



Report on the 3rd QUEST Convention in Vienna From Carmine Zoccali, ERA-EDTA Registry Chairman and Kitty Jager, ERA-EDTA Registry Managing Director

For the second year in a row the QUEST convention was held in the heart of Europe, in Vienna, one of the most elegant European capitals. We started our journey in much different ambience, in a nice medieval city of Spain full of history, Toledo. Toledo is at the border of the region of La Mancha which is famous because of Don Quixote, a fascinating character of world literature. Yet, however fascinating, the profile of Don Quixote is not the ideal testimonial for a new venture. In reality what we set in motion in Toledo was not a specific project but an initiative, i.e. not a precise project but "...our readiness to embark on new ventures, a first step of a series of actions..." which, in a way, is the typical Don Quixote attitude. We needed an initiative rather than a specific project because our aim was that of reversing the perception that the ERA EDTA was a centralised, secluded structure. In other words we needed to go from a top-down to a bottom up approach.



Carmine Zoccali

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The new ESPN Registry: an attempt to improve the collection of paediatric RRT data and stimulate European paediatric research collaboration

From Enrico Verrina and Jane Tizard
ESPN representatives in the ERA-EDTA Registry



Enrico Verrina

Over the past 6 years all analyses on paediatric patients were based on the limited data set collected by the ERA-EDTA Registry from national and regional registries, currently including more than 2600 paediatric RRT patients. In addition, a number of separate paediatric renal registries have sent data to Amsterdam on more than 2000 patients to be used for joint analysis. Since February 1st, 2007, however, the European Society of Paediatric Nephrology (ESPN) has started a separate registry in order to be able to collect more detailed paediatric data from a larger number of countries.

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Scientific Registry News – one abstract and some references to interesting papers using registry data Paul van Dijk Medical Informatician of the ERA-EDTA Registry

Abstract

In Europe there is considerable variation in mortality on renal replacement therapy (RRT). The causes of this variation are still poorly understood. We hypothesized that differences in mortality in the general population contribute to differences in mortality on RRT.

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Paul van Dijk



Scientific Registry News – one abstract and some references to interesting papers using registry data

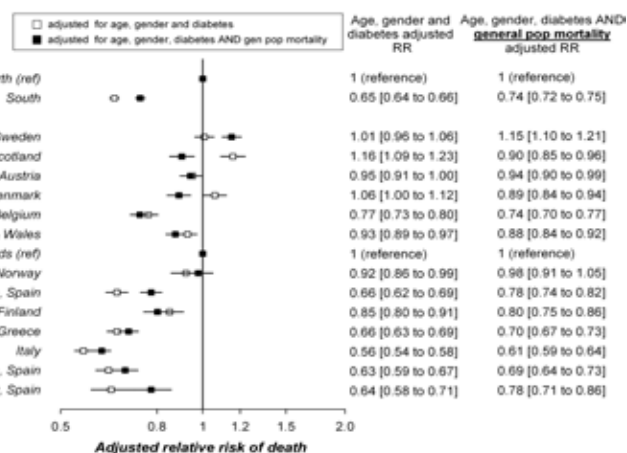
Paul van Dijk

Medical Informatician of the ERA-EDTA Registry

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To evaluate this relationship, we studied general population statistics obtained from Eurostat and the individual data of 67,692 patients on RRT from 15 national and regional renal registries. These 15 registries were divided into two geographical regions: North and South Europe. Cox regression was used to assess the relative risk of death (RR) for each region with adjustment for age, gender, diabetes, and additionally general population mortality. In patients on RRT the age, gender and diabetes adjusted RR of death was 0.65 (95% CI (0.64-0.66)) for South compared to North, while in the general population the age and gender standardized RR of death was 0.91. After adjustment for general population mortality in addition to age, gender, and diabetes, the RR of death for patients on RRT in the South changed from 0.65 to 0.74 (95% CI (0.72-0.75)), which indicates that general population mortality accounted for 26% of the region-related mortality

difference on RRT. In conclusion, within Europe there exist considerable international differences in the mortality of patients on RRT. Twenty-six percent of the European north-south mortality difference in RRT could be attributed to differences in general population mortality. Our data support the hypothesis that general population mortality is an important factor to take into account when making RRT mortality comparisons.



Country and region specific adjusted relative risk of death (on a natural logarithmic scale) for incident patients on RRT (started RRT during the period 1996-2000 with follow up until December 31st 2003).

van Dijk PC, Zwinderman AH, Dekker FW, Schon S, Stel VS, Finne P, Jager KJ. Effect of general population mortality on the north-south mortality gradient in patients on renal replacement therapy in Europe. *Kidney Int* 2007;71:53-59.

