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ORIGINAL ARTICLE

End-stage renal disease among Roma and non-Roma: Roma are at risk

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Abstract
Objectives Ethnic differences in the occurrence of end-stage renal disease (ESRD) are reported on various populations across the world, but evidence on Roma is lacking. The aim of this study was to explore the relative risk (RR) of ESRD for Roma who constitute a major minority in Slovakia.
Methods Patients treated by means of hemodialysis during 2005–2008 were questioned for their ethnicity. Rates of ESRD among Roma and non-Roma based on hemodialysis data were calculated as well as the RR of Roma for ESRD. The latter was repeated after standardization for differences in age of both populations.
Results Roma represented 11.6 % of all hemodialyzed patients. The RR of ESRD for Roma was 1.34, compared to the majority population. After age standardization, the RR for Roma was 2.85.
Conclusion This study shows that the risk for ESRD is significantly higher for Roma than for non-Roma. A genetic propensity of Roma to renal failure may partially explain the higher risk. Moreover, a poorer control of risk factors for ESRD in Slovak Roma contributes to the increased risk.

Keywords Roma · Ethnicity · End-stage renal disease · Incidence · Prevalence · Etiology

Introduction

Ethnic differences in the occurrence of end-stage renal disease (ESRD) have been shown for many parts of the world. The incidence of ESRD in African Americans is 2–3 times higher compared to the Caucasian Americans (U.S. Renal Data System 2009). Similarly, the incidence of ESRD in Australian Aborigines is significantly higher compared to non-indigenous inhabitants, the age-adjusted rate reaches 20-fold in some age categories (McDonald

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et al. 2010). Published estimates of ESRD incidence among inhabitants of India ranged from 150 to 232 people per million population (pmp) per year, compared to 76–193 people pmp per year in European countries (Agarwal and Srivastava 2009; ERA-EDTA Registry 2010; Modi and Jha 2006; Prabahar et al. 2008). Indo-Asian immigrants in the United Kingdom (UK) have approximately 3–5 times higher incidence rates of ESRD compared to the majority population in the UK (Lightstone 2003). Genetic factors have been found to be contributing to the deterioration of renal functions in the Indian population, and may partially explain this higher incidence (Tripathi et al. 2008).

In Slovakia as well as in several other European countries, Roma constitute a major ethnic minority. They may have come to Europe from the Indian subcontinent (Zeman et al. 2003). Reliable estimates of the size of the Roma population in Slovakia are difficult to obtain; according to the Slovak national census in 2001 about 90,000 Roma were living in Slovakia, 1.7 % of the population. The Institute of Informatics and Statistics of the Slovak Republic (Infostat) provides more reliable estimates of approximately 380,000 Roma in 2001, representing about 7 % of the Slovak population (Vano 2002). Other sources come to higher estimates, ranging from 8 to 12 % (Koupilova et al. 2001; Kröhnert et al. 2008).

There is lack of evidence on the occurrence of ESRD among Roma. This could be hypothesized to be high, considering the high occurrence of ESRD in India where Roma may have come from (Agarwal and Srivastava 2009; Modi and Jha 2006; Sakhuja and Sud 2003) and among the Indian immigrants in Europe (Lightstone 2003). Therefore, our aim was to compare the occurrence of ESRD between Roma and non-Roma and to calculate the relative risk (RR) of Roma for ESRD by age groups.

Methods

Patients

The total sample consisted of 1,407 ESRD patients treated by means of hemodialysis in Slovakia in years 2005–2008, representing 32.5 % of all dialyzed patients on average. This comprised 1,361 adult patients treated in one of the 18 Fresenius dialysis units all over Slovakia and all pediatric patients up to 19 years of age ($n = 39$) treated in one of the four tertiary centers for pediatric nephrology in the same period.

Data and data collection

Data on adults obtained from the lists of all patients dialyzed at all centers participating in the study with patients' details. Data on children were collected using questionnaires sent by e-mail to the heads of pediatric dialysis and transplantation centers in Slovakia. For each patient, data on age, gender, primary renal disease and date of the beginning and end of dialysis (if applicable) were retrieved from the medical records. The primary renal diseases were recorded as diagnosed by every centre in Slovakia. Ethnicity was measured based on patients' self-identification and the assessment of the nephrologist. In case of a mismatch the opinion of the third person (the head nurse) was decisive.

