

# Kidney diseases in Roma and non-Roma children from eastern Slovakia: are Roma children more at risk?

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## Abstract

**Objectives** To compare the occurrence of primary renal diseases (PRD) in Roma and non-Roma children.

**Methods** Data on all outpatients ( $n = 921$ ) from a tertiary pediatric nephrology centre (<19 years) in eastern Slovakia were collected. We assessed early signs and symptoms and PRD for Roma and non-Roma children.

**Results** The proportion of Roma among patients was relatively small regarding early signs like proteinuria but large regarding PRD with gross clinically apparent symptoms (e.g. Alport syndrome,  $p < 0.01$  and systemic lupus erythematosus,  $p < 0.05$ ).

**Conclusions** The overall proportion of Roma children in outpatients with kidney problems is smaller than the estimated proportion of Roma in all children in Slovakia, in particular for early signs, but not for major renal diseases.

**Keywords** Children · Ethnicity · Primary renal disease · Roma

## Introduction

Ethnic differences in the occurrence of primary renal diseases (PRD) among children have been shown for different parts of the world (NAPRTCS 2008; Lewis et al. 2010). In the British national registry, the proportion of patients from ethnic minority groups varies widely between categories, with congenital nephrosis being the one with the largest proportion of ethnic minority patients (Lewis et al. 2010). Similarly, a large proportion of minority patients has been found in the North American Pediatric Renal Trials and Collaborative Studies for focal segmental glomerulosclerosis (NAPRTCS 2008). Ethnic minorities are reported to be overrepresented among end-stage renal disease (ESRD) patients, while at the same time they are underrepresented in earlier stages of chronic kidney disease (Tarver-Carr et al. 2002; Gao et al. 2007).

In several European countries Roma constitute a major ethnic minority. Reliable estimates of the size of the Roma population are difficult to obtain, of the age-structure of this population even more so. The Institute of Informatics and Statistics of the Slovak Republic (Infostat) provided a reliable estimate that Roma make up approximately 7 % of the whole Slovak population, and 13.3 % of inhabitants under the age of 20 years (Vano 2002). Recent estimates on the whole Slovak population are similar (7.5 %) (Ministry of the Interior of the Slovak Republic 2013).

Evidence is lacking on the degree to which Roma children are referred to nephrological care, overall and regarding specific diagnoses. On the one hand, their proportion may be larger in this type of care than in the general population, as the proportion of Roma among ESRD patients has been shown to be larger than expected on the basis of their proportion in the general population (Kolvek et al. 2012). On the other hand, factors such as a

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lack of knowledge and a lack of means may hamper their access to specialized care, which would lead to underrepresentation (Erasmus MC-University Medical Centre Rotterdam Rotterdam 2007; Jarcuska et al. 2013).

The aim of this study was first to compare the proportion of Roma and non-Roma children in a tertiary pediatric nephrology clinic with that in the general population, and second to compare the proportion of Roma and non-Roma regarding early signs of PRD and specific PRD.

## Methods

### Patients

The sample consisted of the records of 921 patients under the age of 19 years (as of June 15 2010), which represented the active records of the outpatient clinic in the tertiary pediatric nephrology centre in Children's University Hospital, Kosice, as of that date.

### Data and data collection

Clinical variables were derived from the medical files. For each patient data on age, gender and PRD or the presenting symptoms of the nephropathy were retrieved from the medical records. Ethnicity was assessed based on patients' self-identification and the assessment of the nephrologist. In the case of a mismatch the opinion of a third person (the nurse) was decisive. Data on the proportion of Roma and non-Roma children in the catchment area were obtained from the Infostat (Vano 2002). Data on patients <19 years of age were compared with the number of inhabitants <20 years of age due to the unavailability of ethnicity data per birth year in individual years (Statistical Office of Slovak Republic 2011).

