NEWSLETTER - N° 32 - May, 2024

60th Anniversary ERA Registry

By Vianda Stel, Director ERA Registry

This year we celebrate the 60th anniversary of the European Renal Association (ERA) Registry. The origin of a European Registry on patients with kidney failure receiving kidney replacement therapy (KRT) leads back to 1964. A year later, an initial report included data on 271 patients commencing hemodialysis, 6 patients starting peritoneal dialysis and 258 patients who received a kidney transplant[1]. Nowadays, 54 national and regional renal registries from 36 countries in Europe or bordering Europe and the Mediterranean Sea provide data on KRT patients to the ERA Registry in Amsterdam. The latest 2021 data showed that more than half a million patients with ESKD received KRT in the participating countries[2].

The long-standing existence of renal registries is essential in characterizing the burden of KRT which can also be used for healthcare planning. In addition, renal registry data play a crucial role in identifying disparities in the number of patients on KRT and their outcomes across individual countries and continents[3,4]. As a result, renal registry data may identify underlying clinical problems and could play an important role in optimizing kidney care. In celebration of the 60th anniversary of the ERA Registry, NDT and CKJ have jointly published a special collection of 20 papers from the ERA Registry published in NDT or CKJ that are still of value today. The accompanying editorial highlights the main findings of these 20 articles alongside the key value of renal registries[5].

Besides conducting research, the ERA Registry has an active role in teaching nephrologists and researchers about epidemiology mainly in the nephrology context. To this end, the ERA Registry gives an introductory course on epidemiology at various locations in Europe every year and hosts research fellows to contribute to their training in epidemiology, data analyses and writing scientific articles. In addition, the ERA Registry publishes basic and advanced level methodological papers in collaboration with colleagues from Leiden (Netherlands) and Reggio (Italy).

A last important activity of the ERA Registry is assisting in coding and definitions in nephrology, such as in the ERA primary renal disease (PRD) codes, ERA causes of death (COD) codes and treatment modality codes. The ERA Registry plays a key role in ensuring that countries collect these data and code them in a similar way and in providing updates in these coding systems when needed.

References:

[1]Alberts C, Drukker W. Report on regular dialysis in Europe. Proc Eur Dial Transplant Assoc 1965; 2: 82–87.

[2]Boerstra B, Boenink R, Astley M et al. The ERA Registry Annual Report 2021: a summary. CKJ 2024; 17 (2), sfad281. https://doi.org/10.1093/ckj/sfad281

[3]Stel VS, Boenink R, Astley M et al. A comparison of the epidemiology of kidney replacement therapy between Europe and the United States: 2021 data of the ERA Registry and the USRDS. NDT 2024;0: 1-11. https://doi.org/10.1093/ndt/gfae040

[4]Kramer A, Boenink R, Mercado Vergara CG et al. Time trends in preemptive kidney transplantation in Europe: an ERA Registry study. NDT accepted for publication

[5]Stel VS, Jager KJ, Ortiz A. 60 years European Renal Association (ERA) Registry data on kidney disease: visualizing differences in clinical practice. NDT and CKJ epub

The incidence of ESKD not treated with kidney replacement therapy in Europe

By Samar Abd ElHafeez, research fellow at ERA Registry

The European Renal Association (ERA) Registry collects data on end-stage kidney disease (ESKD) patients treated with kidney replacement therapy (KRT) across Europe for many years. However, patients with ESKD not treated with KRT are unaccounted for, resulting in an incomplete understanding of the true burden of ESKD in Europe. This knowledge is crucial for identifying those at risk of not receiving KRT, whether due to personal choice or lack of access, and for shaping effective public health policies.

We conceived a new study to estimate the incidence of ESKD patients treated with and without KRT, by age and sex, in Austria, Belgium, England, Spain, Sweden and Wales in order to address this gap. We utilized ERA Registry data to identify ESKD patients who started KRT. Data from the National Bureaus of Statistics were used to identify the total number of individuals who died from ESKD (either as main or associated cause of death according to the International Classification of Diseases, Tenth Revision classification system). The latter was used as a proxy to estimate the number of ESKD patients not treated with KRT under the assumption that survival is relatively short in ESKD patients who are not treated with KRT.

Our preliminary findings reveal that despite geographical variation in the ratio of incident ESKD patients not treated with KRT compared to those who were treated with KRT, in each country the proportion of patients with ESKD that received KRT was lowest in the oldest patients. Notably, older ESKD female patients were less likely to receive KRT than older ESKD male patients.

These results emphasize the importance of prioritizing the assessment and management of ESKD particularly in older (female) patients and underscores the need for comprehensive education and shared decision-making to determine the optimal treatment choice for patients suffering from ESKD.

For more details, please attend the ERA Registry session (S 0.3) on Friday, May 24, 2024, 08:30 – 09:45 CEST

Variation in the evaluation of kidney transplant recipient candidates

By Brittany Boerstra, PhD student at ERA Registry

Before patients with end-stage kidney disease (ESKD) can undergo kidney transplantation, their suitability for kidney transplantation is assessed using a transplantation work-up. Several international guidelines have outlined the most important factors in determining patient suitability for kidney transplantation[1,2]. However, there is little universal agreement among guidelines and it is unclear whether the recommendations put forth in guidelines have been adopted in clinical practice. To address this gap, we performed a scoping review on the evaluation of kidney transplant recipient candidates, specifically investigating the content of the transplantation work-up and contraindications to waitlisting.