Population data on the majority population (2005–2008) were obtained from the Statistical Office of the Slovak republic (2011). Population data on Roma were obtained from Infostat and represent a middle prognostic variant of the Roma population development (Vano 2002). The estimate of the number and age–sex structure of Roma living in the Slovak Republic as of 31 December 2001 was based on data from the period between the censuses in 1980 and 2001, i.e., an estimation algorithm was constructed based on the 1980 census and then calibrated using the 1991 and 2001 censuses. Using this calibrated algorithm, numbers were estimated to forecast the development of the Roma population in the Slovak Republic to the year 2025 (Vano 2002).

Statistical analyses

Relative risks of ESRD for Roma compared to the remainder of the Slovak population were estimated for 15-year age categories (0–14, 15–29, 30–44, 45–59, 60–74, 75+). First, we estimated the relative risks of ESRD for Roma compared to the remainder of the Slovak population per 15-year age category (0–14, 15–29, 30–44, 45–59, 60–74, 75+). Next, we estimated the summary of the relative risks across all ages using direct standardization to account for the large differences in age distribution between Roma and the remainder of the Slovak population. In order to do this, we computed the expected numbers of ESRD cases among Roma per 5-year age category as the product of the number of Roma in the population in that age category, and the rate of ESRD in the majority population in that age category. We then estimated a standardized ratio for Roma as the observed number of ESRD, summarized across all age categories, divided by the expected number of cases of ESRD across all age categories. Finally, Poisson regression analyses were used to model the risks for ESRD because of the number of primary renal diseases. The differences were considered significant at a p level of 0.05. Standardization was done in Microsoft Excel.

Results

Data concerned 1,407 patients (778 males, 629 females); 146 of them were identified as Roma, 3 patients were of

Table 1 Estimated relative risk (RR) of end-stage renal disease (ESRD) in Roma compared to the majority Slovak population over the period 2005–2008

Age groups	Majority population		Roma population		RR for ESRD (standardized) [95 % confidence interval]
	Total population[a] (*n*)	Dialyzed patients[a] (*n*)	Total population[a] (*n*)	Dialyzed patients[a] (*n*)	
0–14	873,572	21	129,278	5	1.82 [1.18–2.82]
15–29	1,308,243	41	128,983	10	2.77 [2.03–3.79]
30–44	1,192,744	96	87,591	20	3.42 [2.75–4.26]
45–59	1,132,677	240	49,574	29	3.14 [2.61–3.76]
60–74	615,426	304	13,938	16	2.47 [1.94–3.16]
75+	273,140	109	3,053	3	2.38 [1.35–4.20]
Total	5,395,802	810	412,416	83	2.85 [2.56–3.17]

[a] Average per 2005–2008 period

Table 2 Proportions of primary renal diseases (PRD) of dialyzed patients in Roma and majority population over the period 2005–2008

PRD	Majority population[a], *n* (%)	Roma population[a], *n* (%)
Diabetic nephropathy	158 (19.5)	20 (24.1)
Interstitial nephritis	155 (19.1)	14 (16.9)
Glomerulonephritis	103 (12.7)	11 (13.3)
CAKUT	24 (3.0)	3 (3.6)
Hereditary nephropathy	5 (0.6)	6 (7.2)
Other	164 (20.2)	14 (16.9)
Unknown/unavailable	201 (24.8)	15 (18.1)
Total	810 (100.0)	83 (100.0)

CAKUT: congenital anomaly of kidneys and urinary tract

[a] Average per 2005–2008 period

other non-Slovak ethnicity. The share of Roma among hemodialyzed represented 11.6 %.

Roma patients with incident ESRD were on average younger than other patients. The mean age of incident Roma at the time of hemodialysis initiation was 52.1 ± 14.7. Compared to the mean age of the incident majority patients 61.6 ± 14.7 the age of the Roma patients at the time of hemodialysis initiation was significantly lower.