### Statistical analyses

First, we calculated the ratio of observed versus expected numbers of Roma patients. Next, we tested the statistical significance of the differences using a  $z$  statistic (Fleiss 1981). The differences were considered significant if  $p$  was <0.05. SPSS 20.0 and SAS 9.1 were used for the statistical analyses.

## Results

### Proportion of Roma and non-Roma children among patients

The data comprised 921 patients (478 boys); 97 of them (51 boys) were identified as Roma. The mean age of

patients at the time of data collection was  $11.8 \pm 5.2$  years ( $12.3 \pm 5.6$  in Roma vs.  $11.8 \pm 5.2$  in non-Roma;  $p > 0.05$ ). The proportion of Roma children in all patients was 10.5 %. This was smaller than the estimated proportion of Roma children in the general Slovak population (13.3 %;  $p < 0.05$ ).

### Proportion of Roma and non-Roma children according to diseases and risk factors

The proportion of Roma among patients was in particular significantly smaller ( $p < 0.01$ ) regarding early signs and risk factors such as proteinuria and hypertension (Table 1). On the other hand, the proportion of Roma was larger than expected based on the proportion of Roma in the total population for diseases with obvious clinical signs, such as gross hematuria, generalized swelling, rash. Examples were Alport syndrome ( $p < 0.01$ ) and systemic lupus erythematosus ( $p < 0.05$ ).

## Discussion

We compared ethnic differences in the proportion of Roma and non-Roma children in specialized nephrological care in eastern Slovakia. We found that Roma were overall underrepresented in this care. The proportion of Roma was especially small in patients without obvious signs and symptoms, while the proportion of Roma was relatively large among patients with PRD presenting with obvious signs, such as gross hematuria or generalized swelling.

The small overall proportion of Roma children among these patients contrasts with the relatively large proportion of Roma pediatric ESRD patients, as recently reported for the same population (Kolvek et al. 2012). An explanation for this contrast might be that Roma patients do not show up until after their kidney disease has progressed to ESRD and do not reach pediatric clinics with early signs and risk factors. This fits with our previous finding that among incident patients requiring dialysis, a rather large proportion of Roma had not been previously seen by a nephrologist (22 %), whereas all non-Roma children had already been seen previously (Kolvek and Podracka 2012). One possible explanation is that Roma have poor access to specialized nephrology care, as compared with non-Roma, which may hold even more for children due to their dependency on parents. Lack of means, problems with transportation, or discrimination have all been suggested as possible explanations (Babinska et al. 2013; Erasmus MC-University Medical Centre Rotterdam Rotterdam 2007; Jarcuska et al. 2013; Kolarcik et al. 2009; Sudzinova et al. 2013). Financial barriers to access are rather unlikely as primary as well as specialized care in Slovakia is fully

**Table 1** Diagnoses in Roma and non-Roma patients, primary renal diseases (PRD) and other diagnoses: the proportion of Roma and non-Roma children per diagnosis and the ratios of the proportions of Roma in the diagnosis group and in the population; Slovakia 2010

