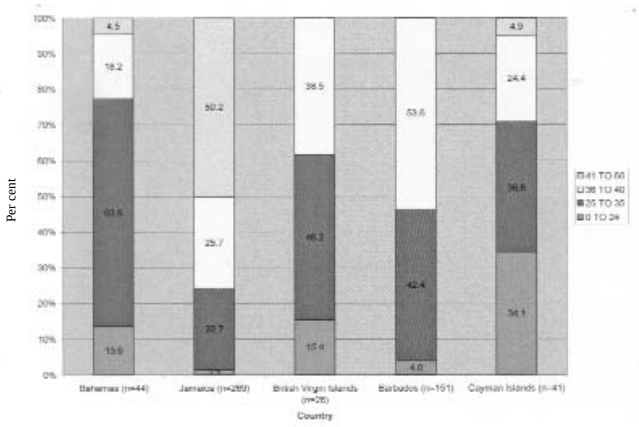

Fig. 3: Serum albumin concentration for the countries (g/dL).

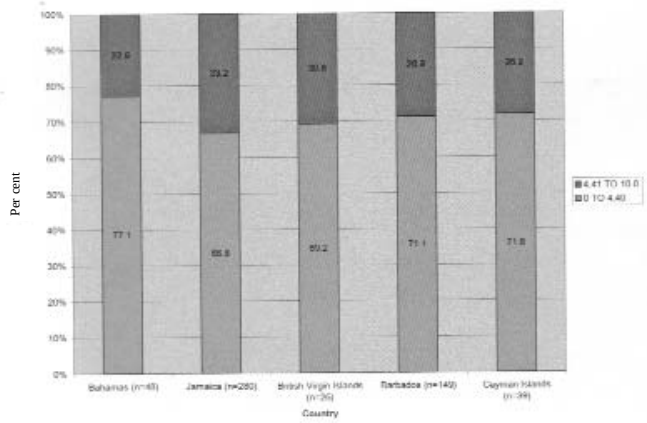

Fig. 6: Serum calcium phosphate product for the countries ($mmol^2/L^2$).

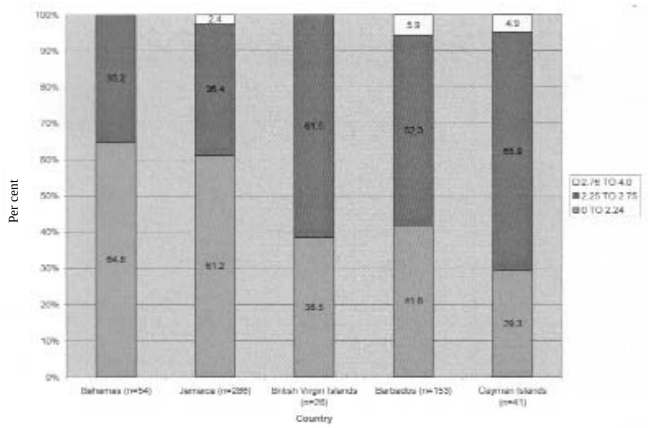

Fig. 4: Serum calcium concentration for the countries (mmol/L).

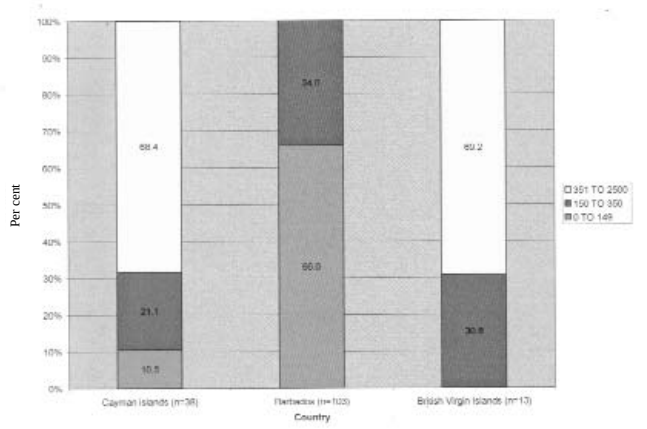

Fig. 7: Serum total parathyroid hormone concentration for the countries (pg/dl).

was also analyzed similarly (Fig. 6). Total serum parathyroid hormone level was reported for the Cayman Islands, Barbados and the British Virgin Islands (Fig. 7). There was no report from Jamaica, Trinidad and Tobago and Bahamas.

