Patient reported and clinical outcomes in paediatric end stage renal disease: Understanding factors affecting quality of life, access to transplantation and mortality
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Propositions belonging to the thesis:

Patient reported and clinical outcomes in paediatric end stage renal disease;

Understanding factors affecting quality of life, access to transplantation and mortality.

Lidwien Anne Tjaden, June 2016

1. End-stage renal disease and its treatment have a severe impact on quality of life of children as it affects both physical and emotional functioning and interferes with normal daily life. Regular assessment of HRQoL including the implementation of patient reported outcomes should therefore become part of standard care in order to identify specific areas for interventions (this thesis).

2. Kidney transplantation, although the best treatment option for children with ESRD, has important impact on the quality of life to an extent that is generally underestimated (this thesis).

3. Frequent home overnight haemodialysis should be the preferred alternative for children with ESRD that cannot be transplanted as it enhances overall condition, improves freedom and consequently quality of life and the development of autonomy (this thesis).

4. After 30 years of RRT, adult survivors of paediatric ESRD have an impaired physical, but a remarkably good mental health related quality of life (this thesis).

5. Important parameters of successful treatment in childhood also include the level of achieved independency and social participation in adulthood (this thesis).

6. Black and Asian paediatric ESRD patients in Europe are about half as likely to receive a renal transplant compared with white patients. Known biological aspects of racial background like primary renal disease can only partially explain this difference, making it likely that other biological and socio-environmental aspects are involved (this thesis).

7. Asian children with ESRD in Europe are at high risk of modifiable cardiovascular disease risk factors like uncontrolled hypertension and anaemia. Early identification and management of these risk factors could potentially improve long-term outcomes (this thesis).

8. Restrictions on the registration of racial background as anti-racist policy may hamper detection of disparities in health care and consequently can be disadvantageous to the minority groups.

9. Not everything that counts can be counted and not everything that can be counted counts.
   —Albert Einstein

10. Perfection is achieved not when there is nothing more to add, but when there is nothing left to take away. —Antoine de Saint-Exupery (1900-1944).

11. It is not our differences that divide us. It is our inability to recognize, accept, and celebrate those differences. —Audre Geraldine Lorde (1932-1992)