Our findings, consisting of 20 included studies, show that the content of the kidney transplantation work-up varied between the studied centers, but common domains included screening for infections, heart disease, peripheral arterial disease (PAD), and malignancy. Within the infections domain, screening for human immunodeficiency virus, hepatitis B and C, cytomegalovirus, and the Epstein-Barr virus was common and similar among studied centers. Within domains for heart disease, PAD, and malignancy, screening varied in the type of investigations used and the frequency of their use, suggesting a lack of cohesiveness among nephrology units evaluating kidney transplant recipient candidates.

While kidney transplantation is the best kidney replacement therapy for most patients with ESKD, contraindications serve as a balancing act between the improved quality and length of life offered by kidney transplantation and the increased risk of peri- and post-operative complications. Among the studied centers, obesity and age-related factors were the most commonly reported reasons prohibiting a patient from being waitlisted. However, strict cut-offs for BMI and age are less often used as sole determining factors for kidney transplant recipient candidacy, and instead, a combination of (smaller) contraindications may cause a patient to be deemed "unsuitable" for transplantation.

Both the criteria used to evaluate kidney transplant recipient candidates and the presence of contraindications influence the "type" of patient admitted to the waiting list. However, further research is needed to investigate current practices prior to kidney transplantation. In turn, these findings may aid in the standardization of practices and criteria used to evaluate kidney transplant recipient candidates, which could improve kidney transplantation access and outcomes.

For more details, please attend the Focussed Oral Session on Kidney Transplantation (clinical and immunology) on Friday, May 24, 2024, 08:30-09:45 CEST

References:

[1]Abramowicz D, Cochat P, Claas FH, et al. European Renal Best Practice Guideline on kidney donor and recipient evaluation and perioperative care. Nephrol Dial Transplant. Nov 2015;30(11):1790-7. doi:10.1093/ndt/gfu216

[2] Chadban SJ, Ahn C, Axelrod DA, et al. KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation. Transplantation. Apr 2020;104(4S1 Suppl 1):S11-s103. doi:10.1097/tp.0000000000003136

ERA Registry Activities during the 61th ERA congress May 23-26, 2024, Stockholm

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Management assistant

Nick Chesnaye, PhD
EQUAL coordinator | Epidemiologist

Ronald Cornet, PhD
IT advisor | Senior Medical Informatician

Arno Weerstra, MSc
Software Engineer

ERA Registry Symposium
Friday, May 24, 08:30 - 09:45 CEST (Room A4)

- Age and sex specific eGFR reference values in healthy individuals: The European CKD Burden Consortium – **Megan Astley**
- The incidence of ESKD not treated with kidney replacement therapy across Europe – **Samar Abd ElHafeez**
- Evolution of symptom burden in older men and women with advanced CKD – **Nicholas Chesnaye**

Kidney Transplantation (clinical and immunology)
Friday, May 24, 08:30 - 09:45 CEST (Focussed Oral Room 7)

- Substantial variation in the evaluation of kidney transplant recipient candidates prior to waitlisting: a worldwide scoping review – **Brittany Boerstra**

Chronic Kidney Disease
Friday, May 24, 08:30 - 09:45 CEST (Focussed Oral Room 8)

- Prescribing patterns in older people with advanced chronic kidney disease approaching the end of life – **Matthew Lets**

Creative Labs 1
Friday, May 24, 10:15 - 11:15 CEST (Room T6)

- How to turn your nephrology unit Green – **Maria Pippias**

Dialysis
Friday, May 24, 12:00 - 13:15 CEST (Focussed Oral Room 10)

- Trends in kidney replacement therapy in Central and Eastern Europe- data from the ERA Registry – **Marjolein Bonthuis**

Creative Labs 2
Friday, May 24, 2024, 15:15 - 16:15 CEST (Room T6)

- A crash course in prediction models – **Merel van Diepen**

Outcome of kidney transplantation: associations with adherence and age
Saturday, May 25, 08:30 - 09:45 CEST (Room A6)

- Patient characteristics, treatment history and prognosis of adult survivors of childhood kidney replacement therapy- an ERA Registry study – **Iris Montez de Sousa**

Creative Labs 4
Saturday, May 25, 12:00 - 13:00 CEST (Room T6)

- How to review a paper – **Vianda Stel**

Chronic Kidney Disease
Saturday, May 25, 12:00 - 13:15 CEST (Focussed Oral Room 1)

- Longitudinal haemoglobin levels and mortality in an elderly population with advanced chronic kidney disease: insights from the EQUAL Study – **Gianmarco Lombardi**
- Longitudinal serum bicarbonate and mortality risk in older patients with advanced chronic kidney disease: analyses from the EQUAL cohort – **Gianmarco Lombardi**

Creative Labs 3
Saturday, May 25, 14:10 - 15:10 CEST (Room T6)

- A nephrologist's guide to prevent post-transplant diabetes – **Rachel Hellemans**

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