Egyptian renal data system (ERDS) 2020: an annual report of end-stage kidney disease patients on regular hemodialysis

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Received: 12 November 2021
Revised: 25 November 2021
Accepted: 30 November 2021
Published: 11 February 2022

Journal of The Egyptian Society of Nephrology and Transplantation 2022, 22:1–28

A patient registry is the collection of uniform data (clinical and others) to evaluate specified outcomes for a population defined by a particular disease or therapy (target disease or therapy) and that serves one or more predetermined scientific, clinical, or policy purposes. Our aim is to establish a renal database for hemodialysis patients (as a first step) that would help in providing the optimal health care to improve quality of life and prolong survival. Egyptian renal data system (ERDS) was established out of the firm belief that delivering a clear picture of the incidence, prevalence, and outcomes of hemodialysis-related problems in Egypt is the needed action to identify the real magnitude of the problem. ERDS is the Egyptian national registry of nephrology patients. It was founded and is run by the Egyptian Society of Nephrology and Transplantation (ESNT), the only official Egyptian Non-Governmental Organization representing nephrologists and officially managing some issues of the nephrology specialty in Egypt. ERDS until now registers data about patients with End stage kidney disease (ESKD) on chronic hemodialysis, but the plan is to include more patient groups in the future. Two types of data were collected; data about the dialysis units as a whole and data specific to each patient. Data entered by all units were exported from the digital system as a . csv file that can be opened by Microsoft Excel. Data analysis was carried out by Microsoft Excel functions and Microsoft Power Business Intelligence. Results were represented by different sectors.

Keywords:
end stage kidney disease, registry, hemodialysis, renal replacement therapy, transplantation

Journal of The Egyptian Society of Nephrology and Transplantation 22:1–28

1110-9165

History of Egyptian renal registry

The first Egyptian renal registry report was done by personal efforts of Professor Adel Afifi in the period from 1996 until 2008 [1]. It included numerical information on 3937 hemodialysis (HD) patients out of an estimated 14 639 patients with end-stage kidney disease (ESKD) in Egypt at that time, as well as the etiology of ESKD. Egyptian Society of Nephrology and Transplantation (ESNT) efforts to establish a renal registry system were initiated by Professor Tarek El Baz during the period of his presidency of ESNT (2010–2013). Professor Gamal Saadi was the one who established the registry chapter during his presidency of ESNT (2014–2017), in continuation of these efforts. In 2016, a preliminary report of HD registry was presented in the ESNT annual conference, which again included only numbers and etiology. With maintained efforts of the following ESNT president, Professor Mohamed Hany Hafez, the ESNT finally presented its first official annual report in 2018. A second report was also presented in 2019. Now under the supervision of the current president of ESNT and the head of Egyptian Renal Data System (ERDS), Professor May Hasaballa, we are publishing this third report.

Aim and vision of Egyptian Renal Data System

A patient registry is the collection of uniform data (clinical and others) to evaluate specified outcomes for a population defined by a particular disease or therapy (target disease or therapy) and that serves one or more predetermined scientific, clinical, or policy purposes. The resulting clinical database describes a file (or files) derived from the registry. Patient registries have common objectives. These are as follows[2]:

(1) Describe the natural history of the target disease.
(2) Determine the clinical response and cost-effectiveness of treatments for the target disease. Monitor safety and harm of therapeutic products and services for the target disease.
(3) Evaluate access to and quality of health care for the target disease.

In 1964, just 1 year after the birth of the European Dialysis and Transplant Association (EDTA), Dr Willem Drukker, a Dutch nephrologist, started a European registry including data on dialysis patients. Dialysis was still an experimental therapy that was provided to a very restricted number of patients with ESKD. This first report of this new registry contained 271 patients starting HD and six peritoneal dialysis patients, with a mortality in the next year, which was as high as 40–50% [3].

The Dialysis Outcomes and Practice Patterns Study (DOPPS) and the ERA-EDTA have recently complemented the EURO DOPPS registry. It is another new and exciting activity that further extended the collaborative research network. The idea behind the current ERA-EDTA registry is that by working together, most of the nephrology data can be made available [4].

Other well-established national renal registries include the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Canadian Organ Replacement Registry (CORR) [5,6].

The US Renal Data System (USRDS) was established in 1988 to collect and analyze information on the incidence, prevalence, morbidity, and mortality of ESKD in the United States [7].

Unfortunately, in many areas of the world, the global distribution, availability, and quality of renal registries are unclear, and the burden of ESKD in many low-income and middle-income countries is not fully understood, owing to a lack of national registries [8].

Our aim is to establish a renal database for hemodialysis patients (as a first step) that would help in providing the optimal health care to improve quality of life and prolong survival. This can be better achieved with the collaboration of different health care authorities. ERDS was established out of the firm belief that delivering a clear picture of the incidence, prevalence, and outcomes of hemodialysis-related problems in Egypt is the needed action to identify the real magnitude of the problem. Only then, we will be able to assess the nephrology practice in different hemodialysis-related issues [e.g. anemia and chronic kidney disease (CKD)–mineral bone disease (MBD)], and excel. This would also guide to structure and develop protocols that suit our local demographics and thus help in the setting of effective treatment plans and preventive campaigns with the proper direction of resources. Moreover, data derived from patient registries is a basis for clinical research and development.

Methodology

ERDS is the Egyptian national registry of nephrology patients. It was founded and is run by the ESNT, the only official Egyptian Non-Governmental Organization representing nephrologists and officially managing some issues of the nephrology specialty in Egypt. ERDS until now registers data about patients with ESKD on chronic HD, but the plan is to include more patient groups in the future.

ERDS 2019 and 2020 data were collected by voluntary or semivoluntary self-reporting of Egyptian HD units, with calls for participation done by the following:

(1) Phone calls and personal WhatsApp messages sent from a central ERDS board consisting of eight persons, and 27 other principal key persons, who are influential senior professors and prominent nephrologists selected to cover all of the 27 governorates of Egypt. Many of them were the heads of the nephrology departments of their universities, had influential official positions in the ministry of health in their governorates, and/or had informal influence.
(2) Mass messages, mainly reminders sent on WhatsApp groups, were created for this purpose.
(3) Announcements in real-life and online conferences, some of which were scientific and some were dedicated for promotion and training on the ERDS.
(4) A dashboard on the software platform showed the progress of the different HD units, and detailed progress statistics were reviewed by the ERDS team in meetings that were sometimes weekly and sometimes also involved the 'Key Persons.' Accordingly, close follow-up phone calls and personal WhatsApp messages were made by the 'ERDS Board,' 'Key Persons,' and more junior doctors working as a part of the ERDS team, to motivate HD units that were lagging behind the others in terms of data entry.
(5) Near the end of the reporting period of ERDS 2020, paper mails were sent to the official addresses of private HD units, informing them that the submission of data about their units to ERDS is a required part of renewing their annual licenses.

Factors motivating nephrologists to participate were as follows:

(1) Participants' understanding of the benefits to the country and nephrology community at large, of having a national registry.
(2) Dialysis units were informed that the data that they register on the system would be available to them to export, allowing them to statistically analyze and create research papers from their data if they wanted.
(3) Respect of members of the ESNT board and ERDS team as they reached out personally to managers of HD units to motivate them.
(4) The fear of missing out on participation, and the shame of having their institutions not being represented in such a large-scale study, the results of which was regularly presented in details in the annual ESNT conferences of 2019, 2020, and 2021 and published on the ESNT website.
(5) Direct orders given to junior doctors by more senior doctors who were higher than them in the chain of command, like the heads of their departments. The seniors could be convinced by any of the above factors.
(6) Nephrologists who showed the best performance in terms of number of patients entered and the completeness of data entered for patients were appreciated and rewarded:
    (a) Full registration and accommodation in the annual ESNT conference.
    (b) Certificates of appreciation.
(7) Fear of 'punishment' by delays in renewals of licenses of HD units was a very minor factor as the official 'paper mails' were only sent in the last month of the reporting period, and no clear punishment was stated in the mail. It was only subtly implied. This factor is expected to be more important in future ERDS reports, by more clear and strict coupling between submission of data and license renewal.

In ERDS 2020, 73 persons were eventually involved in the data entry process, mostly junior nephrologists, but with some participation of senior professors, nurses, and administrative personnel. Data from a total of 3393 patients were entered, with the involvement of 62 HD units from 17 governorates.

The participants in ERDS 2020 were required to enter the data of their units as completely as possible using cloud-based 'Yashfii' software that was customized specifically for the needs of the ERDS. Software could be accessed remotely over the internet by the web browser of any personal computer, tablet, or smartphone, through a website link 'https://www.Yashfii.com/esnt,' that was sent to participants.

Training on data entry was provided for ERDS 2019 and 2020 by the following:

(1) Real-life meetings, in conferences, and by on-site visits, sometimes to remote governorates.
(2) Online meetings.
(3) Training videos that can be watched by clicking the following link:

    https://drive.google.com/drive/folders/1HuQPbr_65_IKJKHwcz7F8op5ZuQ6B3xy

Two types of data were collected:

(1) Unit data: data about the dialysis units as a whole. The 'unit data' page included one sheet that had 16 questions requesting observational cross-sectional data. This included asking about the location and type of HD units, working hours of HD machines, the patterns of staffing, and the water unit test.
(2) Patient data (data specific to each patient): the sheets requested observational retrospective and cross-sectional data including mainly demographic data, clinical disease data, laboratory data, medications, and HD prescription data for the same group of patients. The 'patient data' page included nine sheets that collectively had 103 questions. These included the following:
    (a) Sixty primary questions that were always open for users to answer.
    (b) Forty-three other secondary questions that only appeared if previous primary questions were answered in a specific way. For example, the secondary question, type of glomerulonephritis (GN), would only appear for users if the answer to the previous primary question titled original kidney disease was GN.

The nine 'patient data' sheets were as follows:

(1) Demographic and administrative data: age, whether the patient was 'dependent' on an assistant, who sponsors the cost of HD sessions, and contact information.
(2) Clinical data: height, weight, original kidney disease, date of dialysis initiation, and comorbidities.
(3) Virology: diagnosis, treatment, and vaccination status where relevant of hepatitis B, hepatitis C, HIV, and coronavirus disease 2019 (COVID-19).
(4) Anemia data: relevant laboratory tests and treatment.
(5) MBD: relevant laboratory tests and treatment.
(6) Hypertension and diabetes: treatment status.

(7) HD data: HD access, types of filters used, and efficiency of HD.
(8) HD access: current and previous vascular accesses used and access failures.
(9) Fate of patient: data about fitness for transplantation, transfer to other units, and mortality.

The digital formats of questions in both 'unit data' and 'patient data sheets' included the following:

(1) Multiple-choice questions allowing a single answer per question: for example, original kidney disease, dependence, need of a wheelchair, and vaccinated for hepatitis B virus (HBV).
(2) Multiple-choice questions allowing multiple answers per question (checkboxes): for example, comorbidities and types of HD filters used.
(3) Numerical answer questions (that validated the response, accepting only numerical answers, including numbers with decimal places): for example, hemoglobin, ferritin, and calcium levels.
(4) Integer answer questions (that validated the response, accepting only numerical answers, but not allowing decimal places), for example, number of blood transfusions throughout the reporting period.
(5) Date answer questions: for example, date of initiation of HD and date of transfer to another unit.
(6) Short-text answer questions were rarely used, for example, the name of the emergency contact persons.

Data sources

(1) Some units answered most of the questions by copying from paper files or electronic files that they already had available for each patient. For example, all units are required by the government to keep a record of the virology status. The date of initiation of HD in the current unit is also usually found in files, and many units also have a table of laboratory tests and records of the drugs. However, most units needed to collect at least some raw data, as at least parts of the data were not available in patient files.
(2) Meetings or phone calls with dialysis unit managers, nurses, administrative staff, and/or HD machine technicians: for example, to ask about the number of nurses and consultants in the unit consultants, and the number of hours that dialysis machines worked.
(3) History taking from patients and their relatives: for example, comorbidities, original kidney disease, and sometimes date of initiation of HD.
(4) Direct observation or measurements: for example, height, dry weight, and HD prescription used in the latest session.
(5) Miscellaneous paper-based and electronic sources, like laboratory printouts, laboratory excel files, digital laboratory information management systems, and drug sheets.

Data analysis

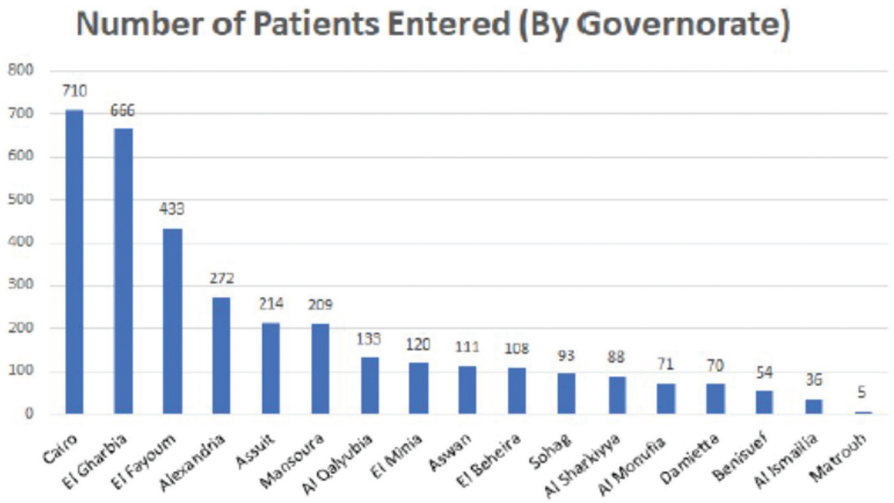
Data entered by all units were exported from the digital system as a .csv file that can be opened by Microsoft Excel. Data analysis was carried out by the following:

(1) Microsoft Excel functions including filters (for cleansing and review of data), calculation formulae, pivot tables, and chart creation.
(2) Microsoft Power Business Intelligence was also used as an integrated tool for cleansing data, calculations, and creation of charts.