Diagnosis	Non-Roma patients <i>n</i> (%)	Roma patients <i>n</i> (%)	Observed/Expected <sup>a</sup> %/%	Sig. <i>p</i>
Number of inhabitants <20 years	All non-Roma <20 1,128,458	All Roma <20 173,956		
Established PRD	435 (84.3)	81 (15.7)	1.18	n.s.
Glomerulopathy	69 (74.2)	24 (25.8)	1.94	<0.01
Idiopathic nephrotic syndrome	58 (78.4)	16 (21.6)	1.62	n.s.
Other glomerulonephritis	11 (57.9)	8 (42.1)	3.17	<0.01
Hereditary nephritis	7 (38.9)	11 (61.1)	4.59	<0.01
Alport syndrome	3 (21.4)	11 (78.6)	5.91	<0.01
CAKUT (including MMC)	267 (88.7)	34 (11.3)	0.85	n.s.
Vasculitis	32 (84.2)	6 (15.8)	1.19	n.s.
SLE	3 (50.0)	3 (50.0)	3.76	<0.05
SHP	29 (90.6)	3 (9.4)	0.71	n.s.
HUS	13 (100.0)	0 (0.0)	0.00	n.s.
Cystic disease	13 (81.2)	3 (18.8)	1.41	n.s.
PKD	10 (90.9)	1 (9.1)	0.68	n.s.
Juvenile nephronophthisis	5 (83.3)	1 (16.7)	1.26	n.s.
Interstitial nephritis	10 (83.3)	2 (16.7)	1.26	n.s.
Wilm's tumor	9 (100.0)	0 (0.0)	0.00	n.s.
Others or unknown	13 (86.7)	2 (13.3)	1.00	n.s.
No PRD established <sup>b</sup>	389 (96.1)	16 (3.9)	0.29	<0.01
Total	824 (89.5)	97 (10.5)	0.79	<0.05

CAKUT congenital anomalies of kidneys and urinary tract, HUS hemolytic-uremic syndrome, MMC meningocele, PKD polycystic kidney disease, SHP Schönlein-Henoch purpura, SLE systemic lupus erythematosus, n.s. not statistically significant

<sup>a</sup> Observed share of Roma patients/Expected number based on their share in the population

<sup>b</sup> Patients referred for hypertension, proteinuria, erythrocyturia, enuresis or a history of urinary tract infection, i.e. those in whom no certain PRD was confirmed

covered by the compulsory insurance which is paid by social security when there is a lack of means.

However, other barriers may occur. One reason could be the attitude of Roma toward their own health and to the health of their children. Studies comparing Roma with non-Roma have shown that Roma perceive the relationship between lifestyle and health much less as being strictly causal; the issue of health and disease is understood rather fatalistically (Petek et al. 2006; Van Cleemput et al. 2007). Evidence on the way Roma care for their children is completely lacking. A third and possibly crucial reason why Roma children show up only after obvious clinical symptoms have developed is a poor understanding of the disease, leading them not to respond to early signs.

On the other hand, this study shows that Roma children are overrepresented in certain PRD, particularly those which typically present with obvious signs and symptoms, such as gross hematuria, generalized swelling and typical rash. This may first be due to a poor response to early signs, which makes progress of the disease to ESRD more likely. A different genetic load may add to the explanation of the larger proportion of Roma among patients with Alport

syndrome and SLE. A higher genetic risk of SLE has been described in other minorities as well, especially African-Americans (NAPRTCS 2008). A recent study showed similarly increased rates of chronic kidney disease among Roma adults compared with non-Roma adults as well (Rosenberger et al. 2014). Other diseases have been found to be overrepresented in Roma due to higher genetic risk (Bouwer et al. 2007; Gabrikova et al. 2013).

A strength of this study is that it presents a sample that covers a large region with a large Roma minority. The size of the sample can also be considered a strength. Our main limitation is that the information on the proportion of Roma in the population was based on estimates. However, we think that these estimates are rather valid. Moreover, differences are so pronounced that their statistical significance remains unaffected by likely inaccuracies in these estimates.

Earlier diagnosis of kidney diseases in Roma children might be achieved by improving their access to specialized care. More evidence is needed on the process leading to poorer access, with a focus on the increased health literacy of Roma parents, the behavior of professionals,

communication barriers and lack of means. This further research should focus in particular on segregated Roma settlements with the poorest living conditions and educational status.

## Conclusions

Roma are underrepresented in specialized care for children with kidney problems, which contrasts with their overrepresentation among ESRD patients. An explanation for this contrast might be that Roma patients do not find care until after their kidney disease has progressed to ESRD. The significantly smaller proportion of Roma among patients referred for symptoms found in this study supports this explanation. Access of Roma children to specialized care thus requires utmost attention.

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**Conflict of interest** None declared.

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