

Newsletter N. 27 - May 2019

The effect of living donor source on survival of transplant recipients: Results from a successful Registry fellowship By Marlies Noorg

As part of its Young Fellowship Programme, the ERA-EDTA makes available Registry fellowships each year. These fellowships are designed to enable young people to train in clinical epidemiology at the ERA-EDTA Registry office in Amsterdam.



In 2018 Samar Abd ElHafeez from Alexandria, Egypt was one of the researchers who was granted a Registry fellowship. She visited the Registry office for six weeks and worked on a research project that focused on the effect of different living donor sources on the survival of kidney transplant recipients in the ERA-EDTA Registry. Because so far there are no large international studies on this topic,

Samar used data from the Registry to compare patient- and graft survival of kidney transplant recipients between those who received a kidney from an living related donor (LRD) or a living unrelated donor (LUD).

For her study she included all adult patients who received their first transplant between 1997 and 2016 from 22 national and regional renal registries that participate in the ERA-EDTA Registry. Over 13 thousand patients received a kidney from

a living donor in the study period. Of these transplants, 78% were from an LRD and 22% from an LUD and there was a linear increase in the number of both types of transplants over time. In unadjusted survival analysis, the risk of death was 69% higher in LUD than in LRD transplants. However, after adjusting for potential confounders this association disappeared. Also for graft survival, Samar found in the unadjusted analysis that the risk of graft failure was 17% higher in patients who received a kidney from a LUD. But also for this outcome the association was no longer present after adjustment for potential confounders. In conclusion, this study shows that both patient- and graft survival of LRD and LUD transplant recipients is similar. These findings underline the importance of further stimulation of living kidney donation, especially from unrelated donors in whom health is unlikely to deteriorate.

Further information:

The results of this study are also presented during the poster session on Friday 14 June (poster number FP765). The abstract was awarded as one of the best abstracts by young authors. The next call for registry fellowships will probably open in the beginning of 2020. If you are interested, please keep an eye on the website http://web.era-edta.org/young-fellowship-programme-1.

The European EDITH Nephrologist survey on treatment modality choice



By Rianne de Jong, PhD student EDITH project and Vianda Stel, EDITH project leader

The European EDITH project, which is cofinanced by the European Commission, focuses on the differing CKD treatment modalities along with organ donation and transplantation practices and their impact on health expenditures and patient outcomes. The EDITH consortium consists

of 10 partners from all over Europe together with collaborating stakeholders including the European Kidney Health Alliance, renal registries, ERA-EDTA, the European Kidney Patients Federation, the French Agence de la Biomédecine and national kidney foundations.

As part of the EDITH project, the ERA-EDTA Registry aims to gather the opinion of patients, nephrologists and transplant surgeons on factors that influence the choice of treatment modalities for patients with end-stage kidney disease.

To this end, in 2018 no less than 8500 dialysis and kidney transplant patients from more than 30 European countries

kindly completed the EDITH Kidney patient survey. The help of all these patients is much appreciated and will guide the European Union how to improve ESKD care.

Thereafter, in the spring of 2019, we invited European nephrologists and kidney transplant surgeons to fill out the EDITH Nephrologist survey. The first part of this

survey covers the same topics as the patients' survey (i.e. information provision and decision making). The second part focuses on experienced barriers on the level of the patient (e.g. comorbidity, lack of motivation, unsuitable living circumstances), on the level of the nephrologist (e.g. knowledge or attitude) and on the level of the healthcare system (e.g. lack of skilled staff, insufficient reimbursement, legal barriers). Also, satisfaction about the uptake of all different modalities was investigated. Finally the survey aims to collect European initiatives to increase the uptake of different treatment modalities.

The first results of the EDITH Nephrologist survey will be presented during the ERA-EDTA Registry Symposium (Friday 14 June, 8:00-9:30 PM).

Results from both the EDITH Kidney patient survey and the EDITH Nephrologist survey give important information on treatment choice by both patients and doctors and could help to improve the access to different forms of dialysis, kidney transplantation and comprehensive conservative management in European

countries. See also www.edith-project.eu.

