# Do we need Improvement in the Balkan Renal Registries?

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#### Introduction

Renal replacement therapy (RRT) of end-stage renal disease (ESRD) by hemodialysis, peritoneal dialysis and renal transplantation became available in 1960s. The incidence and prevalence of ESRD are continuously increasing in the United States, Canada, Australia and Europe. ESRD is of considerable public health importance not only for its high mortality rate and impaired quality of life, but also for its high cost of RRT. (1) The financial burden of RRT led to an inevitable epidemiology research of data about the number of ESRD patients in different renal centers throughout countries and regions of the world.(2). The epidemiology data of patients receiving RRT are of interest to health care planners and providers to forecast equipment, facility, manpower and other resource requirements.(1) The epidemiology data are collected by renal registries, but the extent and accuracy vary widely. Some countries have national renal registries and others have not, but may extend their collected data directly to international renal registries such as the European Renal Association Registry (ERA-EDTA), Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), Canadian Organ Replacement Registry (CORR), Latin American Registry, Asian-Pacific Registry, United States Renal Data System Registry (USRDS). In 1997 the International Federation of Renal Registries (IFRR) was founded for international comparison and improvement and standardization of different renal databases.(3,4)

The European Renal Registry studies the epidemiology and demography of renal disease in the ERA-EDTA area and promotes studies on renal diseases and their treatment outcomes. The registry can be used as source of information for international comparison, time trends, case finding ( 'rare' diseases, patients and events), as instrument for harmonisation, for definitions, coding and terminology, can assist in setting up new registries and as platform for international collaboration and studies. The registry compares the incidence, prevalence of RRT, treatment modality and survival.

The **Balkans** is the historic and geographic name used to describe southeastern Europe. The distinct identity of the Balkans owes as much to its fragmented and often violent common history, dominated by wars and rebellions, as to its mountainous geography. The countries commonly included in the Balkan region are: Albania, Bosnia-Herzegovina, Bulgaria, Croatia, Republic of Macedonia, Greece, Serbia and Montenegro, the European part of Turkey, and sometimes Romania and Slovenia are included

in the list as well. Many regions in the countries listed as Balkan states can be in many respects rather distinct from the remainder of the region, and usually prefer not to be called *Balkan countries*. Prime examples of this are Romania, Slovenia and Croatia, sometimes also Greece.(5) Except for Greece and Turkey, the common feature for the rest of the Balkan countries is the fall of the communist regimes that have led to a transformation of the health systems allowing faster growth of dialysis facilities and development of the renal care infrastructure. Considering this, differences regarding data from the national renal registries shoud be expected. Slovenia, Albania and Romania are not contributing data to the European Renal Registry, and Bulgaria started contributing this year, but only partly.

The aim of this study was to compare combined data from the national renal registries of Balkan countries contributing the ERA-EDTA Regsitry or from other sources with combined data from renal registries of the Western and Northern European Countries and regions contributing the ERA-EDTA Registry.

#### Methods

Data regarding incident and prevalent patients in 2003, mean age of incident and prevalent patients, incidence and prevalence by cause of renal failure and prevalence by established therapy were compared between the countries of the Balkan region and the countries of Western and Northern Europe contributing to the ERA-EDTA Registry.

**Table 1.** Prevalence of ESRD patients (alive on the 31<sup>st</sup> December 2003)

| Country            | Unadjusted  | Adjusted     |  |
|--------------------|-------------|--------------|--|
|                    | (pmp)       | (pmp)        |  |
| Bosnia-Herzegovina | 432.4       | 454.2        |  |
| Croatia            | 789.7       | 778.0        |  |
| Rep. of Macedonia  | 540.3       | 580.1        |  |
| Serbia&Montenegro  | 491.2       | 425.4        |  |
| Bulgaria           | 333.4       | /            |  |
| Turkey             | 433.5       | 605.9        |  |
| Greece             | 880         | 848.1        |  |
| Romania            | 250         | /            |  |
| Balkans (mean)     | 518.8±215   | 615.12±169.4 |  |
| Europe (mean)      | 826.7±170.9 | 786.6±154.0  |  |
| p<                 | 0.01        | n.s.         |  |