Urea Reduction Ratio (URR) was calculated for Bahamas and Jamaica (Fig. 8). The percentage of persons with URR over 65% were 80.6% for Jamaica and 60.9% for Bahamas.

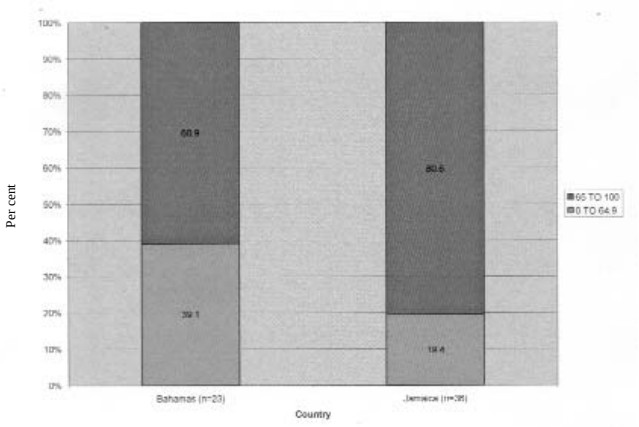

Fig. 8: Urea reduction ratio for Bahamas and Jamaica (%).

Vascular access type was reported for the Bahamas (n = 172), with 51.7% having arteriovenous fistula, 11.0% having arteriovenous graft and 37.2% with catheters. There was no report from the other countries.

Total number of deaths reported for 2006 may have been underestimated for some countries. Mortality rate reported for Jamaica was 56 per 1000 ESRD population on RRT and 18 per 1000 ESRD population for Trinidad and Tobago. The Bahamas reported a mortality of 242 per 1000 patients with ESRD on RRT; for the British Virgin Islands the mortality was 148 per 1000 ESRD patients on RRT. The other reporting islands were less than 100 per 1000 ESRD patients on RRT (Table 2).

Table 2: Mortality reported for patients with ESRD on RRT

Country	Mortality per 1000 ESRD population on RRT
Bahamas	242
Barbados	49
The British Virgin Islands	148
Cayman	97
Jamaica	56
Trinidad and Tobago	18

DISCUSSION

In the conception of the Caribbean renal registry, the data required for patients with CKD for each country, would require an enormous task which might not be feasible in the initial stages. The questionnaire created was geared towards patients with ESRD on renal replacement therapy: haemodialysis, peritoneal dialysis or transplantation. However data accrued subsequently over time will involve patients with CKD at different stages as defined by the International Society of Nephrology (ISN). Therefore, the questionnaire will be subject to constant review and update tailored towards relevant information for the Caribbean population. It will be comparable to international renal registries.

The gender distribution in the data reported for the Caribbean islands shows a higher ratio of men compared to women with ESRD on RRT. Barton *et al* reported that out of 605 patients with CKD in the Jamaican population, 57% were male and 43% female. There is no similar data available for comparison from other Caribbean countries. In this report, this was not observed for the Bahamas where there was an equal ratio. This observed trend could also reflect the psychosocial difference in men and women towards chronic disease management. Further extension of the registry to include patients with CKD will enlighten the situation. This could also serve as an area for further public health inquiry.

The mean age reported for the Caribbean countries was between the 5th and the 6th decades of life, although there were cases in the paediatric age group. This poses a challenge to the healthcare sector in terms of medical support, physical aide and hospitalizations. The burden of care is also extended to the family which provides support for the persons with ESRD which may adversely affect gainful employment. This is especially so, in countries where the majority of healthcare cost is still a responsibility of the patients and by extension their family. The cost of healthcare as it stands in the Caribbean is still borne by the patients except in places like Barbados, Cayman Islands and Trinidad and Tobago. The number of paediatric cases reported should also serve as an indicator for an active kidney transplant programme.

The geographic distribution of patients with ESRD shows a higher percentage of persons living in and around the capitals. This has public health implications in terms of placement and availability of dialysis units and renal transplant centres. Access to these facilities is also important for both emergency and routine visit.