The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes Nephrologist survey

We would like to thank all those who have completed the EDITH Kidney patient survey and EDITH Nephrologist survey. We are very grateful that patients, nephrologists and transplant surgeons from all over Europe shared experience to improve ESKD care!



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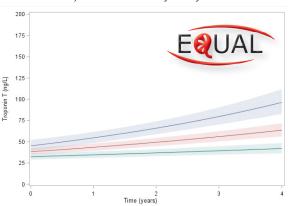


The association between renal function and Troponin T over time in stable CKD patients - Results from the EQUAL study

By Nicholas Chesnaye

The European QUALity study on when to start dialysis, is an ongoing prospective observational cohort study in 65+ CKD stage 4 and 5 patients in six European countries. EQUAL focusses on a combination of patient quality of life, survival, uremic signs and symptoms, nutritional status, and treatment preferences, to provide insight in the benefits and burden of dialysis initiation. The ultimate goal is to determine whether or not, and if so, when, to initiate dialysis in this population. Since its inception in 2012, around 1700 patients have been included, and data on numerous clinical parameters have been collected over the span of 9000 study visits. Presently, an EQUAL biobank containing patient serum and urine samples is underway, which will open up interesting future possibilities for studies in various 'omics' fields. To date, EQUAL has enabled numerous studies in the advanced CKD population, with subjects varying from sex disparities, polypharmacy, quality of life, uremic signs and symptoms, and the role of Troponin T in CKD. The latter study, which will be presented during the poster session on Friday, aims to determine the association between levels of cTnT and glomerular filtration rate. Preliminary results show that almost all patients had at least one hs-cTnT measurement elevated above the 99th percentile of the general reference population (≤14 ng/L). On average, hs-cTnT increased by 16% per year. Each 15 ml/min/1.73m2 lower mean eGFR was associated with a 23% higher baseline hs-cTn T, and 9% steeper increase in hscTn T. Patients on dialysis had on average a 23% higher hs-cTn T compared to patients not (yet) on dialysis. These effects remained largely unchanged after adjustment for patient demographics, cardiovascular risk factors, and pre-existing cardiovascular comorbidities. Compared with other known determinants of Troponin T, the effect of eGFR on hs-cTnT trajectory was somewhat lower than a previous myocardial infarction (15%), but higher than presence of diabetes (4%) and male sex (5%). Our results suggest that renal clearance, at least in part, may be responsible for the elevated hs-cTnT values seen among CKD patients. More importantly, hs-cTnT increases independently over time in those with lower eGFR suggesting that CKD may contribute to chronic myocardial stress in the same range as established cardiovascular disease, although additional data on cardiac imaging would be required to confirm this mechanism.

The unadjusted effect of mean eGFR (ml/ min/1.73m2) on hs-cTn T trajectory.



ERA-EDTA Registry activities during the 56th ERA-EDTA Congress in Budapest, Hungary

CEPD Course - ERA-EDTA Registry

Thursday 13 June, 13:00-16:40 PM Room A2

- Different flavours in RCTs and their analyses Giovanni Luigi Tripepi
- Pros and cons of surrogate outcomes in RCTs - Kitty Jager
- Mendelian randomization to enable causal inference in observational studies -Friedo Dekker
- Directed acyclic graphs (DAGs) to address confounding - Nathalie Staplin

ERA-EDTA Registry Symposium

Friday 14 June, 8:00-9:30 PM Room G1

- The European EDITH kidney nephrologist survey on treatment modality choice -Rianne de Jong
- Trends in excess mortality in patients receiving RRT - Rianne Boenink
- Post-transplant growth patterns in children -Jérome Harambat
- Dynamic prediction of mortality in advanced CKD using Troponin T: Results from the EQUAL study - Nicholas Chesnaye

Registry Posters

Posters presenting studies performed within the national and regional renal registries can be found in the poster area of the HUNGEXPO Congress Centre.

ERA-EDTA Registry booth

Please visit the ERA-EDTA booth in the exhibition hall to meet the Registry staff and for questions on educational activities, research collaborations or other Registry matters.