| <b>Table 2.</b> Percentage of Primary Renal Disease (PRD) in prevalent patients in 2 |
|--|
|--|

| country      | GN    | PN    | PKD  | DM    | HT     | RVD  | Misc. | Unkn  | Missin |
|--------------|-------|-------|------|-------|--------|------|-------|-------|--------|
| Bosnia-Herz. | 25    | 20.9  | 6.2  | 10.3  | 4.8    | 0.7  | 23.8  | 5.9   | 2.4    |
| Croatia      | 25.2  | 16.8  | 8.1  | 16.3  | 10     | 3.3  | 11.4  | 7.8   | 1.1    |
| Macedonia    | 26.3  | 15.5  | 8.9  | 7.9   | 11.5   | 1.5  | 10.8  | 13.7  | 4.0    |
| Serb.&Mont.  | 27.6  | 8.8   | 6.4  | 6.7   | 2.0    | 7.9  | 23.7  | 13.5  | 3.3    |
| Turkey       | 10.9  | 3.5   | 3.8  | 17.6  | 13.9   |      | 10.5  | 17.0  | 22.9   |
| Greece       | 23    | 8     | 8    | 16    | 8      | 2    | 8     | 27    | 0      |
| Balkans      | 23±   | 12.2± | 6.8± | 12.5± | 8.4±   | 3.1± | 14.7± | 14.1± | 5.62±  |
| (mean)       | 6.1   | 6.5   | 1.8  | 4.7   | 4.4    | 2.8  | 7.1   | 7.5   | 8.1    |
| Europe       | 23.2± | 10.5± | 9.2± | 12.7± | 10.03± | 2.6± | 17.3± | 14.0± | 0.38±  |
| (mean)       | 3.1   | 2.7   | 1.9  | 5.1   | 4.1    | 2.1  | 4.2   | 5.2   | 0.84   |
| p<           | n.s.  | n.s.  | 0.01 | n.s.  | n.s.   | n.s. | n.s.  | n.s.  | 0.025  |

GN-glomerulonephritis; PN-pyelonephritis; PKD-polycystic kidney disease; DM-diabetes mellitus; HT-hypertension; RVD-renal vascular disease; Misc.-miscellaneous; Unkn-unknown; Missin- missing data

Data were obtained by the Annual Report 2003 of the ERA-EDTA Registry (6), and for Romania by the study of G.Mirescu published in NDT 2004 (7). Some data were obtained by the questionarries sent to people responsible for the national registries. Balkan countries included in the study were Bosnia-Herzegovina, Serbia and Montenegro, Republic of Macedonia, Greece, Croatia, Turkey, and Romania and Bulgaria for the sections where data were available. European countries included were: regions of France and Spain, United Kindgom, Belgium-Dutch speaking, the Netherlands, Germany, Austria, Finland, Denmark, Iceland, Norway, Sweden and regions of Italy. Statistical analysis was performed using the software Statistica for Windows 6.0. Kolmogorov-Smirnov test was used for non-parametric analysis of comparison between two independant samples, and p<0.05 was taken as significant.

## Results

Although there was a substantial difference in the incident number of patients per million population (pmp) at day 1 of RRT, ranging 83 in the Republic of Macedonia to 162 in Greece, the mean incidence for the Balkans was statistically not different from Western Europe, 119.2±25.1 vs 123.3 ±25.9. The incident number of ESRD patients at day 91, adjusted for age and gender, was also statistically not significantly different between the Balkans and Western Europe, 110.9±34.7 vs 106.5±18.3. The mean age of incident patients at day 91 of RRT significantly differed between the Balkans and Western Europe, 57.7±4.49 vs 63.3±2.2, p<0.005, although Greece with a mean age of 64.9 resembled Europe. The percentage of incident patients by cause of renal failure at day 91 of RRT did not significantly differ between the Balkans and Europe. Except for the Republic of Macedonia, where diabetes mellitus as a cause of ESRD was present in 16.3%, the rest of the Balkan countries showed an incidence rate of more than 20% for DM, up to 28% in Greece and Croatia. European countries showed also great variation in DM as a primary renal disease, being predominant in Germany, Austria, Finland and Belgium, and surprisingly low in some countries as Italy, Norway, Iceland. Therefore, the mean incidence of the percentage of DM as a cause of renal failure between the Balkans and Western Europe did not differ, 23.05±4.5 vs 20.3±7.2.