Processing of data items in which we had multiple entries for the same patient:

(1) Averages of all values were taken, when multiple entries were found for the data items that could naturally be measured multiple times in the reporting period. For example,
    (a) Laboratory values: hemoglobin, ferritin, calcium, and phosphorus.
    (b) Drug doses, for example, erythropoiesis-stimulating agent dosing.
(2) The most recent entry for the following:
    (a) Questions asking for qualitative data, using multiple-choice questions allowing a single answer per question. For example, in the dependence question, a patient cannot be dependent on an assistant and independent at the same time. If dependent is the most recent answer, and the patient was recorded as independent in an earlier date, we assume that there has been a change in the status of the patient (e.g. owing to new cognitive or physical impairment).
    (b) Questions asking for a date.
(3) We counted the multiple data entries from the same patient in a few multiple-choice questions allowing multiple answers per question (checkboxes). For example, in the comorbidities question, a patient can have both stroke and liver cirrhosis. Thus, in these questions, we had a total number of responses that were greater than the number of patients who had answers for these questions.

Figure 1



Number of patients entered by Egyptian governorates (cities) participating in ERDS 2020. ERDS, Egyptian Renal Data System.

Demographic and dependence data

The prevalence of ESKD is increasing worldwide; being 1500 per million population (pmp) in the United States, and ~800 pmp in the European Union. In developing countries, the prevalence may vary from less than 100 pmp in sub-Saharan to ~400 pmp in Latin America [9]. In Egypt, the estimated annual incidence of ESKD is ~74 per million, and the total prevalence of patients on dialysis is 264 pmp [10].

Number of patients entered by Egyptian governorates (cities)

A total of 80 dialysis units from 18 Egyptian governorates (cities) participated with their data in ERDS 2019 report with a total number of 3393 patients (Fig. 1).

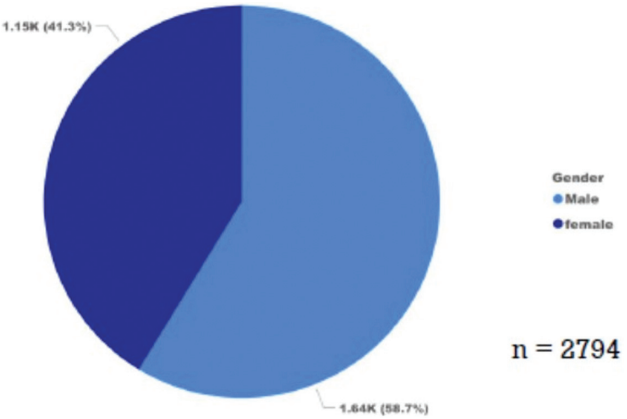
Sex percentages of patients

Most patients were males, which is consistent with studies from most other countries where males outnumbered females in the prevalent and incident populations [11] (Fig. 2).

Age class percentage of patients

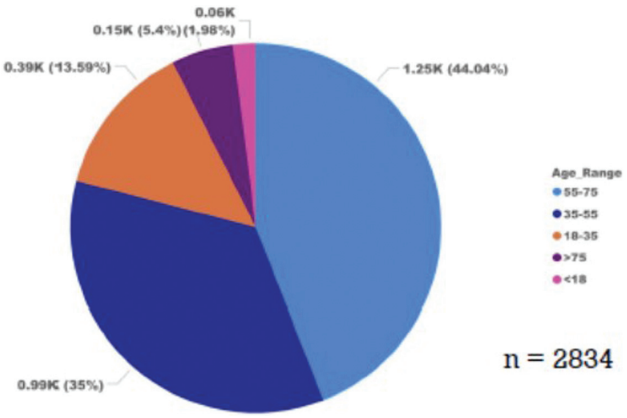
The number of older dialysis patients (Fig. 3) is increasing as is happening in many other countries. For example, in Japan, this trend is linked to the increase in the dialysis patients 70 years of age and over. Older dialysis patients often experience deteriorating physical and psychological functions, and special consideration for older patients has been focused on improving or preventing such deteriorations [12].

Figure 2



Sex percentages of patients.

Figure 3



Age class percentage of patients.

Dependence

Among 1741 of our patients, 12% were using wheelchair. This affects the quality of not only their lives but also the health care provided to patients [13]. Among 1769 of our patients, 42.3% were dependent on an assistant. This finding was very similar to the preceding year (Figs 4 and 5).

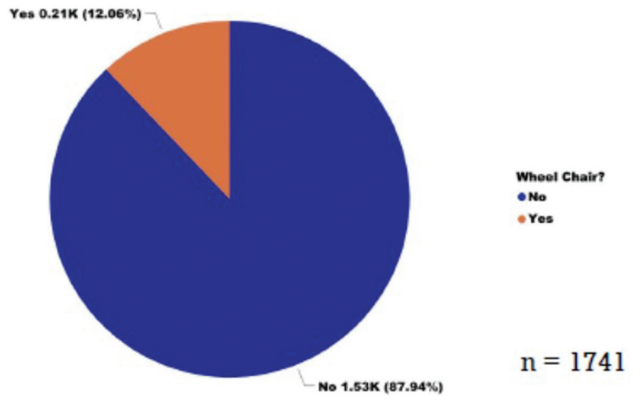
Employment status

Almost half of the patients were unemployed, and a minority of the rest were working full time. Dialysis is a life-changing event for patients at multiple levels. Employment is one of several challenges faced by individuals with progressive CKD transitioning to ESKD. Such patients face multiple disincentives to employment, including medical, logistical, and financial disincentives. The 1972 federal legislation that provided Medicare entitlement for patients with ESKD assumed that most individuals receiving dialysis would remain in or return to the workforce and therefore, would be partially self-funding through the payment of income taxes [14]. This seems to be a worldwide problem. Finnish Registry for Kidney Diseases showed a low employment rate of 33% [15]. A recent study from India reported an employment rate of 29.9% among patients after initiation of dialysis, with rates of loss of employment of 44 and 51% among patients initiating HD and peritoneal dialysis, respectively [16] (Fig. 6).

Dialysis unit data

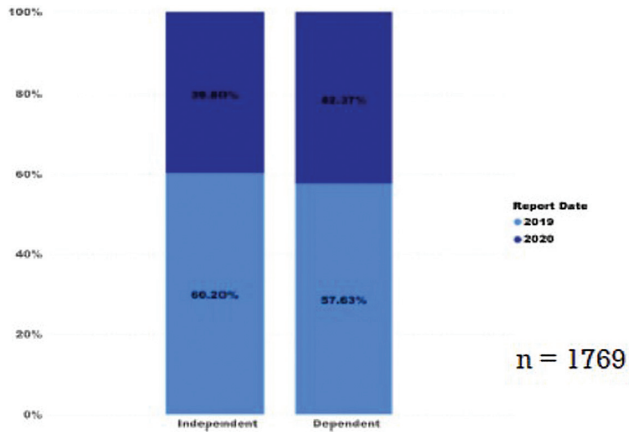
Egypt is a developing country and a home to 102 million and is faced by the challenge of having the

Figure 4



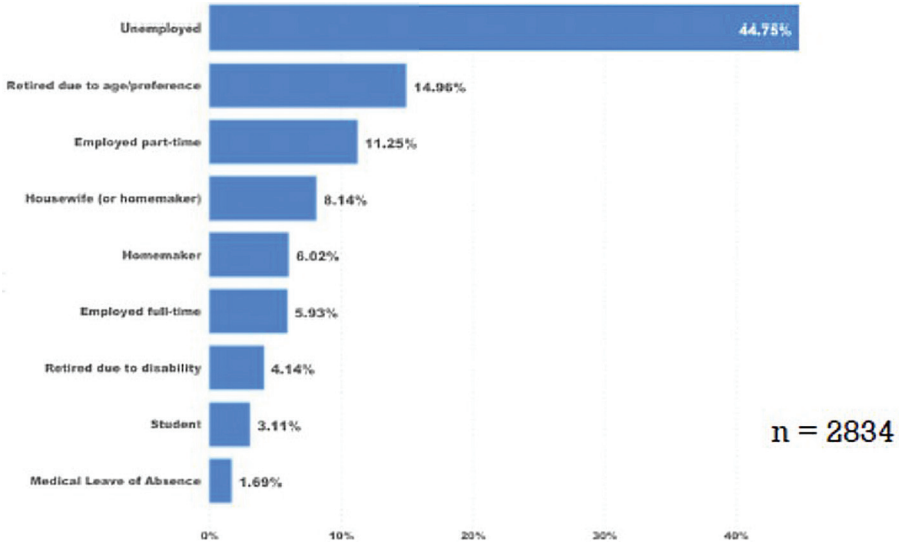
Wheelchair use.

Figure 5



Dependence (on an assistant).

Figure 6



Employment status.

largest population in the Middle East and Northern Africa (MENA) [17]. It is therefore not a surprise that Egypt in 2017 had 1.4 hospital beds for every 1000 people, which is higher than the average of lower middle-income countries of 0.8 but lower than the average of middle-income countries of 2.4 [18].

Egypt has an average of 1.9 nurses and midwives per 1000 persons, which is lower but close to the MENA average of 2.5, and significantly lower than the USA's average of 14.5 [19]. Furthermore, Egypt has an average of 0.5 physicians per 1000 persons, which is significantly lower than the MENA average of 1.3, whereas in USA, the average is 2.6 [20].

This chapter focuses on the type of data that cannot be associated with a specific patient in particular, but rather it needs a higher-level, zoomed-out view on the HD unit as a whole. It is interesting to see how Egypt compares with other countries in terms of high-level statistics, given the aforementioned challenges.

Center type and working hours of dialysis machines

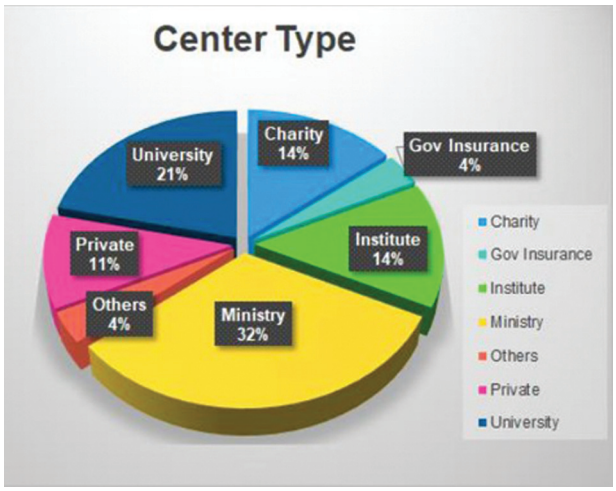
Ministry or university centers together comprise more than half of the dialysis centers that reported their type, but it is notable that the size of each dialysis unit varies, and some units did not report their center type. Thus, a more accurate way to compare cost sponsorship is demonstrated in the following figure, where each HD unit was weighted by the number of patients it serves (Fig. 7).

Government-sponsored centers include ministry, institute, governmental insurance, and university centers (Fig. 8). Together they comprised 78% of dialysis units involved in our ERDS 2020. Note that the label placed on dialysis units is related to how most but not all of patients within each unit are sponsored. For example, the cost of HD of some patients in private centers and charity centers is covered partially or completely by the 'Ministry Commission' funding. There is a high level of governmental spending on patients with ESKD in many countries [21,22]. Most of dialysis machines work for more than 20 000 h (Fig. 9).

Nurse and physician ratios

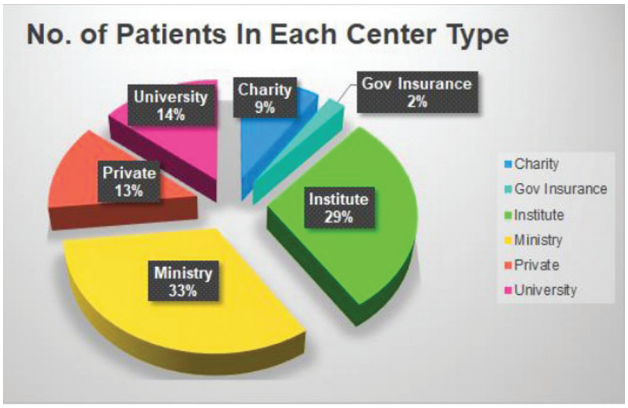
Our data were compared with the Annual Facility Survey from 4035 US HD units [23] (Fig. 10). Nurses in both Egypt and the US share a group of core functions that dialysis technicians do not perform, like recording vital signs, inserting collecting blood samples, and administering medications [24,25].

Figure 7



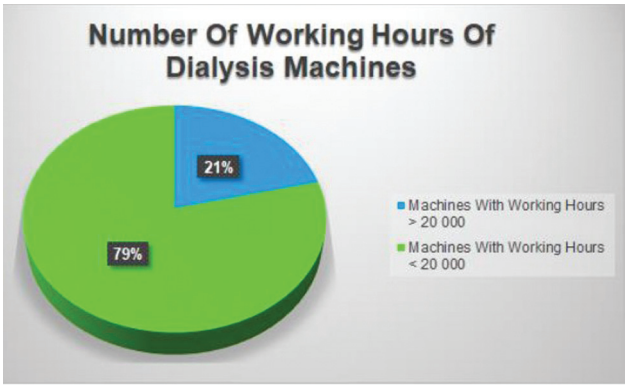
Center type chart (n=62 dialysis units).

Figure 8



Number of patients in each center type (n=3393 patients).

