

Living kidney transplantation in an autistic patient with intellectual disability : a case report

Yasunori Mori¹, Takashi Kikuchi², Yoshitaka Saito¹, Taiji Hayashi², Kazuhiro Nose¹, Tsukasa Nishioka², Hirotsugu Uemura¹

¹*Department of Urology, Kindai University Faculty of Medicine, Osakasayama, Osaka 589-8511, Japan*

²*Department of Urology, Sakai Hospital, Kindai University Faculty of Medicine, Sakai, Osaka 590-0132, Japan*

Abstract

Intellectual disability has been a controversial relative contraindication to organ transplantation. There are few data available in the literature on the outcome of kidney transplantation in patients with intellectual disability. We present the case of a 39-year-old male with intellectual disability who underwent living kidney transplantation. The patient's intelligence level was at an elementary school lower grade level (IQ=56); therefore, we communicated

primarily through his mother. We assembled a team of specialists who were assigned various tasks to facilitate the patient's therapy. The clinical course was successful, without any major problems, due to the fact that we held a joint conference with other departments monthly.

Key words : Kidney transplantation ; Intellectual disability

Introduction

Advances in medical management have improved the prognosis of children with intellectual disability. Children with intellectual disability develop secondary complications that require surgical interventions as they grow. Genetic syndromes and chromosome aberrations are the main causes of mental retardation, and in some cases, congenital anomalies of the urinary tract and chronic kidney disease (CKD) are associated.¹ Thus, treatment for CKD in patients with intellectual disability has become important.

There have been a few reports on kidney transplantation in patients with intellectual disability, but, to our knowledge, kidney transplantation in an autistic patient with intellectual disability has never been reported. It is necessary to consider the criteria regarding the indication of organ transplantation used in these reports.

Here, we present an interesting case of living kidney transplantation in an autistic patient with intellectual disability.

Case report

Patient : A 39-year-old male

Original disease : Chronic glomerular nephritis (CGN)

Past medical history : Autism with intellectual disability, glaucoma (Rt. eye blindness), diabetes mellitus, no history of transfusion

Clinical history : The patient has been receiving hemodialysis for end-stage renal disease due to CGN since March 2012. Because of his intellectual disability, continuous hemodialysis was difficult. Therefore, living kidney transplantation was considered with his mother as the donor. ABO-compatible living kidney transplantation was completed in March 2013. The

patient's intelligence level was at an elementary school lower grade level (IQ=56); therefore, we communicated primarily through his mother. We explained the treatment to the patient. He understood that surgery would allow hemodialysis to be discontinued, but it was difficult to understand all the treatment contents. Therefore, we explained the contents of treatment to his mother, and asked her to explain them to him using sign language. The patient presented with four problems:

1. The patient has difficulty adapting to new environments and developing interpersonal relationships.
2. His IQ is 56, which is at a primary school level; he communicates only through his mother.
3. Postoperative complications (pain control, restlessness, etc.).
4. Problem of medication adherence.

Therefore, we devised a team of specialists assigned various tasks to facilitate the patient's therapy. To address the first problem, he arrived at the hospital one week prior to admission to meet with the urologist, nephrologist, chief ward nurse, ward charge nurse, and the charge nurse in order to get used to the environment. For the second problem, arrangements were made for the patient to be in one room pre- and postoperatively and to be in constant contact with his mother. To address the problem of postoperative complications, we considered sedation after surgery, but his pain control was adequate, the patient did not attempt to remove any tubes, and

midazolam was included intravenously. In addition, on considering the stimulation and bladder irritability that would be caused by a catheter, he used the portable restroom. With regards to problem four, the initial plan was for his mother to administer the medication after adequate instruction by the pharmacist. However, we decided to include the patient in the postoperative plan through the use of animation; through this, the patient became interested in the medication. This allowed us to avoid the problem of poor medication adherence.

The clinical course is outlined in Fig. 1. We followed the new immunosuppressant protocol; he was given immunosuppressant therapy of cyclosporine (CyA)+mizoribine (Miz)+everolimus (EVR)+prednisolone. The renal function was immediately improved. His perioperative management was successful without any abnormal behavior due to the use of midazolam for 2 days postoperatively. The use of midazolam facilitated intraocular pressure control to avoid possible glaucoma, which can lead to eyeball enucleation and blindness around postoperative day (POD) 14. In addition, he was diagnosed with diabetes mellitus based on an abnormal preoperative 75 g OGTT, and started on insulin therapy on POD 17. He could be discharged on POD 40. The clinical course was followed for one year without any complications, and the kidney graft function was stable with an S-Cr level of 2.0 mg/dL.