The comparison of the prevalent number of ESRD patients, unadjusted and adjusted, is shown in Table 1. When adjusted for age and gender, the significant difference in prevalent number of ESRD patients between the Balkans and Western Europe dissappeared. The mean age of prevalent patients between the Balkans and Europe did not significantly differ, 54.3±4.2 vs 58.2±2.8. The percentage of primary renal disease in prevalent patients, unadjusted, is shown in Table 2. The policystic kidney disease is significantly more frequent in Western Europe compared to the Balkans, 9.2±1.9 vs 6.8±1.8, p<0.01. The percentage of established RRT in prevalent patients (unadjusted) in 2003 is shown in Table 3.

Transplantation is significantly more frequent in Western Europe, predominantly cadaveric, whereas dialysis is more frequent in the Balkans.

## Conclusion

Considering how important and valuable the data from renal registries are for the epidemiology research and health care planners in countries, it can be concluded that there is a need for establishing national renal registries in Balkan countries where they do not exist; it is of great importance for the Balkan countries to contribute data from renal registries to the ERA-EDTA Renal Registry for international comparison and obtaining information from the statistical processing that may yield improvement in RRT; as shown in the results, no diferrence exists between the incidence and prevalence of diabetes mellitus as a primary renal disease in ESRD patients between the Balkan and European countries, indicating that the epidemic of diabetes is already present in the Balkans and imposing, perhaps, efforts to be undertaken for planning prevention strategies; kidney transplantation is significantly less represented as RRT in Balkan countries compared to Western and Northern Europe, and efforts shoud be made for its increase, particularly the cadaveric one, and moreover, because the population on RRT is significantly younger in the Balkans.

| Table 3. | Percentage of | of established RRT i | n prevalent ESRI | ) natients | (unadjusted) in 2003 |
|----------|---------------|----------------------|------------------|------------|----------------------|
|          |               |                      |                  |            |                      |

| country            | HD total | PD total | Tx total  | Tx living | Tx cadaver |
|--------------------|----------|----------|-----------|-----------|------------|
| Bosnia-Herzegovina | 94.3     | 2.8      | 1.6       | 1.5       | 0.1        |
| Croatia            | 76.4     | 6.6      | 17.0      | 2.5       | 14.3       |
| Rep.of Macedonia   | 91.0     | 0.4      | 8.6       | 8.2       | 0.4        |
| Serbia&Montenegro  | 78.8     | 5.3      | 14.7      | 11.1      | 3.6        |
| Turkey             | 76.5     | 10.9     | 12.5      | 9.3       | 3.2        |
| Greece             | 74.0     | 8.0      | 18.0      | 9.0       | 9.0        |
| Romania            | 77.6     | 17.6     | 4.8       | /         | /          |
| *Bulgaria          | 82.4     | 3.4      | 14.2      | /         | /          |
| Balkans (mean)     | 81.4±7.4 | 6.87±5.4 | 11.4±5.9  | 6.93±3.9  | 5.1±5.5    |
| Europe (mean)      | 46.2±13  | 7.9±4.1  | 45.1±12.6 | 6.04±6.1  | 37.2±14.1  |
| p<                 | 0.001    | n.s.     | 0.001     | n.s.      | 0.005      |

HD-hemodialysis; PD-peritoneal dialysis; Tx-transplantation

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<sup>\*</sup> Data from 2001