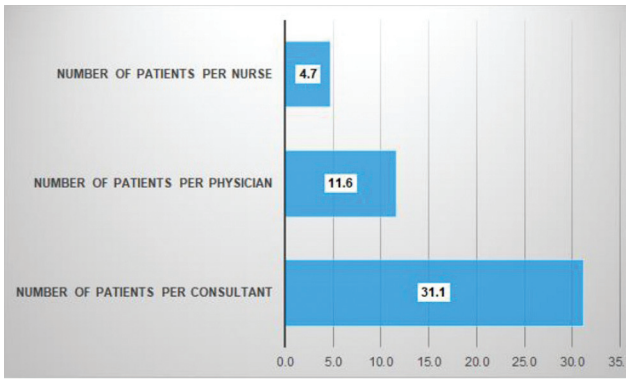
Figure 9



Number of working hours of dialysis machines (n=652 machines).

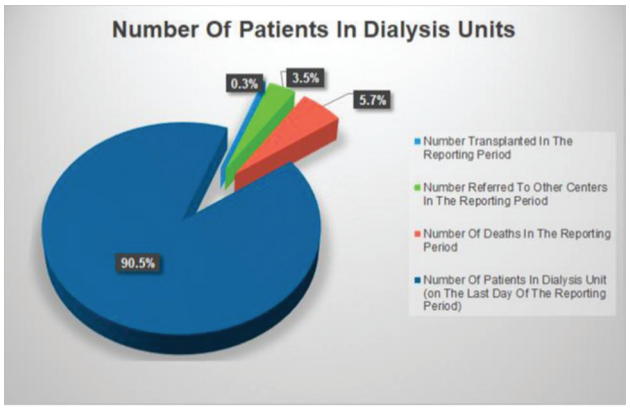
Thus, it is reasonable to say that the average ratio of 4.7 patients per nurse in ERDS in 2020 seems better when compared with the US average of 6.06 patients for each nurse.

Figure 10



Patient-to-health care provider ratio (n=553).

Figure 11



Percent of patients who were transplanted, referred to other units, or who died in the reporting period, as reported in dialysis unit data (n=1857).

Another survey analyzing responses from 422 registered nurses in USA showed that the average patient-to-registered nurse ratio in the dialysis units that they worked in was 9.58, with a SD of 7.14 [26]. Another caveat that is demonstrated by data from the state of California needs to be noted when comparing Egyptian data with US numbers. The state of California reports that on the average, every 12 patients are served by one nurse and three dialysis technicians [27].

Higher patient-to-nurse ratios (which means less staff employed) in this USA study was associated with the following [26]:

(1) More frequent adverse patient events including intradialytic hypotension.
(2) More frequent patient complaints.
(3) More skipped dialysis sessions and shortening of dialysis sessions.
(4) More necessary nursing tasks left undone.

In the aforementioned survey of 4035 HD units in USA, facilities with relatively more social workers had better mortality ratios, whereas facilities with relatively more registered dieticians had better hospitalization ratios than other facilities. However, the staffing ratios of other types of staff were not shown to have effects on morbidity or mortality [23].

On the contrary, mandatory staffing ratios may have detrimental consequences reported by paper documenting the California experience, including the following [27]:

(a) Dialysis units refusing to accept new patients thus decreasing the choice of dialysis units and dialysis shifts available for patients.
(b) Some units unable to meet the requirements may need to close down.
(c) It would become harder to open new units.

Doctors in our ERDS 2020 data were on the average one resident for every 12 patients and one consultant for every 31 patients.

Patients fate

In our 2020 ERDS data, we had a mortality of 5.7% over a reporting period of ~1 year, which can be roughly converted to slightly more than 57 per thousand patient-years [28] (Fig. 11).

This is much less than the mortality rate numbers reported in USRDS, with 164.6 per thousand patient-years.

The 5-year survival rate of patients with ESKD according to the USRDS data was 93.8% for living donor transplant recipients, 83.4% for deceased donor transplant recipients, and 41.4% for HD patients [29].

In spite of this stark evidence of decreased mortality gained by offering more patients renal transplantation, our ERDS 2020 data show that only 0.3% of HD patients received renal allografts in the reporting period of ~1 year. This can be roughly converted to a transplantation incidence rate of slightly more than three transplants per thousand patient-years, in contrast to the USA's rate of 36 per thousand patient-years according to USRDS 2020 [30].

There are wide variations between countries in terms of transplantation prevalence within the ESKD population, from 69 and 60% in Norway and

Finland, to 4 and 2% in Malaysia and Japan, respectively [31], with USA's prevalence being at 29.3% according to the USRDS 2020 report [32].

Our data indirectly highlight how the Egyptian transplantation prevalence is toward the lower part of the gradient.

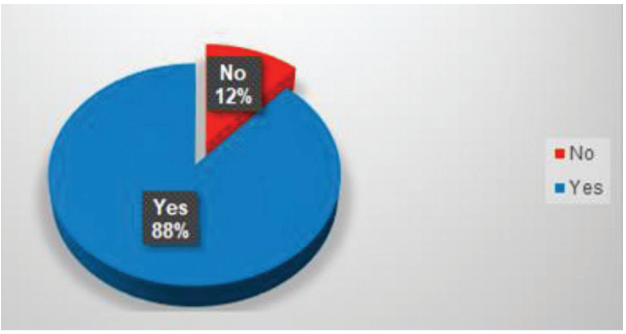
Water treatment unit test

Overall, 88% of the dialysis units involved in ERDS 2020 passed their last water treatment test. Note that usually, after failure in the water treatment test, units take mandatory corrective actions, and they usually pass the following test, but we have not measured this in our study (Fig. 12).

Recommendations

(1) It is advantageous to identify units with low staffing that can be asked to increase the staffing ratio under the umbrella of central bodies as a part of comprehensive quality improvement efforts.
(2) When enough data are collected from many governorates, comparisons of nurse-to-patient and physician-to-patient ratios in different governorates can be done. This could thus better inform central health policies and reforms.
(3) Advocating for higher per-HD-session governmental sponsorship for HD centers to cover both direct and indirect costs of staffing with doctors and nurses.
(4) Encouragement of more renal transplants in Egypt by measures that could include:
    (a) Increasing the awareness of physicians and patients about the survival benefits of renal transplantation, by media, conferences and other forms of continuous medical education
    (b) Increasing the awareness of patients about the survival benefits of renal transplantation, by targeted awareness campaigns, distribution of printed brochures, display of videos, and direct one-on-one counseling.
    (c) Offering generous funds for renal transplantation by private and public health insurance plans.
    (d) Increasing the living donor pool by adopting programs such as paired-donations.
    (e) Action plan to remove barriers restricting deceased donor transplantation and then launching mass awareness campaigns encouraging people to donate their organs after death.

Figure 12



Last water treatment unit test (n=26 units).

Original disease

ESKD has varying causes that are different from country to country and from region to another. However, the same risk factors remain cosmopolitan, for instance, diabetes mellitus, hypertension, GN, autosomal dominant polycystic kidney disease, analgesic nephropathy, and obstructive uropathies are still the universal risk factors.

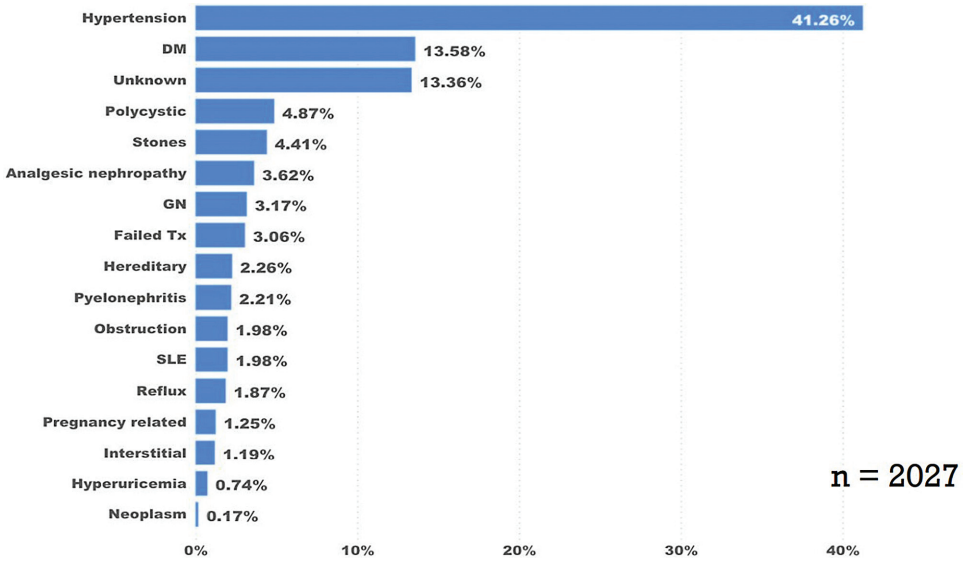
In Egypt, the most widely believed etiology of ESKD is hypertension. This was reported by Barsoum [33] and was reproduced in a larger-scale study in Ain-Shams University [34].

Etiology of end-stage kidney disease in Egypt

According to the registry data 2020, hypertension is still the most common cause of ESKD in Egypt (Fig. 13). Hypertension represented almost 41% of the causes of ESKD in Egypt, and this figure is high enough to alert health communities. This is followed by diabetes mellitus, which represents 13% of the causes. The third common cause was unknown. The number of patients developing ESKD labeled owing to hypertension is increasing in Egypt. However, the diagnosis of hypertensive ESKD is one of the exclusions, and no pathologic data corroborate this classification. Both diseases can be closely associated.

Diabetes is the leading cause of ESKD worldwide, but it occurs only in 13% of our patients. An explanation might be that Egyptian patients on dialysis have an average age that is younger than that in the USA by 15–20 years. Another possibility is that patients with diabetes who develop CKD die before reaching dialysis, and until we have full registration for CKD and diabetes, we may then not know the real effect of diabetes on CKD [29].

Figure 13



Etiology of ESRD in Egypt 2020. ESRD, end-stage renal disease.

The high prevalence of unknown causes reflects the late referral to nephrologists, lack of awareness from the patient's side, and the deficiency of registered data. Polycystic kidney disease then comes next, followed by stones and analgesia-induced nephropathy. Polycystic kidney disease is the most correctly reported cause of ESKD in Egypt and worldwide. Analgesic nephropathy is rather a broad term, but this does not explain the high rate detected in this report.

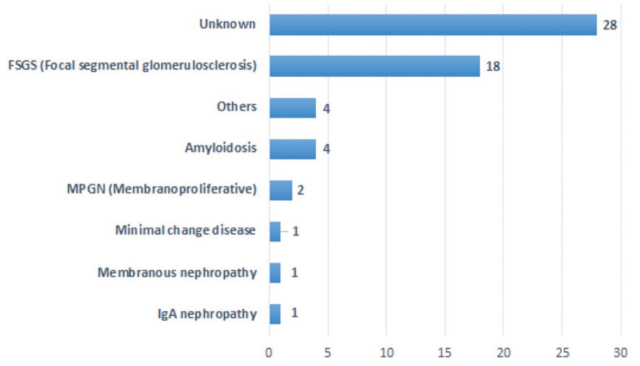
Glomerulonephritis as a cause of end-stage kidney disease

The most common cause of GN in our data is unknown, and this is owing to the absence of the pathology report when physicians report the etiology of ESKD. FSGS is the most widely reported GN (Fig. 14).

Recommendations

(1) Physicians and nurses who are working in data collection should have good training on how to reach the proper etiology from history, examination, and patient files.
(2) Reporting hypertension should only be made if the patient reported hypertension years before development of CKD.
(3) We need to expand on data collection and have registry for patients with diabetes over time to get to know the exact burden of diabetes on CKD in Egypt.
(4) Reporting GN should be based on biopsy as well as patient's medical file and treatment history.

Figure 14



Type of GN (n=59). GN, glomerulonephritis.

(5) Raising awareness of CKD etiologic and risk factors.

Viral diseases

General considerations

HBV and HCV are the most common viral infections among individuals with renal disease [35]. Patients with ESKD are at increased risk of acquiring HBV and HCV infections than the general population owing to their deficient immune response, exposure to blood transfusions, and HD equipment [36].

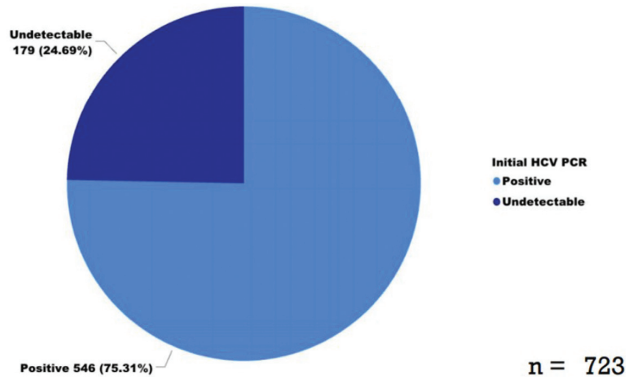
The Egyptian Demographic Health Survey was conducted in 2008 on a large nationally representative sample, and the estimated HCV prevalence was found to be 14.7% among the 15–59-year age group. Accordingly, Egypt had the

highest HCV prevalence in the world till the adoption of a government-sponsored mass treatment program using several combinations of direct anti-viral agents [37,38]. In addition, dialysis patients carry a higher risk, not only, of complications from the severe acute respiratory syndrome coronavirus 2 that causes COVID-19, but also, for the transmission of COVID-19 owing to some of their underlying comorbidities and logistical difficulties of keeping adequate social distancing as recommended by CDC guidelines [39,40].