The RR of ESRD for Roma was 1.34 times higher compared to the majority population. After standardization to the age distribution of the majority population, the overall RR was 2.85 (95 % confidence interval 2.56–3.17), range 1.82–3.42 for RR as standardized in the various 15-year age categories (Table 1) (Rothman et al. 2008).

Poisson regression showed that diabetic nephropathy occurred more frequently as cause of ESRD among Roma than among non-Roma ($p = 0.033$) (Table 2).

Discussion

This is the first study that shows an overview of ethnic differences in Slovak hemodialyzed patients. The results show that the RR of ESRD for Roma is 1.34 times higher compared to the majority population. It is even higher 2.85 after taking into account the much younger mean age of Roma.

An explanation for the higher RR of Roma may be a genetic propensity of Roma to renal failure, possibly associated with a background from the Indian subcontinent (Tripathi et al. 2008). Roma also share with people from the Indian subcontinent a high occurrence of diabetic nephropathy. A significantly higher occurrence of diabetic nephropathy was found in Slovak hemodialyzed Roma, which may contribute to the higher RR for ESRD among Roma. At least a part of the increased risk of ERSD in the Roma population may be related to a delayed diagnosis and a lack of control of the main ESRD risk factors, such as hypertension, diabetes mellitus and smoking. Another contributing factor may be the low birth weight that occurs significantly more frequently among Roma newborns and, according to Brenner's and Barker's theory, might also contribute to the higher occurrence of CKD and ESRD in Roma (Barker and Martyn 1992; Bobak et al. 2005; Brenner and Chertow 1994; Rimarova et al. 2004). A fourth factor that contributes to a higher risk of ESRD among Roma may be consanguinity. Finally, a deprived socioeconomic position or even marginalization of the Roma community may contribute to the burden of ESRD in this particular population (Hurtado and Johnson 2005).

Strengths and limitations

The strengths of our study are that it concerns national data on a several years regarding on a country with a large Roma minority. Limitations are that we did not have a full national coverage, but we could estimate the share of the population covered by our study very accurately and this share has been shown to be unselected (Statistical Office of Slovak Republic 2011). A second limitation might be that we estimated the size and age distribution of the Roma population. However, we used by far the best estimate

available. Moreover, even if the share of Roma in the total population would be twice as high, rates among Roma are still higher than among the majority population showing that this is very unlikely to affect our findings. A limitation might be that the number of ESRD patients was assessed based on the number of RRT patients. As ESRD is fatal, without RRT it seems unlikely that missing ESRD cases might have biased our findings. However, a higher lethality of ESRD among Roma might have occurred. In that case, our figures are an underestimation of the increase in risk among Roma.

Implications for practice and further research

Policies aimed at improving minority health status and access to healthcare in Roma are essential to reduce inequalities in health between the minority and majority populations (Nielsen and Krasnik 2010; Dostal et al. 2010; Skodova et al. 2010). Based on our results, the population's attributable risk for ESRD due to Roma having ESRD was estimated as 37.4 %, i.e. 37.4 % of all cases of ESRD in Slovak children is due to the excess risk in Roma. This causes a significant burden of disease. It can also be considered significant in terms of costs for RRT, as annual costs for dialysis per pediatric patient are approximately 20,000 euro in Slovakia. Physicians should be more aware of the higher risk of Roma for earlier reaching of ESRD and focus more on modifiable risk factors in order to postpone its onset, thus decreasing significantly both this burden of disease and the associated costs. For example screening for hypertension, diabetes mellitus and hematuria in family members of Roma with progressive hereditary nephritis might be done to decrease the overall number of patients who need RRT. Moreover, general measures to increase the access to health care for Roma may also lead to a more timely treatment of risk factors for ESRD.

Conclusion

The RR of ESRD for Roma was 1.34 times higher compared to the majority population. After standardization, the RR was 2.85 (Table 1). The genetic propensity of Roma to renal failure may explain a part of this higher risk, as well as a poorer control of risk factors for ESRD among them.

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Conflict of interest The authors declare that they have no conflict of interest.

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