References to other registry papers

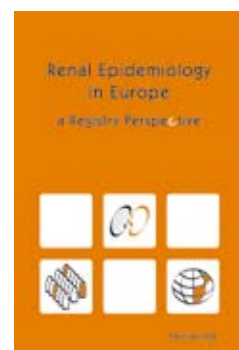
1. Postorino M, Marino C, Tripepi G, Zoccali C. Prognostic value of the New York Heart Association classification in end-stage renal disease. *Nephrol Dial Transplant* 2007;22:1377-1382.
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3. Mitterbauer C, Kramar R, Oberbauer R. Age and sex are sufficient for predicting fractures occurring within 1 year of hemodialysis treatment. *Bone* 2007;40:516-521.
4. Ansell D, Udayaraj UP, Steenkamp R, Dudley CR. Chronic Renal Failure in Kidney Transplant Recipients. Do They Receive Optimum Care?: Data from the UK Renal Registry. *Am J Transplant* 2007;7:1167-1176.
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6. Caskey FJ, Roderick P, Steenkamp R, Nitsch D, Thomas K, Ansell D, Feest T. Social deprivation and survival on renal replacement therapy in England and Wales. *Kidney Int* 2006;70:2134-2140.

PhD Thesis Paul van Dijk From Kitty Jager, ERA-EDTA Registry Managing Director



The PhD Graduation Committee in action

On April 5, 2007 Paul van Dijk successfully defended his PhD thesis 'Renal Epidemiology in Europe – a Registry Perspective' in the presence of the PhD graduation committee. The thesis includes a part of the papers published by the Registry in the past few years. Paul received his doctorate, on which he was congratulated by many colleagues. This was the first PhD thesis based on the data of the ERA-EDTA Registry and we hope that many more will follow.





Report on the 3rd QUEST Convention in Vienna

From Carmine Zoccali, ERA-EDTA Registry Chairman and Kitty Jager, ERA-EDTA Registry Managing Director

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In the Toledo Convention we established 5 working groups (WGs) on diverse topics such as Cardiovascular complications in ESRD, Anaemia, Dialysis adequacy, Ca, P & bone and Electronic Data Extraction. The anaemia WG in Toledo formulated four projects. These projects were intensively discussed via e-mail among WG members. Eventually, two projects, a survey on anaemia correction in Europe followed by a 1-year follow-up, and a European survey on anaemia in renal transplant patients are considered. Both projects are of importance particularly in the light of the recent CREATE and CHOIR studies and on the cautionary editorials that appeared on major medical journals. AMGEN has given his availability for co-financing these projects and hopefully a definitive agreement established along the ethical and regulatory needs of participating national and regional renal registries will be finalised very soon. The electronic data extraction group is perhaps the most important among our WGs, because

streamlining data retrieval from existing clinical files and databases may constitute a tremendous boost for projects of any kind. The group did not convene in Vienna, but it used the previous months to develop a draft implementation guide, specifying proposed clinical data and the messaging model, according to the international communication standard HL7 version 3. The dialysis adequacy WG considered 7 projects and last year, during the first Vienna Convention, decided to focus on a project related with the assessment of practice patterns of dialysis dose measurement in Europe. This is a low budget, much interesting project which has already been started and Dr. Jeroen Kooman and Dr. Cecile Couchoud presented the first data wave of this study during this third Vienna Convention. Other projects are being developed by the WG on cardiovascular diseases in ESRD and by the Ca,P & Bone WG, but these still need further refinements and final consensus among WG members. The cardio-

vascular working group very early came up with a large interventional trial (the PRIMA Study, Protocol Intensified Multifactorial Approach in hemodialysis patients) but preparing a multinational pan-European trial requires agreement on several issues that are still not worked out. Certainly, QUEST this year received an enormous boost by the fact that the European Commission awarded a co-financement to NephroQUEST, a pan-European project on quality of care in ESRD. Hopefully, we will have a specific hands-on convention for starting NephroQUEST in September in Amsterdam.

QUEST has started and we are now in the journey aimed at achieving our goals. This is not an easy journey and we will have setbacks and advancements. We will go step by step aiming at serving regional and national registries and the European renal community at large with a medium-long term vision.