Viral diseases status

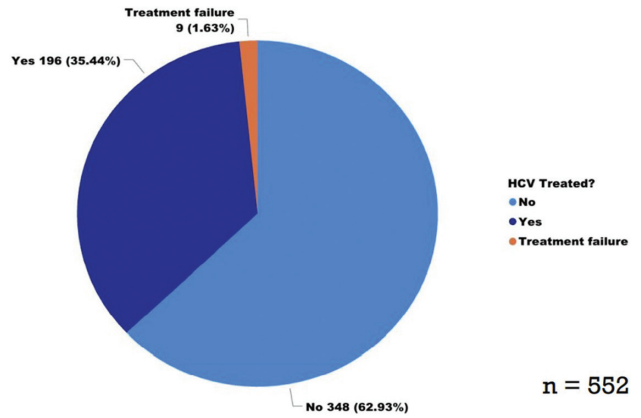
Seropositivity in HD population is present in almost a third of HD Egyptian population. In HCV seropositive HD patients, more than three-quarters of cases showed positive PCR and those are indicated for treatment with oral DAA combinations (Figs 15–20). In HCV seropositive patients with positive PCR who are eligible to treatment with DAAs, only 35.4% of cases received treatment, with 1.6% failure rate. Among HCV cases that received treatment, follow-up HCV PCR was undetectable in

Figure 15



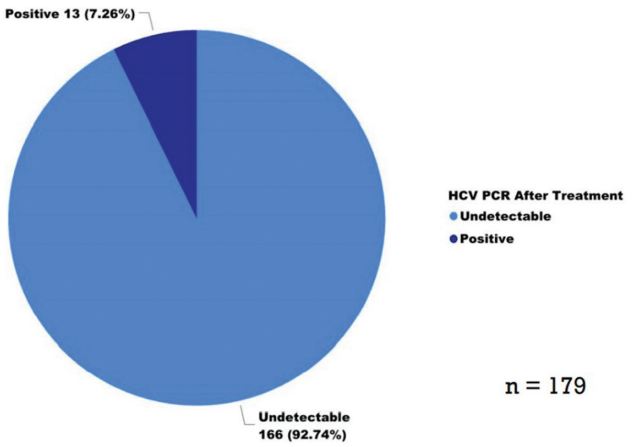
Distribution of initial HCV PCR in HCV Ab-positive patients.

Figure 16



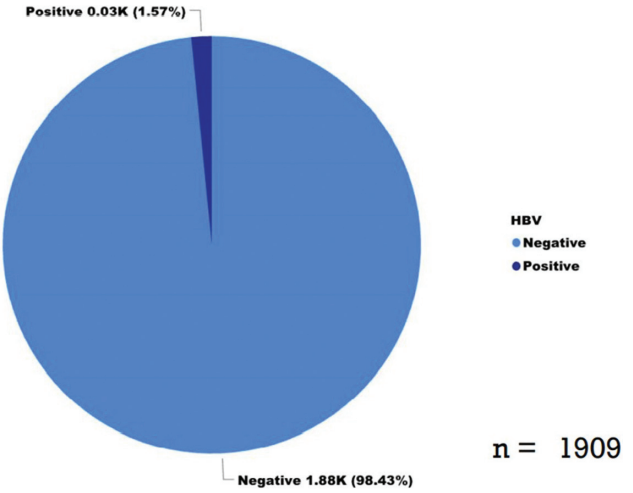
Distribution of HCV treatment scenarios in HCV Ab-positive patients.

Figure 17



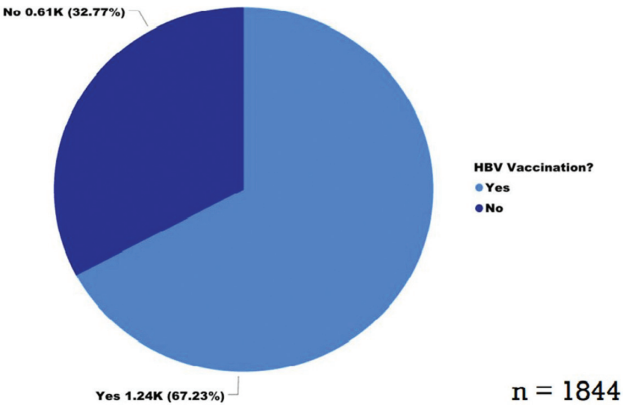
Distribution of HCV PCR after treatment of HCV PCR-positive patients.

Figure 18



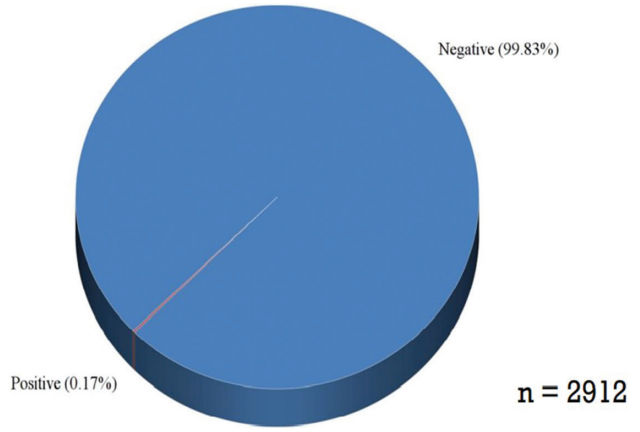
Distribution of HBV infection. HBV, hepatitis B virus.

Figure 19



Distribution of HBV vaccination. HBV, hepatitis B virus.

Figure 20



Distribution of HIV infection.

the majority of cases (92.7%), denoting excellent response to DAAs. Hepatitis B infection among our HD cohort is not prevalent, constituting only 1.5% of cases. HBV vaccination was received in only approximately two-thirds of HBV-negative cases that were eligible to have the vaccine. HIV infection among HD patients is extremely rare constituting only 0.17% of cases.

Coronavirus disease 2019 status

COVID-19 infection was diagnosed among only 11% in a sample of HD patients. In the sample of COVID-19 cases, diagnosis was based on positive PCR with positive computed tomography chest findings in almost half of the cases (52%), positive computed tomography chest findings alone in 44% of cases, and only positive PCR in the minority of cases (3%). The rate of COVID-19 vaccination was low (6.5%) at the time of data collection. The mortality rate in COVID-19-positive cases was relatively high (35%) (Figs 21–24).

Recommendations

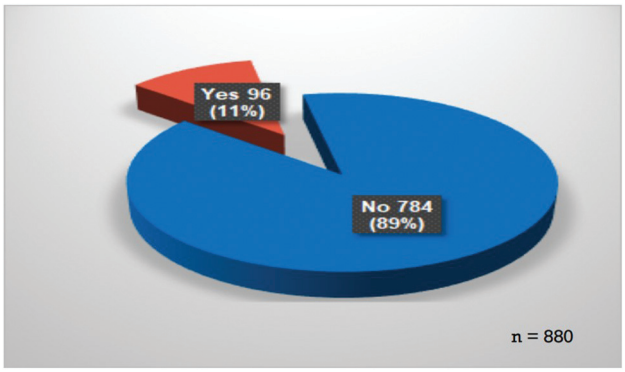
(1) All eligible HCV-positive cases with positive PCR should be encouraged to receive treatment with oral DAAs according to the national guidelines.
(2) All HBV-negative cases are recommended to receive HBV vaccination according to CDC and national guidelines.
(3) CDC Interim Additional Guidance for Infection Prevention and Control Recommendations for Patients with Suspected or Confirmed COVID-19 in Outpatient HD Facilities should be applied.

Anemia profile

General considerations

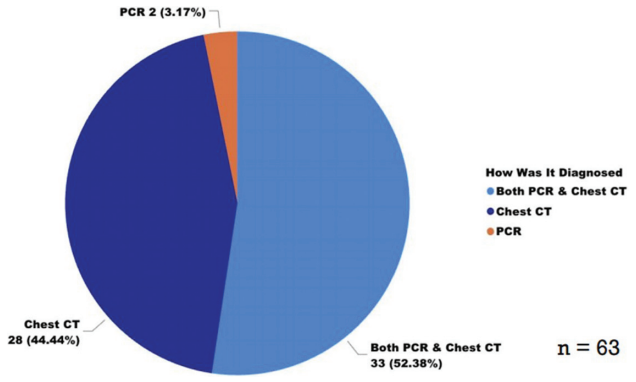
Despite continuous quality improvement efforts, reaching clinical targets of HD patients, for example, hemoglobin, is far from levels achieved worldwide. This is demonstrated by the wide variations in the achievement of anemia management targets observed among countries participating in DOPPS, thus pointing to the difficulties in implementing clinical guidelines [41].

Figure 21



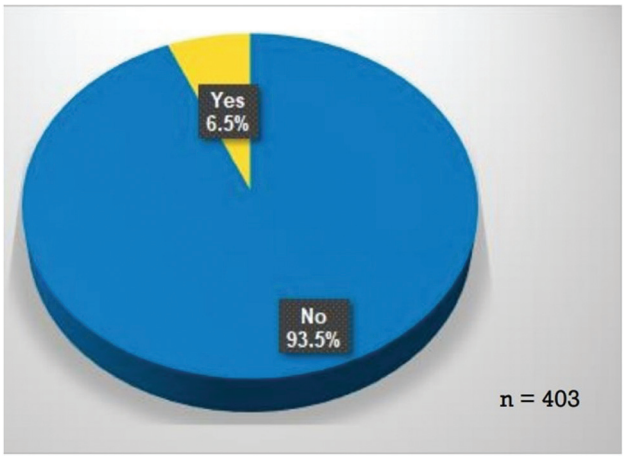
COVID-19 diagnosed. COVID-19, coronavirus disease 2019.

Figure 22



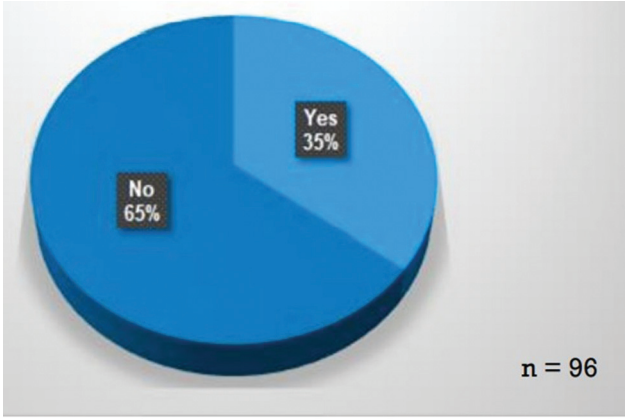
How was COVID-19 diagnosed. COVID-19, coronavirus disease 2019.

Figure 23



COVID-19 vaccination. COVID-19, coronavirus disease 2019.

Figure 24



COVID-19 mortality compared with diagnosed. COVID-19, coronavirus disease 2019.

A large body of research demonstrates that the attainment of such targets is of life-saving importance. For example, Plantinga et al. [42] examined the achievement of five clinical targets, one of which was hemoglobin more than or equal to 11 g/dl in 668 incident US HD patients. Attainment of each of the five targets was individually strongly associated with decreased mortality, hospital admissions, and resource use, and attainment of more targets was associated with better outcomes.

Large epidemiological studies have shown that mortality and morbidity are reduced when the hematocrit (Hct) level is in the range of 33–36%, which conforms with the K/DOQI targets. Hct greater than 30% (or hemoglobin >11.0 g/dl) is associated with an 18–40% decreased risk of death and hospitalizations. Further increasing Hct to the 33–36% range is associated with a further 7% reduction of risk of death and hospitalizations [42]. Gilbertson et al. [43] showed that persistently or transiently low hemoglobin levels was associated with increased mortality. For every 1 g/dl increase in mean hemoglobin level, mortality and hospitalization risks were declined by 10–12% [44]. Significantly improved outcomes may therefore be expected through achieving the recommended hemoglobin levels [45].

In addition to the effect on mortality, many studies have also shown the effect of achievement of hemoglobin targets on quality of life. Shrestha et al. [46] showed that variables like hemoglobin and Hct have a positive correlation with all of the four domains of the KDQoL scale. This background motivated us to measure the achievement of hemoglobin targets nationwide in Egypt, mirroring international efforts to do so.

Highlights of guidelines used as benchmarks in our analysis

We used the latest available KDIGO guidelines that were relevant to patients with stage 5 CKD on HD (CKD) [47]. The most important guidelines were as follows:

(1) Erythrocyte-stimulating agents (ESAs) and hemoglobin targets, KDIGO suggests the following:
   (a) ESA therapy should be used to avoid having the hemoglobin concentration decrease less than 9.0 g/dl by starting ESA therapy when the hemoglobin is between 9.0 and 10.0 g/dl (2B).
   (b) ESAs should not be used to maintain hemoglobin concentration above 11.5 g/dl in adult patients with CKD (2C).
   (c) ESAs should not be used to intentionally increase the hemoglobin concentration above 13 g/dl.

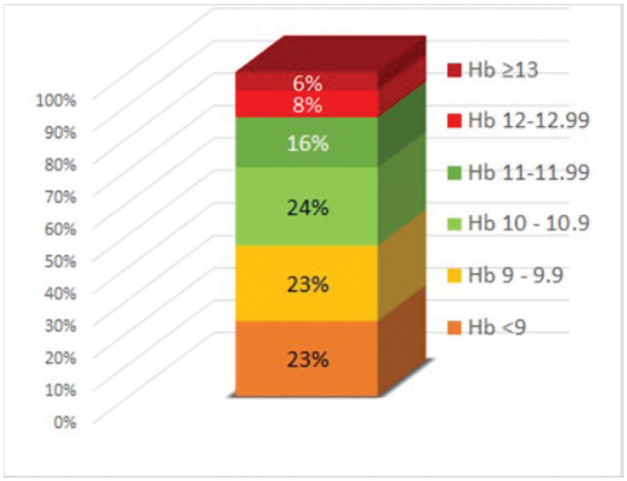
(2) Treatment with iron agents: KDIGO suggests a trial of intravenous iron if (2C):
   (a) An increase in hemoglobin concentration or a decrease in ESA dose is desired.
   (b) TSAT is less than or equal to 30% and ferritin is less than or equal to 500 ng/ml.

