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Appendix: Overview of the data collected from 1970 to 2015

Paediatric end-stage renal disease and renal replacement therapy in Switzerland: survival and treatment trends over four decades

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Description of the data

Paediatric care

The Swiss Paediatric Renal Registry contains clinical information from the charts. Primary renal disease is classified according to the International Classification of Diseases 10th revision (ICD 10), additionally according to the European Society for Paediatric Nephrology (ESPN) registry [1]. It contains data on co-morbidities, first renal replacement therapy and its start date, date of birth, height and weight, blood pressure and serum creatinine. Follow-up includes height and weight, blood pressure, haemoglobin, albumin, serum creatinine, calcium, parathyroid hormone, high-density lipoprotein, cholesterol, triglycerides, new co-morbidities and use of growth hormone, erythropoietin stimulating agents and anti-hypertensive drugs. Changes of renal replacement therapy, graft failure, complications and death are noted with date and cause(s). To allow international collaboration, data was recoded and reorganized between 2008 and 2010 according to the requirements of the ESPN registry [1]. Follow-up is recorded until transition to adult care. To allow life-long follow-up, names and contact information are collected separately from clinical data. The datasets analysed during the current study are available from the corresponding author on reasonable request.

Adult care

Quality of life, current and past renal replacement therapy, hospitals involved, current medication, somatic and mental health, health behaviour, socioeconomic situation, education and professional life are part of a questionnaire-based follow-up in adulthood. For clinical follow-up data after transition, adult registries (e.g., Swiss Transplant Cohort Study [2]) are contacted for data sharing in collaborative studies [3]. Current address or date of death are searched in community registries if needed for specific research questions. Cause of death after transition can be searched by linkage with cause of death statistics [4] for a specific publication.

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