The new ESPN Registry: an attempt to improve the collection of paediatric RRT data and stimulate European paediatric research collaboration

From Enrico Verrina and Jane Tizard

ESPN representatives in the ERA-EDTA Registry

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Mathilde Cardous-Ubbink (epidemiologist) will work part time to run this ESPN Registry in close collaboration with Jane Tizard and Enrico Verrina (both paediatric nephrologists and ERA-EDTA Registry Committee members) and Paul van Dijk and Kitty Jager (ERA-EDTA Registry staff members). Until recently paediatric data have been obtained from 12 relatively small national and regional 'adult' RRT registries. In addition, a more detailed comparison of the UK and Italy has been reported. A recent survey by the ESPN Registry revealed that nephrologists collecting paediatric data at a national basis from 8 additional large countries were willing to contribute their more extensive data

to a European paediatric database. Currently, an inventory is being made to see how many patients are in those registries, over which time period and which data are being collected, how often and which methods are used to determine laboratory values and which coding systems (especially for the Primary Renal Disease) are being used. In consultation with these paediatric registries, the second step will be to define a core paediatric data set with specific paediatric items (e.g. data on growth and pubertal development) that will need to be collected from all these registries. These core data will be reported on an annual basis. In addition, special multicenter studies on specific paediatric

research subjects can be initiated and run within this network of paediatric registries. All interested nephrologists and registry representatives are kindly encouraged to send us proposals for research questions.

ESPN Registry activities and information on paediatric registries in general will be provided at the new ESPN Registry website (www.espn-reg.org) to facilitate the exchange of information.

We hope that the ESPN Registry will further increase the amount and the quality of paediatric RRT data and will lead to high quality collaborative European research projects to improve paediatric ESRD patient care.

A series of articles on Epidemiology in Kidney International From Carmine Zoccali, ERA-EDTA Registry Chairman and Kitty Jager, ERA-EDTA Registry Managing Director

Many renal physicians consider Epidemiology as the unattractive science of Renal Registries that is either too simple to warrant serious attention or too difficult to understand. Yet, clinical epidemiology is the established basic science to clinical medicine and knowledge about it will not only improve the performance of medical research, but also the understanding of professional literature. This has been well understood by the many nephrologists and nephrology researchers who applied to participate in the ERA-EDTA 'Introductory courses in Epidemiology' that are organized twice a year since 2004. So far, more than 150 colleagues successfully completed the course and some of them still maintain contacts with the faculty.

It is a tremendous honour for the

course faculty to be offered the opportunity to transfer the course lectures and hands-on sessions into a series of papers on epidemiology subjects for Kidney International. The articles will explain epidemiological concepts at an introductory to intermediate level providing ample examples derived from current nephrology literature. The writing style will be simple and, as mathematical formulas may put off some readers the use of these formulas will be minimal and restricted to those cases where they are absolutely needed to make the basic learning points.

The series will cover subjects like measures of disease occurrence, measures of effect, study design, bias and confounding, survival analysis methods, analysis of interaction, ways to explore causality and a number of other

themes. The papers will be further supported by additional educational material provided on the Kidney International website. The authors will include the course faculty, consisting of ERA-EDTA Registry Office staff (Academic Medical Center, Amsterdam), Registry Committee members and epidemiologists and biostatisticians from CNR Reggio Calabria (Italy) and Leiden University Medical Center (The Netherlands). We hope you will like the series!



Kitty Jager

The Seventh ERA-EDTA Epidemiology Course will be held in Leiden (The Netherlands) on September 22-24, 2007

On September 22-24, 2007 the ERA-EDTA Registry organizes the seventh ERA-EDTA Epidemiology Course in Leiden, The Netherlands. Ton Rabelink and Frideo Dekker are the hosts of this course. On the basis of surveys among the participants of the six previous courses, these courses can be considered a true success. The application procedure for the Leiden course has started early June 2007 and the deadline for application is July 1, 2007.

More information on this course is available on www.ndt-educational.org/leiden2007.asp.



Registry activities during the XLIV ERA-EDTA Congress in Barcelona, Spain (June 21-24, 2007)

22 June - 10.30 to 12.00 a.m. - ERA-EDTA Registry Symposium.

23 June - 10.30 to 12.00 a.m. - Compact Primers and Updates for the Nephrologist - Clinical Epidemiology.

More information available at www.eraedta2007.org

Poll

We would like to have your opinion on this Newsletter together with your suggestions for improvement. Please, visit our poll at www.era-edta.org/eraedtaregistrypoll.htm.

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