The markers used in CKD/ESRD, as outlined in guidelines for kidney disease, includes haemoglobin/ haematocrit, serum albumin, serum calcium and phosphorus (11). Some or all of these markers were reported by some countries to the registry. Haemoglobin or haematocrit is a marker used to assess relative well being of the patients (12). When above the recommended value, patients reported favourably on well being and a better activity tolerance. The recommended haemoglobin concentration of 11.0–13.0 g/dL was achieved by some countries while others fell short of the standard recommendation. The percentage of patients achieving haemoglobin concentration above 10.0 g/dL was 16.9% for Jamaica, 75.6% for Cayman Islands, 35.9% for Barbados and 68.8% for Tobago (Fig. 2). In the Bahamas and British Virgin Islands all patients had haemoglobin below 10.0 g/dL. The use of erythropoietin subcutaneously or intravenously negates the need for blood transfusion and also reduces the possibility of rejection from allosensitization in the likely event of transplantation (13). The issue of cost of erythropoietin must be borne in mind. In cases of significant acute blood loss and in symptomatic patients, blood transfusion would be necessary.

Nutrition is of vital importance in chronic diseases. Serum albumin level is used as a marker of nutrition in CKD/ESRD (11, 12). It is recommended that the serum albumin should be between 35–40 g/dL or above (11). More than three-quarters of the reported Jamaican dialysis patients receiving RRT have serum albumin above this range while it was fifty per cent for the Barbados patients. In the Bahamas, the British Virgin Islands and the Cayman Islands more than fifty per cent of their patients had values below the recommended range. Careful attention to nutrition in these patients is important to prevent protein-energy malnutrition and improve quality of life. Data on serum albumin were not available for Trinidad and Tobago. The protein requirement can be different based on RRT modality. It is increased in peritoneal dialysis due to loss of albumin in the dialysate.

Serum calcium, phosphate and parathyroid hormone (PTH) levels were evaluated as markers of bone disease in patients with CRF/ESRD (11). The British Virgin Islands (61.5%), Barbados (52.3%) and the Cayman Islands (65.9%) had patients with serum calcium within the recommended range of 2.25–2.75 mmol/L. Jamaica (64.8%) and Bahamas (61.2%) had patients with serum calcium below 2.24 mmol/L. The British Virgin Islands (57.7%), Barbados (47.7%) and The Cayman Islands (50.0%) had patients with serum phosphate within the recommended range of 1.10 – 1.80 mmol/L. Jamaica (44.2%) and Bahamas (40.7%) had patients with serum phosphate above 1.80 mmol/L. However when the calcium phosphate product was calculated it was found that all the countries had over two-thirds of their patients above the recommended value of 4.40 $mmol^2/L^2$. Patients with levels above this are at increased risk of soft tissue and vascular calcification and death (14–16).

To normalize for differences in the size and habitus of patients, a dose of haemodialysis (prescribed or delivered) is best described as the fractional clearance of urea as a function of its distribution volume (Kt/V). The delivered dose of haemodialysis may also be assessed using the Urea Reduction Ratio (URR). The Haemodialysis Adequacy Work Group acknowledges the ease of calculation and resultant popularity of the URR. Of the three methods that the Haemodialysis Adequacy Work Group considered appropriate for measuring the delivered dose of haemodialysis, the URR is the simplest to execute. The URR has been shown to be a statistically significant predictor of mortality for ESRD patients (17–18). In Jamaica, 80.6% had URR greater than 65% (n = 36) while in the Bahamas it was 60.9% (n = 23).

A diagnosis code will be created for increase uniformity and consistency in data collation. There is a need to include immunization records.

The mortality rate reported for member countries in these data is believed to be under-estimated (Table 2). The cause of death was presumed in some cases and the post mortem rate was low. The main causes of death were under three main categories: cardiovascular complications, sepsis and unknown. Cardiovascular complications included myocardial infarction and cerebrovascular accident. Sepsis was generally presumed to be secondary to the presence of an indwelling dialysis catheter in patients receiving haemodialysis.

It is evident from these data that most Caribbean countries do not have active renal transplant programmes. The decline in active renal transplantation in some countries is thought to be related to availability of financial resources for immunosuppressive drugs and induction agents. Also, the psychosociocultural behaviour in the Caribbean towards organ donation could be a contributing factor. However the capacity for follow-up of these cases in the Caribbean is adequate.