(3) It is notable that DOPPS categories are only slightly different, with hemoglobin concentration stratified at one g/dL intervals (10–11, 11–12, 12–13 g/dl, etc.) [48].

Anemia laboratory profile

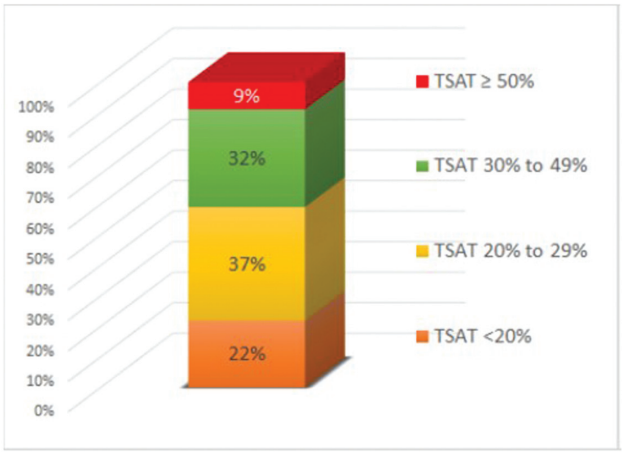
When comparing our findings to more recent surveys, having 40% of the patients in our ERDS 2020 data with hemoglobin 10–12 g/dl is relatively lower than many of the levels of other countries, and this shows that there is room for more improvement (Figs 25–27). For example, in DOPPS of Gulf Cooperation Council (GCC) countries between 2012 and 2018, achievement of hemoglobin targets of 10–12 g/dl ranged between 46.6% in UAE (United Arab Emirates in 2016–2018) and 75.3% Qatar (in 2016–2018). Our studied units hemoglobin were thus closest to those of UAE. Meanwhile, in the DOPPS studies of Germany between 2012 and 2015, achievement of hemoglobin of 10–12 g/dl ranged between 48.4 and 63.0% [49], whereas between August 2010 and February 2020 in USA, it ranged between 57.2 and 69.9% [50].

Figure 25



Percent of hemoglobin levels in patients with ESKD in ERDS 2020 data (n=2324). ERDS, Egyptian Renal Data System; ESKD, end-stage kidney disease.

Figure 26



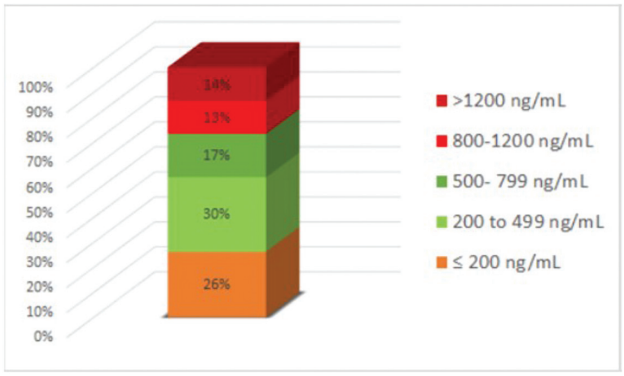
Percentage of TSAT levels in patients with ESKD in ERDS 2020 data (n=875). ERDS, Egyptian Renal Data System; ESKD, end-stage kidney disease.

Having 78% of patients in our data achieving transferrin saturation targets of more than 20% is less of an achievement than the USA DOPPS of August 2010 to February 2021, which ranged between 81.2 and 90.9% [51].

However, it is a larger achievement than the DOPPS I and DOPPS II of USA (67.9 and 73.4%, respectively). This is also very close to most of the countries involved in all the GCC DOPPS studies of 2012 to 2018, where the median achievement of TS more than 20% was 76.6% [52].

Approximately 47% of patients have ferritin levels between 200 and 799 ng/ml. These findings are

Figure 27



Percentage of ferritin levels in patients with ESKD in ERDS 2020 data (n=921). ERDS, Egyptian Renal Data System; ESKD, end-stage kidney disease.

similar to those of the USA DOPPS of August 2010 to February 2021 and also to some of the countries of the GCC DOPPS studies of 2012–2018, where respectively 40.3–58.2% (median 50.4%) [53], and 44.1–74.1% (median 58%) of patients had such levels [54].

Anemia management, erythrocyte-stimulating agent therapy

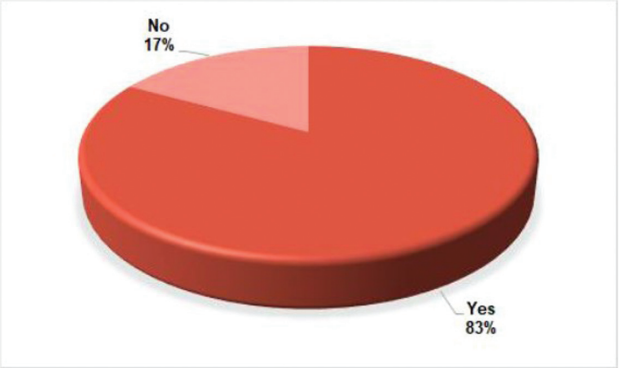
Overall, 83% of patients received ESA treatment in the reporting period, which is slightly lower than the median of the countries of the GCC DOPPS studies of 2012–2018 (92.7%) but higher than some of the GCC countries, like Bahrain and UAE, whose values were 68.30 and 75.80% patients, respectively [55]. This is also close to 90.30%, the median of the USA DOPPS of August 2010 to February 2021 [56] (Figs 28–32).

The majority of patients of ERDS 2020 (88.2%) used erythropoietin alpha exclusively as an ESA. This prescription pattern is similar to the pattern seen in USA DOPPS of 2011–2014 where an average of 95.4% of patients were prescribed erythropoietin alpha. It is notable that gradually over the following years in USA, there has been a gradual relative decline in the use of erythropoietin alpha, as in the USA DOPPS of 2017–2020, the average was 47.7% [57].

A similar decline could be seen in GCC DOPPS from an average of 56% in 2012–2015 to an average of 24.3% in 2016–2018, but such low values cannot be seen yet in our Egyptian data [58].

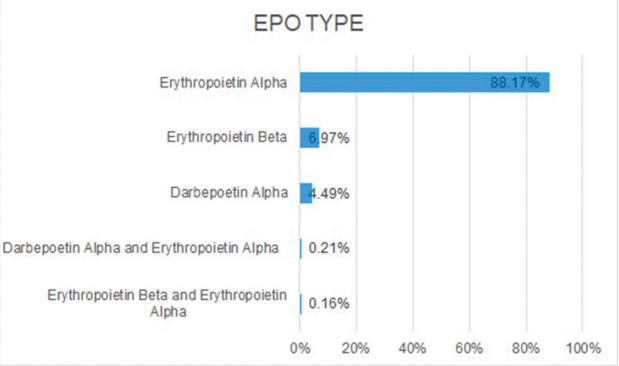
Almost half of the prescriptions of erythropoietin alpha of ERDS 2020 comprised 4000 IU or less, which demonstrates that we generally use lower dosing

Figure 28



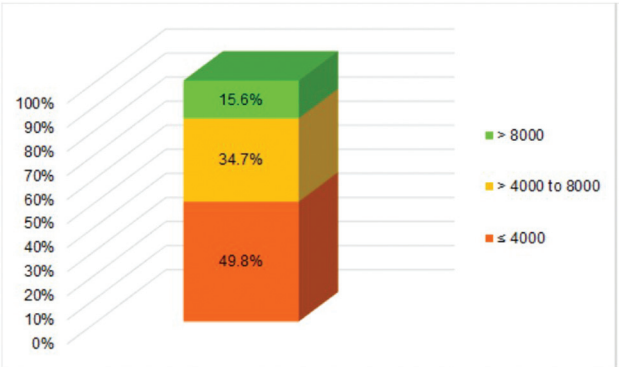
Distribution of erythropoiesis-stimulating agent treatment in ERDS 2020 data (n=2303). ERDS, Egyptian Renal Data System; ESA, erythrocyte-stimulating agent.

Figure 29



Different types of ESA used by patients with ESKD in ERDS 2020 data (n=1893). ERDS, Egyptian Renal Data System; ESA, erythrocyte-stimulating agent; ESKD, end-stage kidney disease.

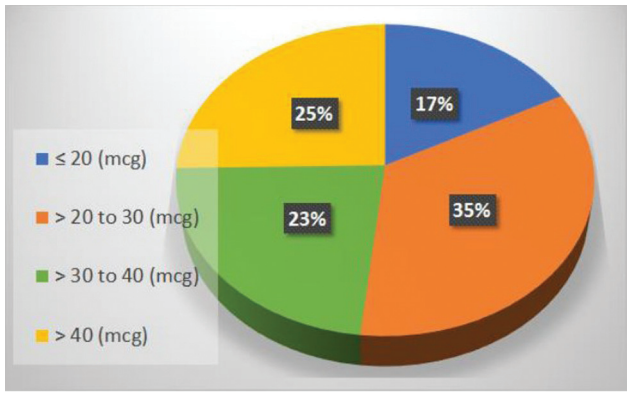
Figure 30



Weekly Erythropoietin Alpha dose of ERDS 2020 (n=1668). ERDS, ERDS, Egyptian Renal Data System.

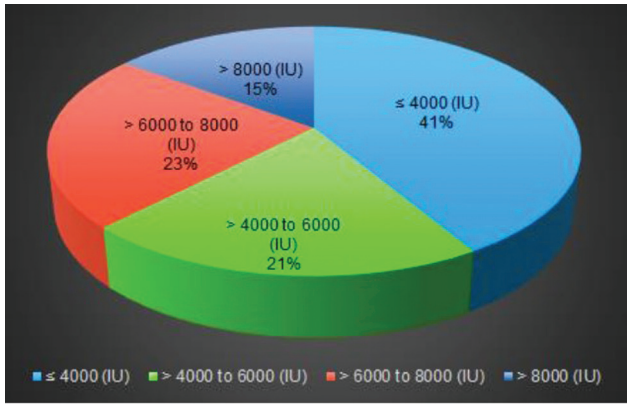
than USA DOPPS of 2011–2020, where on an average, only 35.4% of patients who received erythropoietin alpha had doses less than 5000 IU [59].

Figure 31



Weekly Aranesp dose in ERDS 2020 data (n=87). ERDS, ERDS, Egyptian Renal Data System.

Figure 32



Weekly Recormon dose in ERDS 2020 data (n=135). ERDS, ERDS, Egyptian Renal Data System.

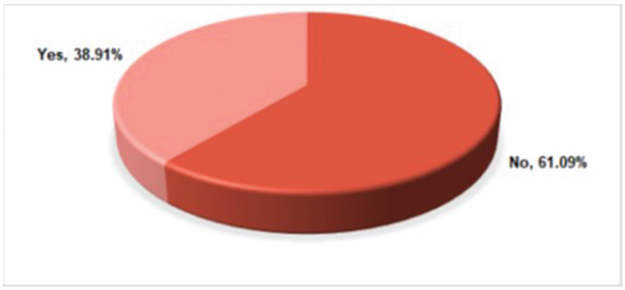
Anemia management, iron therapy, and blood transfusion

Only 38.9% of ERDS 2020 patients receive intravenous iron treatment. This is less than all of the USA DOPPS findings of 2010–2020 and less than most countries studied in GCC DOPPS studies of 2012–2018, where the median number of patients receiving intravenous iron therapy was 74.3 and 58.3%, respectively [60,61]. Overall, 82% of patients did not receive blood transfusion. Within the subset of patients who received blood transfusions, 62% received 1 or 2 units in the reporting period (Figs 33–35).

Recommendations

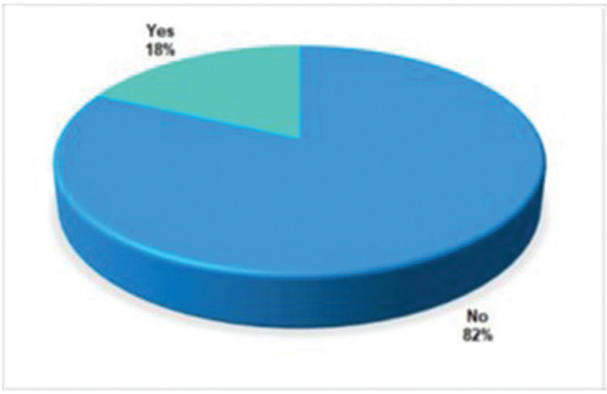
(1) Periodical publishing of ERDS data at least annually proved to lead to better compliance with guidelines and better patient outcome [41,62]. The following recommendations can be

Figure 33



Distribution of intravenous iron treatment in ERDS 2020 data (n=2246). ERDS, Egyptian Renal Data System.

Figure 34



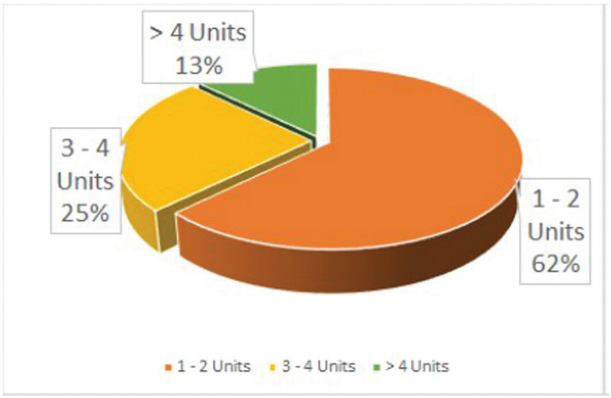
Blood transfusion of ERDS 2020 (n=2243). ERDS, Egyptian Renal Data System.

applied to improve anemia status of the patients and also to improve all related comorbidities of ESKD:

(a) Performing regular laboratory investigations (hemoglobin monthly and iron status every 3 months) [47].
(b) Prescriptions revised immediately after new laboratory results are available.

