QiN-Kid – a German registry for pediatric dialysis patients

Eva Nüsken1, Christina Taylan1, Gero von Gersdorff2, Mathias Schaller2, Claudia Barth3, Lutz Weber1, Jörg Dötsch1

1Department of Pediatrics, Pediatric Nephrology, University Hospital Cologne, Cologne, Germany, 2Department of Medicine II, QiN-group, University Hospital Cologne, Cologne, Germany 3Curatorium for Dialysis and Kidney Transplantation, Neu-Isenburg, Germany

Methods

All patients dialyzing at one of the participating centers were eligible for inclusion into QiN-Kid. There were no exclusion criteria. Patients were counted if they had at least one dialysis in 2012 and grouped according to the modality used most often during that year. All data entered into the documentation system were available for analysis. Multiple values were averaged. Age was determined as of Dec. 31, 2012. Systolic blood pressure was calculated from values taken before dialysis for hemodialysis (HD) and from monthly visits for peritoneal dialysis (PD), respectively, and expressed as percentage of patients >90th centile of healthy peers. Height was calculated as standard deviation score (SDS) from the German KiGGS (2003-2006) reference population. Cause of renal disease was selected by the treating physician from a prespecified list of categories. Based on the data transferred to QiN-Kid, we analyzed several parameters in order to give an overview on the situation of pediatric dialysis patients in Germany: cause of renal disease, current age and height of the patient, systolic blood pressure (percentage of patients >90th centile of healthy peers) as well as several laboratory parameters (percentage of patients with hemoglobin levels <10 g/dl, parathyroid hormone >300 pg/ml, ferritin levels <100 μg/l or >500 μg/l and serum albumin <35 g/dl).

Results

157 patients included (01-12/2012 at least one dialysis), grouped according to the type of dialysis most often documented

- Peritoneal dialysis, PD, n=90; hemodialysis, HD, n=62; home hemodialysis, HHD n=1; undetermined, n=4,

Data quality (clinical parameters documented):

- Blood pressure (n=148)
- Height (n=156)
- Renal disease (n=122)

Summary

Based on a common documentation system installed in 16 pediatric dialysis centers, QiN-Kid was started as a national registry in Germany. Apart from being an ideal data base for future scientific analyses, this will contribute to quality improvement efforts in the care of pediatric dialysis patients.

Background

In Germany, 16 pediatric dialysis centers treating the majority of patients in the country, are run by an incorporated association with charitable status (Curatorium for Dialysis and Kidney Transplantation, KFH). All centers work with a common computerized documentation system, which can be used as a data base for scientific analyses. As soon as informed consent by a legal guardian is obtained, all data can be transferred automatically to QiN-Kid, a German registry for pediatric dialysis patients (Fig. 1).

Conclusions

Our analysis is in accordance with prior studies concerning basic epidemiologic findings (age, renal disease, type of dialysis). In a significant number of patients, we still observe hypertension, anemia, severe secondary hyperparathyroidism and failure to thrive. Future subanalyses might help to identify patients at risk and to optimize treatment protocols. We wish to thank all centers for their cooperation.

Contact: eva.nuesken@uk-koeln.de, gero.von-gersdorff@uk-koeln.de