Availability of haemodialysis units, although the commonest modality of RRT, is less than adequate as the number of patients requiring dialysis is still rising. Hence, there is need for more units to accommodate the ever-growing population of persons with CKD.

The mean age for patients on RRT was close to the retirement age and this brings into question the need for resources for a population that is no longer capable of earning and are therefore dependent. There is a need to develop nationwide programmes to prevent or decrease renal disease and slow progression to ESRD.

CONCLUSION

Hypertension, diabetes mellitus chronic and glomerulonephritis are the commonest causes of ESRD across most of the Caribbean countries. However, it is sometimes difficult to elucidate the cause of CKD and hence ESRD, especially in patients with both hypertension and diabetes mellitus. This group of patients makes up a significant number of causes of CKD and therefore should be categorized separately. There is diversity in the causes of CKD as represented in each country and some causes are peculiar to the country. For example, recreational drug induced nephritis in the Bahamas may represent the nature of the societal environment. Peritoneal dialysis is only offered in some of the islands and transplant is even rarer. More males than females are on long term renal replacement therapy in most of the islands.

The registry, though in its conception, needs to have a standardize form of data collection. This will allow for comparison between the Caribbean territories and comparison to international registries.

Long term renal replacement therapy modalities are available in the Caribbean, though haemodialysis is the commonest modality in all the six reporting countries. Peritoneal dialysis and renal transplant have not found there way into being readily available forms of RRT, although this trend is already changing.

Causes of morbidity and mortality need special attention in order to define the risk for cardiovascular disease. Areas contributing to mortality and morbidity can then be

properly identified and risk stratified. There is great disparity in the mortality reports and measures need to be put in place to ensure proper data collection and reporting.

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Appendix 1: Renal Registry Questionnaire*

1. NAME: _____ DOCKET NO. _____
2. SEX: M □ F □ Deceased. Yes No
3. AGE: ___ years 3A. OCCUPATION: _____ PARISH:
4. CAUSE OF DEATH: _____
5. TYPE OF RENAL FAILURE: ACUTE (# 3 months) □ CHRONIC (> 3 months) □
6. BLOOD INVESTIGATIONS: (most recent values)

   Haemoglobin _____gdl Urea _____mmol/l Creatinine _____ µmol/l

   Creatinine one year ago (if applicable) _____ µmol/l

   PTH ____ Ca^{++} _____ PO_4 _____ Serum Albumin _____

   Uric acid _____ Alkaline Phosphatase _____ Lipid profile _____
7. UNDERLYING CAUSE(S): (primary or dominant cause)

   Primary hypertension □ Diabetes Mellitus □ Sickle cell disease □

   Systemic lupus erythematosus □ Chronic pyelonephritis □

   Interstitial nephritis (chronic analgesic use) □ Others □
8. FAMILY HISTORY OF DISEASE: (1^{st} or 2^{nd} degree relatives)

   Primary hypertension □ Diabetes Mellitus □ Renal disease □ Others _____ □
9. SMOKING HISTORY: Current smoker □ Ex-smoker □ Never smoked □
10. USE OF NEPHROTOXIC AGENTS: (eg Chronic NSAID use, aminoglycosides)

    No □ Yes □ (please specify) _____
11. RENAL REPLACEMENT THERAPY: No □ Yes □

    If Yes, please specify with date of commencement: □

    Haemodialysis Renal transplant Chronic ambulatory peritoneal dialysis (CAPD)
12. KIDNEY SIZE: (if available) Left ____cm Right _____cm
13. Comorbidities
14. NAME OF DOCTOR: _____ DATE: _____

*This has been revised

Appendix 2: End-Stage Renal Disease Death Form

NAME:
AGE:
GENDER:
DATE OF BIRTH:
DATE OF DEATH:
DIALYSIS CENTRE:
PLACE OF DEATH: ☐ HOSPITAL ☐ DIALYSIS ☐ HOME ☐ OTHER
AUTOPSY PERFORMED: ☐ YES ☐ NO
CAUSES OF DEATH: ☐ primary ☐ secondary
TYPE OF RENAL REPLACEMENT:
FREQUENCY OF DIALYSIS:
WAS DIALYSIS DISCONTINUED BEFORE DEATH: ☐ yes ☐ no
LAST DIALYSIS DATE PRIOR TO DEATH: