

Title of Paper: To Transplant or not to transplant? Ethical issues concerning kidney transplantation in severely mentally disabled children

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Abstract:

Renal transplantation is the treatment of choice for patients with end stage renal disease (ESRD). However, the indications and contra-indications for transplantation in severely mentally disabled children remain controversial. We present a case of a 4 year old girl with severe mental retardation and pre-terminal renal failure and discuss the decision-making process for organ transplantation in these group of patients, based upon available literature.

The case concerns a 4 year old girl who had severe perinatal asphyxia, with subtotal cortical atrophy, blindness, severe mental retardation, spasticity and epilepsy. Her GFR was ~15 ml/min/1.73m² due to renal cortex necrosis. Initially a “Do not resuscitate” code was given to the child. However, this was removed later during the first year of life because her neurologic condition slightly improved and her epilepsy was under control. After ceasing the barbiturates, the girl made subtle progress in her psychological development (smiling and making sounds in response to touch and voice of parents). The family put extraordinary efforts to take care of the girl and to mobilize her neurological capacity using physiotherapy, stimulation techniques, etc. Given her low kidney function, the possibilities of renal replacement therapy were reconsidered. Her mother offered to donate a kidney and was found medically fit for donation. However, the Ethical Board of the hospital didn’t support renal transplantation in this child based on her severely impaired mental state (developmental level of 3-4 months), spasticity and overall poor prognosis. This case will be discussed in light of the existing medical literature. The opinion of the audience will be evaluated based on a questionnaire.

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