(2) Implementation of more proactive quality improvement efforts, suggesting corrective actions according to findings of self-assessments, has also been shown to improve the achievement of guideline targets [63,64].
(3) Managerial reforms could include the following:
(a) More specialization of prescribers, longitudinally prescriptions made to the same patients by the same doctor for a long period of time.
(b) More specialization of prescribers, vertically on a specific part of the prescription like anemia management.
(c) Senior oversight and supervision of prescriptions.

Figure 35



Number of blood transfusions (n=302).

(4) Implementation of quality improvement programs that use individualized computer-based dosing of ESAs [65].

Mineral and bone disorder

General considerations

The majority of patients with CKD are at an increased risk of developing disturbances of bone and mineral metabolism; these disturbances lead to a constellation of bone lesions, which were previously referred to as renal osteodystrophy (ROD), with affected patients manifesting with symptoms such as bone pain, muscle-tendon rupture, pruritus, and high incidence of fractures [66].

Subsequently, evidence has shown that patients with ROD are also predisposed to cardiovascular calcification with associated high morbidity and mortality rates [67]. Unfortunately, the term ROD does not encompass this important extraskeletal manifestation.

The KDIGO work group recommended a broader term, CKD–MBD, for the systemic disorder of mineral and bone metabolism owing to CKD and that the term ROD should exclusively be used to describe disorders in bone morphology associated with CKD [68].

Clinicians largely depend on trends in the levels of parathyroid hormone in conjunction with levels of serum phosphate, calcium, and alkaline phosphatase as markers of bone turnover to guide in the treatment of mineral bone disorder [69]. Overall, 45% of the studied populations had calcium level within the range according to the KDIGO recommendation (8.4–9.5), and 8% had calcium level between 9.5 and

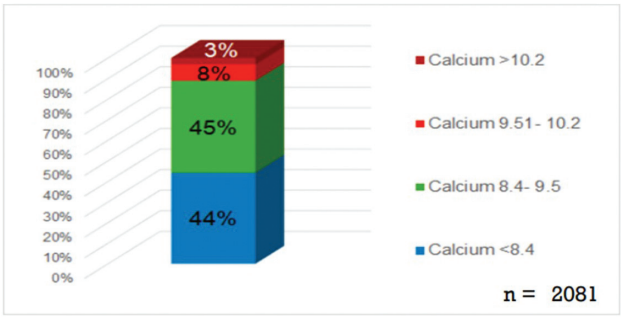
10.2, which makes 53% of patients within the acceptable range.

Baseline data report of the China DOPPS 2021 revealed that 66.5% patients had corrected calcium within the target range (8.4–10.2 mg/dl), which is a bit higher than our results [70]. On the contrary, DOPPS 1 from seven countries (US, Europe, and Japan), representing a total sample of 17 236, reported serum calcium levels 8.4–9.5 in 40.7% of patients (which is very similar to our results). More patients were hypocalcemia rather than hypercalcemic, whereas in the DOPPS 1, 9.3% of patients had lower concentrations and 50% had higher concentrations, probably related to the use of high calcium dialysate at that time [71].

Chronic kidney disease–mineral bone disease laboratory data

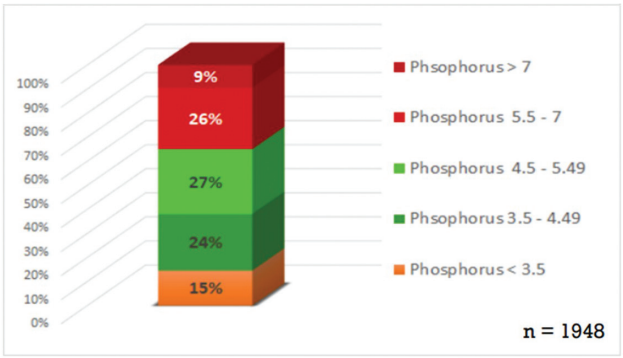
Overall, 51% of the studied populations had phosphorus level within the target range (3.5–5.5 mg/dl), whereas only 41.5% of patients had serum phosphorus level in the target range in the China DOPPS 2021. Similarly, in DOPPS 1, it was only 40% (Figs 36–40).

Figure 36



Calcium levels by categories (g/dl).

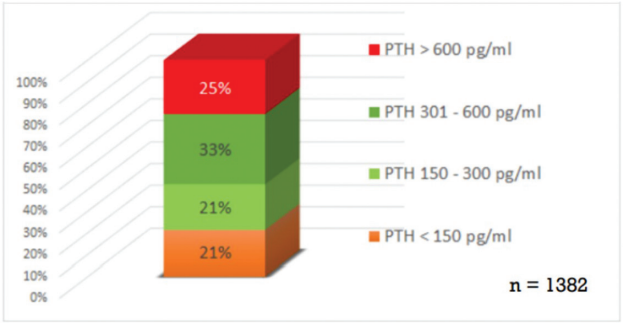
Figure 37



Phosphorus levels by categories (g/dl).

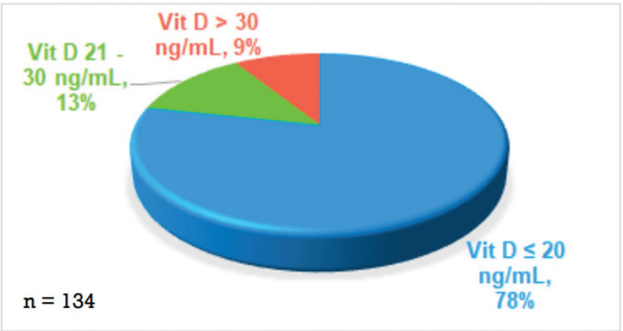
Patients with hyperphosphatemia were almost twice as much as those with hypophosphatemia. Overall, 54% of the studied populations had parathyroid hormone levels within the target range according to KDIGO. This was similar to the results of China DOPPS 2021, which was 51.2% of patients. Vitamin D level was measured in 134 patients, and 78% of them had vitamin D levels less than 20 ng/ml. Alkaline phosphatase was measured in 329 patients, and 26% were within the normal range.

Figure 38



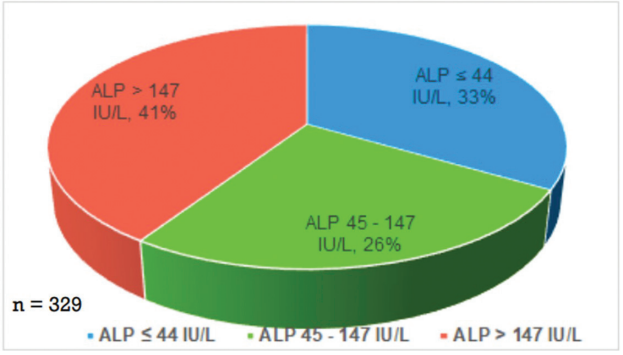
PTH levels by categories (pg/ml). PTH, parathyroid hormone.

Figure 39



Vitamin D level categories.

Figure 40



Alkaline phosphatase levels.

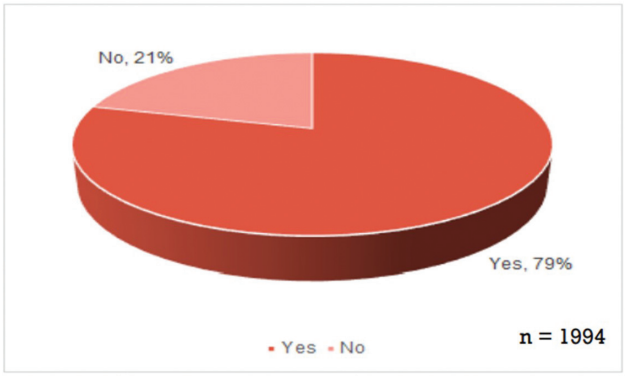
Chronic kidney disease–mineral bone disease drug therapy and parathyroidectomy

Of the studied populations, 79% received calcium-based phosphorus binders (Figs 41–48). At the time of the study, 54% of patients were on calcium carbonate and 45% on calcium acetate. Sevelamer was available only for 1% of patients, and lanthanum carbonate was not available at all. Overall, 8% of patients received calcium-free phosphate binders, and 46% of patients received alpha calcidol. Only 1.5% of patients received native vitamin D treatment in spite of the fact that the majority of the specimen studied for vitamin D were vitamin D deficient. In addition, 10% of patients received cinacalcet for controlling secondary hyperparathyroidism, and 2.5% of patients underwent parathyroidectomy as the last resort for controlling secondary hyperparathyroidism.

Recommendations

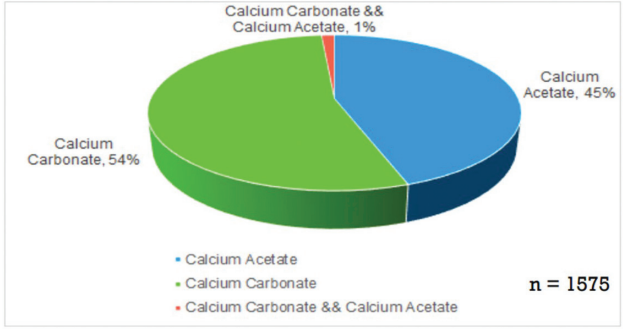
(1) Parathyroid hormone level in conjunction with serum phosphorus, calcium, and alkaline phosphatase levels as markers of bone turnover should be assessed on regular bases to guide the treatment of mineral bone disorder.

Figure 41



Calcium-containing phosphate binder use.

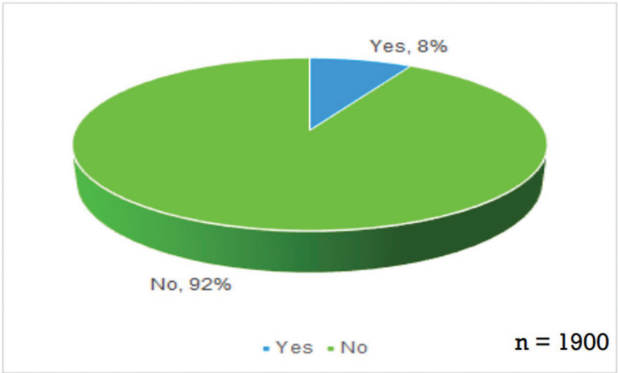
Figure 42



Type of calcium-containing phosphate binder in patients using them.

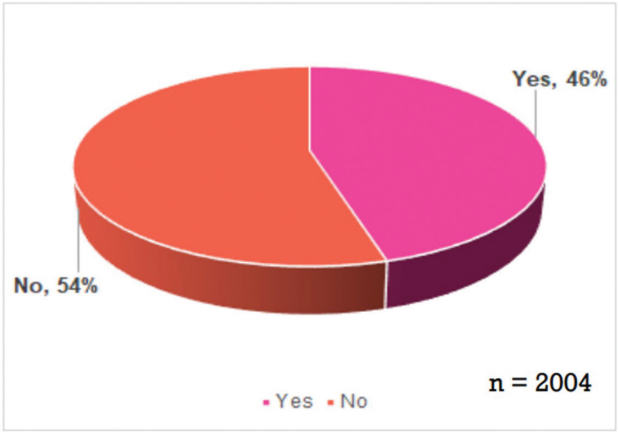
(2) Apparently, native vitamin D is not routinely tested; it is recommended that this test be done for hypocalcemic patients and native vitamin D replaced if proves to be deficient.

Figure 43



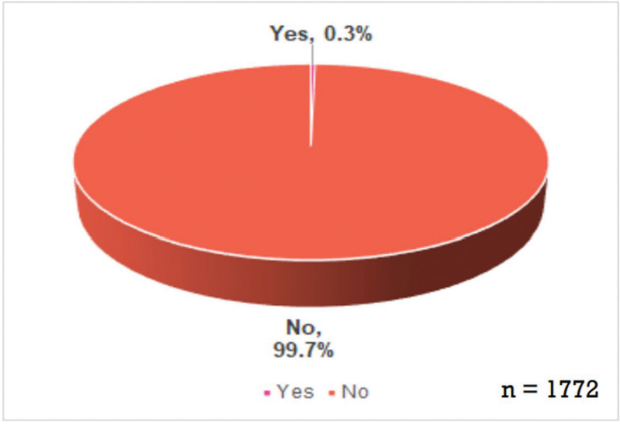
Calcium-free phosphate binder use.

Figure 44



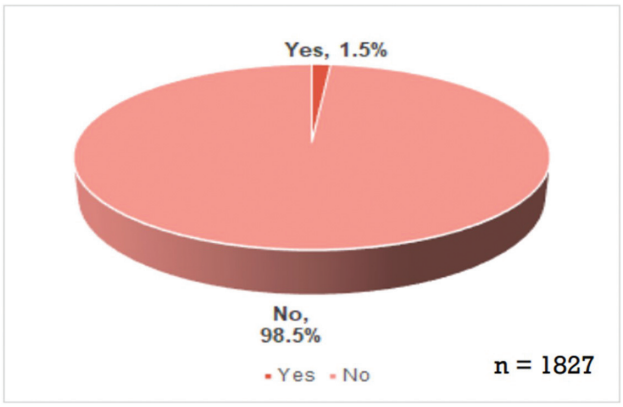
Alphacalcidol treatment.

Figure 45



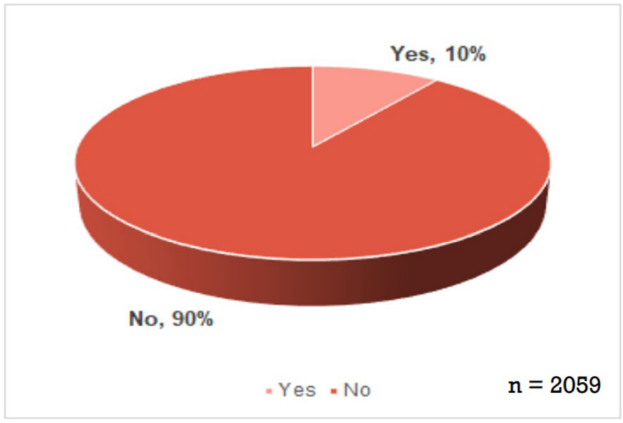
Paracalcitol treatment.

Figure 46



Native vitamin D treatment.

Figure 47



Cinacalcet treatment.

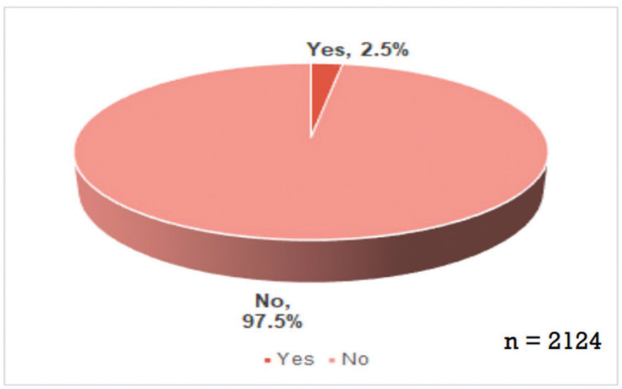
Hypertension and diabetes mellitus control

General considerations

In diabetic dialysis patients, spontaneous resolution of hyperglycemia and the apparent normalization of glycated hemoglobin levels, independent of treatment, are commonly observed and referred to as burnt-out diabetes [72].

In one study of 23 618 diabetic dialysis patients from a large US dialysis organization, up to one-third were observed to have glycated hemoglobin levels less than 6% [73]. Frequent hypoglycemic episodes may result in the discontinuation of insulin and oral antidiabetic medications in dialysis patients [74]. HD patients require antihypertensive drugs to control blood pressure (BP). Almost all patients have had past history of hypertension before starting dialysis and have received multiple antihypertensive medications. It has been reported by several cohort studies including Japanese Society for Dialysis Therapy registry and

Figure 48



Parathyroidectomy.

meta-analyses that BP control by antihypertensive drugs leads to better cardiovascular outcomes [75]. However, any optimal regimen to control BP and to reduce mortality has not yet been established. Dihydropyridine calcium channel blockers are widely used to reduce BP for dialysis patients as well as general hypertensive population [76]. One prospective cohort study from Japan has also demonstrated that the use of β-blockers is significantly associated with reduced risk of mortality in HD patients [77].

Hypertension and diabetes mellitus management data

Hypertension and diabetes mellitus constitute ~55% of the causes of ESKD in Egypt according to ERDS 2020 (Figs 49–51). Beta-blockers and calcium channel blockers are the main hypotensive drugs among the studied populations. Most patients received one hypotensive drug. Most patients received insulin therapy for controlling hyperglycemia.

Recommendations

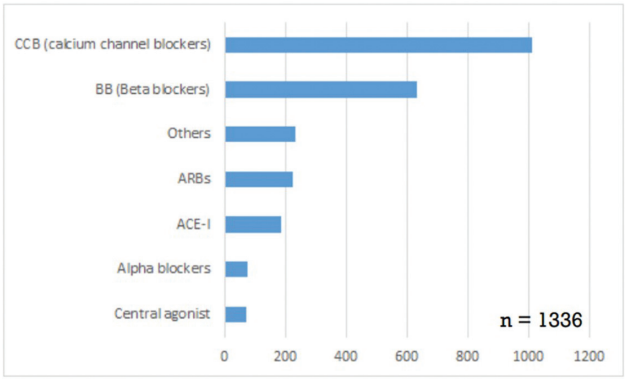
(1) Proper control of body weight helps control of BP, reduce antihypertensive medications, and should be highly recommended.
(2) Blood sugar is liable to changes in the dialysis patients and should be strictly followed up.
(3) Proper selection of antihypertensive and antidiabetic medication in relation to dialysis is crucial to get the best outcome, which would reflect on the cardiovascular status and the patient's well-being.

Vascular access

General considerations

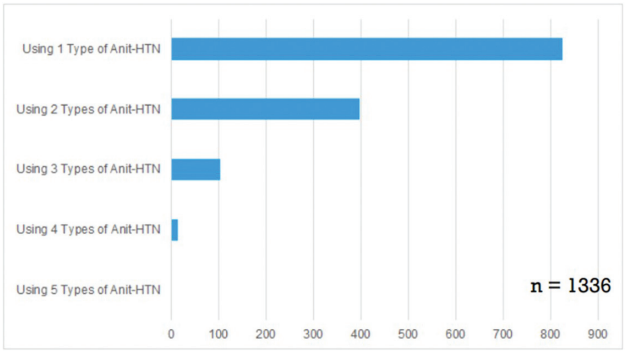
HD continues to be the single most prevalent modality of renal replacement therapy in Egypt. Quality is an

Figure 49



Antihypertensive medications used (category).

Figure 50



Anti-hypertensive medications used (number per patient).

important factor that determines the longevity on dialysis, and that quality in turn depends, to a great extent, on the reliability and integrity of the patient's vascular access [78].

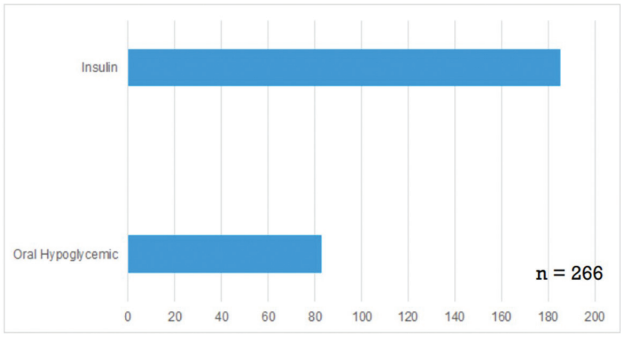
The three types of vascular access available for HD are arteriovenous fistulas (AVFs), arteriovenous grafts, and central venous catheters, and each access type has advantages and disadvantages [79].

A well-functioning vascular access is a mainstay to perform an efficient HD procedure through providing reliable, complication-free way to deliver prescribed dialysis [80].

Vascular access type and failure

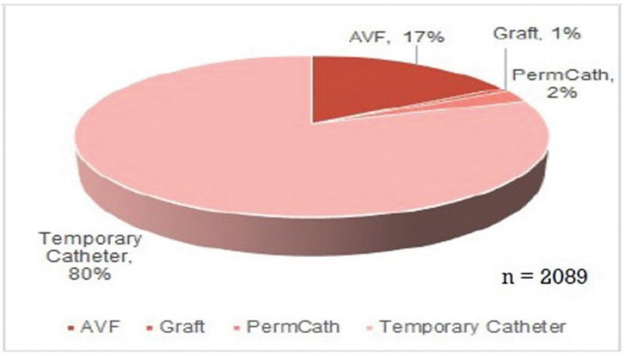
In 2020, 80% of patients with ESKD in Egypt started HD using a temporary vascular access (Figure 52). Starting HD through AVF was only found in 17% of the patients, which suggests that there was a late referral for nephrologists, a delayed preparation of the patients for HD, or noncompliance from the patient side to follow-up (Figs 52–55).

Figure 51



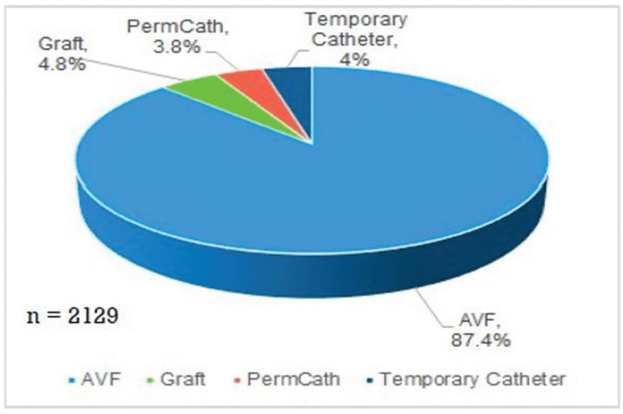
Hypoglycemic medications used.

Figure 52



Vascular access type at initiation of hemodialysis.

Figure 53

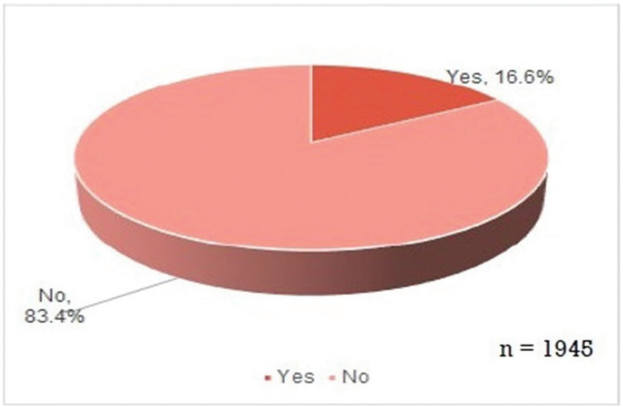


Current vascular access type.

Our data found that AVF was on top followed by other vascular access types, which proves that AVF creation is accessible and there are no limitations to create it early enough before initiation of HD (Figure 53).

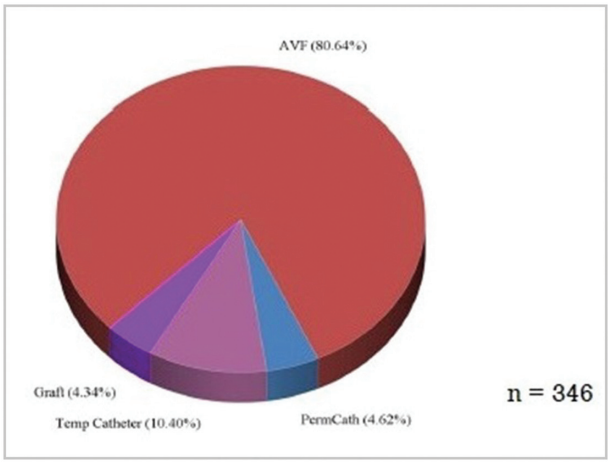
Failure of vascular access was present in less than quarter of the patients (Figure 54). Of 346 patients reported as having vascular access failure, most of them had failed AVF (Figure 55). We did not assess different

Figure 54



Previous vascular access failure.

Figure 55



Type of failed vascular access.

causes or timing of the failure, but this mandates the importance of vascular access surveillance and regular checkup.

Recommendations

From the available data, we recommend the following:

(1) Early referral of patients with CKD to nephrologists is mandatory for early creation of AVF and preparation for HD.
(2) Patients must be educated about the importance of early AVF creation and the benefits of HD initiation through it.
(3) Vascular access regular surveillance is important for early detection of any complication to deal with. Early management of vascular access complication increases its life span and ensures good HD quality.

Dialysis adequacy and data

General considerations

The adequacy of HD refers to how well toxins and waste products are removed from the patients' blood and has a major effect on their well-being. Dialysis delivery should be adequate to improve adequacy of life and to prolong survival [81]. Studies have indicated an increase in morbidity and mortality among patients with inadequate dialysis [82]. Measures of dialyzer urea clearance have been the basis for assessing dialysis adequacy since the National Co-operative Dialysis Study (NCDS) [83]. Of the two commonly used measures of dialyzer urea clearance, the UK Renal Registry has historically reported the urea reduction ratio (URR), the percentage fall in serum urea following a mid-week dialysis session. Although the alternative Kt/V is a better method for measuring dialysis dose because it takes account of the size of a patient and urea removal by ultrafiltration, it requires data items not routinely collected by all UK renal centers [84,85]. URR is the most commonly used measure of urea clearance in dialysis centers in Europe in daily practice [86] and predicts minimum dialysis dose in the majority of patients consistently with Kt/V [87].

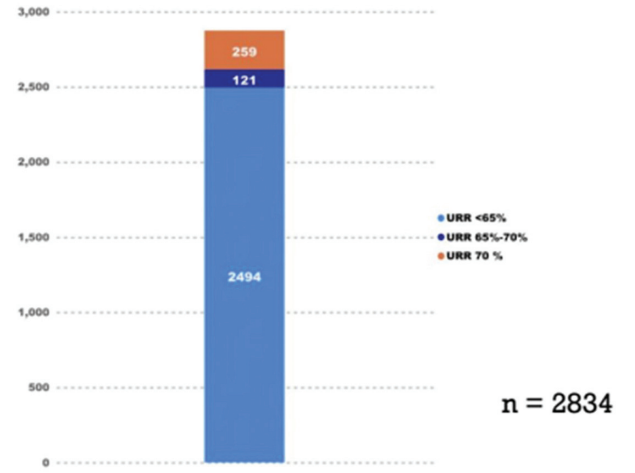
Dialysis adequacy assessment

Data of the URR were available for analysis of 2834 patients, and only 380 patients met the renal association clinical practice guideline for URR (>65%) (Figs 56–58). Kt/V data were available for analysis from 2834 patients, and only 378 of them met the renal Association clinical practice guideline for Kt/V (>1.2). This was in contrast to studies done in developed countries where URR ranged from 60 to 90% and Kt/V was more than 1.2 [88,89].

The substantial discrepancy in HD adequacy between developed and developing regions may be explained by the frequent use of high-flux dialysis and higher blood flow rates in the developed countries than in the developing regions. A lot of HD centers in Egypt do not adequately follow the KDOQI guidelines, and this could have resulted in the lower proportion of adequate HD.

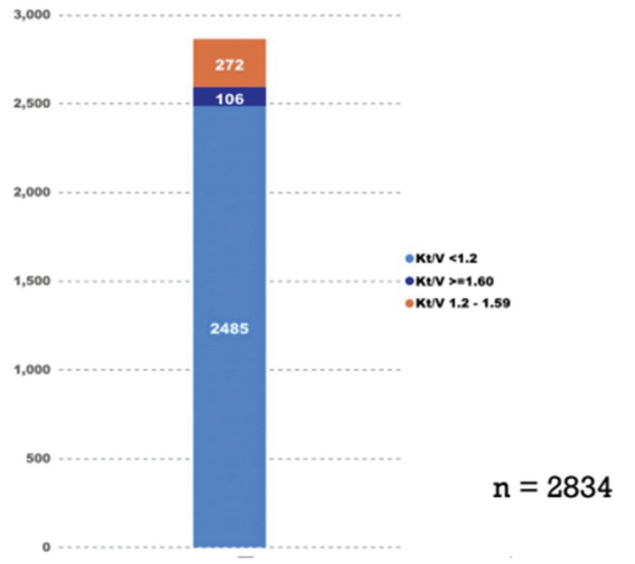
Dialyzer sterilization can be achieved via steam, ethylene oxide (ETO), electron beam, or gamma irradiation. The preferred method of sterilization is steam serialization. Steam-sterilized membranes have been found to improve endothelial cell viability when compared with ETO or gamma rays-sterilized ones [90].

Figure 56



Urea reduction ratio (URR) by categories.

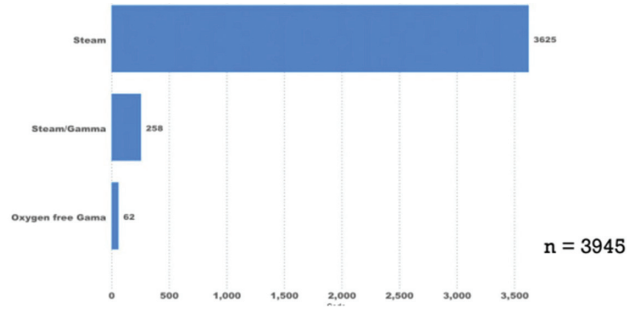
Figure 57



Kt/V by categories.

Most manufacturers have now opted to stop using ETO following various reported IgE-mediated allergic reactions despite studies suggesting that ETO reactions are preventable by adequate degassing of the dialyzer by the manufacturer and by adequate rinsing of the dialyzer just prior to using electron beam sterilization. On the contrary, it has been reported to cause significant thrombocytopenia following dialysis. Although most dialyzers are now sterilized by the steam method, most bloodlines are still sterilized with ETO, and so allergic reactions can still occur [91,92]. Among 3945 patients, more than 90% of them were using filters with steam sterilization.

Figure 58



Filter sterilization.

Recommendations

(1) It is recommended to use high-flux dialyzers and proper blood flow rates and ensure that patients are receiving full timesessions.
(2) In the setting of documented dialysis inadequacy, ensure that the first recommendation is applied and that the patient is receiving adequate anticoagulation and test for access recirculation. If needed, dialysis frequency can be increased.
(3) If isolated ultrafiltration is mandatory, its duration must not be included in the total dialysis time.

Morbidity and mortality

General considerations

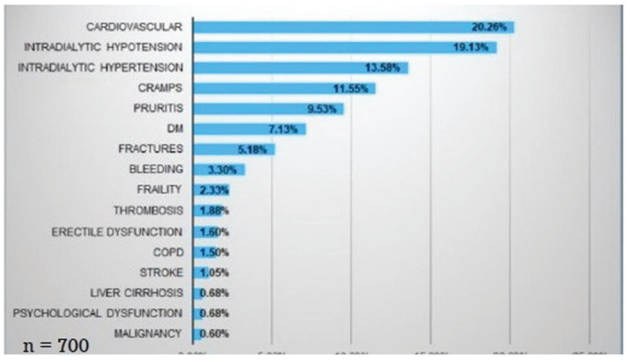
Maintenance HD prevents death from uremia; nevertheless, mortality among patients with ESKD remains high owing to other factors. Patients with ESKD have a worse overall survival compared with the general population [93]. According to the USRDS 2018 report, between 2001 and 2016, adjusted relative mortality rates declined by 29% [29]. The most common causes of death in ESKD are cardiovascular disease, infection, and withdrawal from dialysis [94–97].

Causes of morbidity and mortality

In relation to Figure 59 and Figure 60, the most common cause of morbidities in patients with ESKD is cardiovascular diseases; however, cardiovascular disease was not the commonest causes of death in the same studied period. In fact, the commonest cause of mortality was unknown. Considering the high prevalence of CVD, it is possible that mortality in this group of patients was due to arrhythmia or sudden cardiac arrest (Figs 59–60).

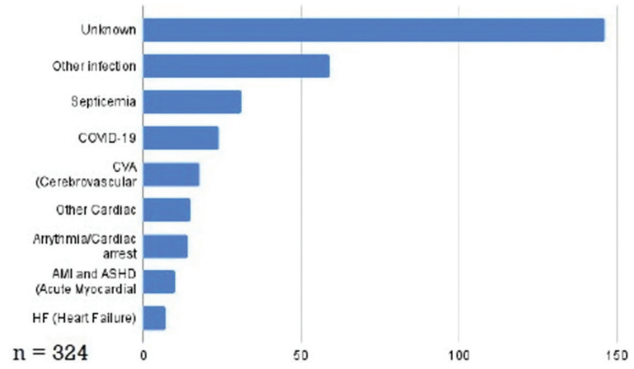
Intradialytic hypotension and hypertension were common, which reflect the importance of adequate

Figure 59



Percentage of different morbidities from total number of ESRD. ESRD, end-stage renal disease.

Figure 60



Causes of mortality.

dry weight analysis. Malignancy was the least common cause of morbidity. Infection and septicemia were among the common causes of death, which may be partly related to the high prevalence of the use of temporary catheters at HD initiation.

Recommendations

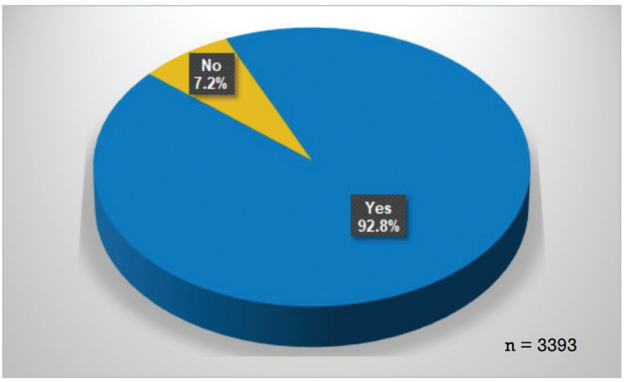
(1) Regular cardiovascular assessment is mandatory for early detection of any cardiovascular disease and early intervention.
(2) Avoidance of all precipitators of infection and septicemia in HD patients, including the wide use of temporary catheters.
(3) Frequent dry weight assessment of patients to ensure adequate volume status and controlled BP.

Transplantation

General considerations

Renal transplantation is considered the best therapeutic option for patients with CKD. It is associated with the best survival and the best quality of life with less hospitalization and rehospitalization compared with dialysis. Moreover, it is a cost-effective modality [98–100].

Figure 61



Patient fitness for transplantation.

Fitness for renal transplantation

It is reported that 92% of patients in the dialysis unit are fit for transplantation according to their treating physicians; this number may be a bit exaggerated as our criteria for fitness includes only medical condition regardless of willingness. This points to the great gap between supply and demand (Fig. 61).

Recommendation

(1) Raising awareness on transplantation as the best option for renal replacement therapy is badly needed for patients, physicians, and the public.
(2) Currently, living donation, the only available option for transplantation in Egypt, should be highly encouraged.
(3) Establishment of programs for paired donation.
(4) Implementation of cadaveric donation programs.
(5) This requires the collaborative work of all health care authorities, media, religious, and other scholars.

Difficulties and achievements of Egyptian Renal Data System

General considerations

Establishing a registry is a major task, demanding considerable resource investment from payers, health care providers, and technical/administrative staff to initiate and maintain the operation of the registry [101].

ESKD and its current standard of care, renal replacement therapy (RRT; which includes dialysis

and/or kidney transplantation), result in substantial economic and societal costs. Despite affecting up to 0.03% of the total population in developed countries, ESKD consumes up to 3% of annual health care budgets in many countries [102].

Initially, we were confronted with resistance owing to lack of awareness and familiarity of staff about its utmost importance, together with the already existing workload.

With a lot of enthusiasm and the firm belief of our mission, there was persistence from the registry team trying to convince health care providers by personal contact, raising awareness, and changing the primitive excel sheet to an advanced friendly online software platform.

We also selected key persons in different regions who were anticipated to make change through raising awareness and motivation and called for volunteers to train and help in training, and a good number of motivated doctors responded.

Training was carried out through troubleshooting videos, zoom meetings, face-face meetings, and responding to WhatsApp inquiries. Those involved in data entry were appreciated and rewarded. By time, the medical personnel started to realize the difference it makes to be aware of what we are dealing with in terms of numbers and outcomes.

Obstacles and challenges

(1) Egypt had a limited pool of health care providers and resources.
(2) Personnel in the dialysis units considered it an extra workload and extra time spent with entering information to the registry.
(3) There was excessive missing data in the files, which calls for an action to investigate what hinders the process (limited resources or otherwise).
(4) The registration procedure is not compulsory; furthermore, a big sector of the Ministry of Health centers refrained from joining without a direct order from the Ministry of Health.
(5) During the COVID-19 pandemic, there was shuffling of patients and doctors across centers. Moreover, some nephrologists were quarantined, whereas others were diseased with coronavirus alone or with their families.
(6) Some dialysis units that already had data stored digitally but not on our ERDS software provided us with excel files, which we imported digitally into ERDS.

On the contrary, our current system has a number of strengths

(1) The use of a web-based site for the present purpose proved to be feasible. The process was easy to perform, was not time-consuming, and was appropriate for the longitudinal follow-up of patients.
(2) The program allows prompt analysis of the data after its arrival at the central database and guaranteed anonymity and confidentiality.
(3) An administrative secretary of the registry used all media platform of the ESNT (website, e-mail, social media, and meetings) to constantly invite the dialysis centers' managers to participate in our dialysis registry.
(4) We have been trying to make effective collaborations with existing registries or societies, which could help enhance data collection and dissemination for the currently existing registry. We are also approaching local governments and health authorities to develop and expand our ERDS.
(5) We continue to dedicate efforts to include more centers in the registry and increase the representativeness of the sample. We expect to see an increased participation rate in the future when our Egyptian nephrology community recognizes how easy and quick the process of entering their HD patient data in our system is.
(6) Finally, the Egyptian registry started to be recognized and referred to in national and international congresses.

Future planning for Egyptian Renal Data System

General considerations

Data of various medical disorders are not available for large parts of the developing world [103]. There is a scarcity of data on ESKD in the developing countries, like Egypt. Several national renal registries have been established but have not been sustainable because of resource limitations. Local registry is important to help in identifying the causes of renal failure and develop management and research initiatives to reduce the burden of kidney disease [104].

In Africa, registry data have been published mainly by North African countries, starting with Egypt and Tunisia in 1975. However, in recent years, despite a great appreciable progressing effort reviving the ERDS, no African country has regularly reported national registry data [105].

This chapter will try to shed light on the future planning in Egypt regarding the ERDS and the elements needed for a successful renal registry.

Future planning and proposed method for data collection in the national renal registry system in Egypt

Given the technology development and emergence of internet in many work areas such as health care, this method is the best and fastest strategy for data collection and transmission owing to the following:

(1) Computer terminals in different renal wards can be connected through a central server, which is in turn connected to the organ provider system and tissue laboratory. In addition, users can register incidents in ERDS through clinical management stations across the wards and outpatient clinics.
(2) Users would access the system through all hospitals and clinics across the country, and patients' data can be entered to the system directly. In addition, this registry would act as an online clinical information system and help in completion of patients' electronic records as well as special data about renal replacement treatments.
(3) Users can restore data on demography, diagnosis, complications during treatment, and chronicles of clinical events including a variety of renal replacement and resulting complications. A summary of clinical events can be received and printed for daily management.
(4) In addition, summary of events can facilitate data transmission among renal centers through ERDS, which is an effective clinical tool for both patients and managers of renal centers. Data saved from different centers are used in policy making and allocation of resources. In this method, data are recorded directly in the national registry system after patient reception and through hospital information management system at the time of patient's hospitalization.

Proposed responsible organizations for the national renal registry system in Egypt

It is proposed that ministry of health, medical universities, and ESNT should establish a national registry system in which there is a committee including nephrologists, epidemiologists, pathologists, urologists, surgeons, and health information managers for policy making and planning, which aim to design and develop Model Disability Survey as well as the national renal registry system. These plans will be communicated to the office of noncontagious disease to be implemented like what was proposed in Iran, being a similar developing country [106]. This initiative could make a substantial effect on the practice of nephrology and the provision of services for adults and children with ESKD in Egypt.

Acknowledgements

The author acknowledge all Egyptian nephrologists for participating in the data entry of ERDS 2020.

Key Persons: Prof. Dr. Manal Eldeeb - Prof. Dr. Effat Eltony - Prof. Dr. Mohamed Tantawy - Prof. Dr. Osama Elmenshawy - Prof. Dr. Kamal Okasha - Prof. Dr. Gamal Elnaggar - Prof. Dr. Ameer Okail - Prof. Dr. Hwaida El Shinnawy - Prof. Dr. Ibrahim Amer - Prof. Dr. Lamiaa Harb - Prof. Dr. Heba Hamdy - Prof. Dr. Hala Al Obaidy - Prof. Dr. Mohamed Salaheldin - Dr. Diana Charles - Dr. Salwa Zaghlol - Dr. Ali Taha - Dr. Ahmed Ezzat - Dr. Ahmed Donia - Dr. Abdalla Geba.

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Yashfii Team: Dr. Ahmed Maher - Dr. Ahmed Sayed - Dr. Mohamed Issa - Dr. Ali Dora.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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