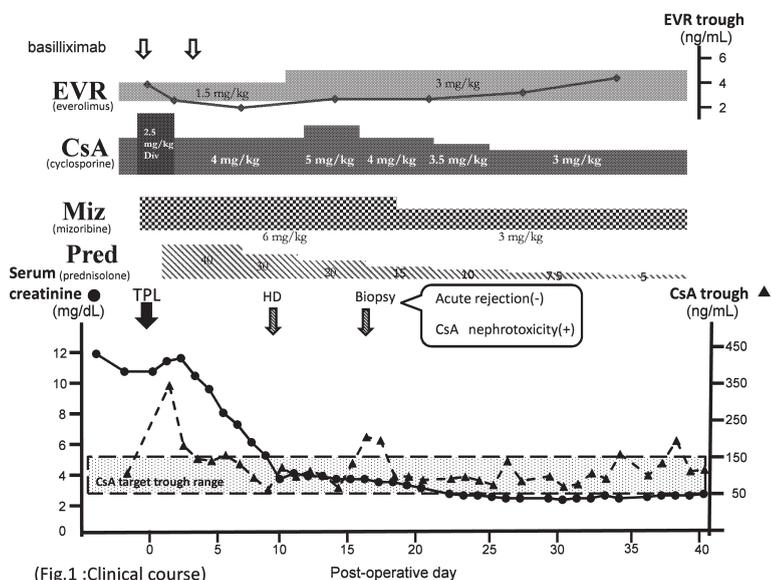


Fig. 1 The clinical course

Discussion

It was recently reported that adaptive organ transplantation affects life expectancy, and relative contraindications for kidney transplantation in the literature include intellectual disability. Because of this, there are few reports of organ transplantation in patients with intellectual disability. A recent American Society of Transplantation report recommends that renal transplant candidates who cannot give informed consent require “the presence of a reliable primary support person” that will ensure follow-up and adherence to the regimen.² Levenson JL et al.³ reported that when the IQ level of patients with intellectual disability was 50-70, 46.1% of the research groups found no contraindications for kidney transplantation. In their study, Beneditti et al.⁴ reported that seven patients (87.5%) with an average IQ of 35-65 were alive with functioning grafts 7 months to 15 years after kidney transplantation.

Ohta et al.⁵ reported that follow-up data showed all grafts were functioning during a mean observation period of 41.1 months (range : 4-187 months). With regards to complications after kidney transplantation, eleven acute rejection episodes occurred in 8 patients (32%) ; all cases were completely reversed with methylprednisolone pulse therapy and deoxyspergualin (DSG) and immunoglobulin (IG). Two patients (4%) who received tacrolimus regimens developed post-transplant diabetes mellitus (PTDM), and two patients (4%) developed post-transplant lymphoproliferative disorder (PTLD). The incidence of PTLD and PTDM in the control group was 1.8% (P=0.13) and 1.2% (P=0.09), with no significant differences compared with a intellectual disability group, respectively. In the present case, the patient developed PTDM, but this was controlled well with insulin. Galante NZ et al.⁶ reported that patients with an intellectual disability had a significantly lower 5-year survival rate (81.2%) than a control group (97.4%), but there was no significant difference between the 2 groups in the 5-year graft survival.

Samelson-Jones E et al.⁷ stated, that people with intellectual disability should not be held to a higher standard than other patients. Estimates of non-adherence rates in transplant recipients derived from long-term follow-up and large patient cohorts vary from 20 to 50%, with an average rate of persistent non-adherence to im-

munosuppressant medication of 23%.^{8,9} Although the number of cases presented is small, the rate of non-adherence was not markedly different from these baseline rates.

When considering the present case, it should be noted that social support is well-established in Japan. Family support is not a problem but it can become difficult due to a lack of experience in hospital management. As stated to address the above four problems, we included other specialists in a joint conference to maximize medical care the success of without problems because we examined each problem and implemented measures. It was our first experience to perform living kidney transplantation in an autistic patient with intellectual disability ; therefore, we devised a team of specialists in advance and carried out a simulation. As a result, we were able to reduce the psychological stress of the patient during the perioperative period without any major problems.

Conclusion

This report is unique in the world as it describes a case of kidney transplantation in a patient with intellectual disability. There are no reports of kidney transplantation in cases of autism with intellectual disability. As the number of organs available has been insufficient to meet all transplant needs, some authorities have felt ethically obligated to distribute organs based on each individual's quality of life (QOL). This was a very rare case. The clinical course was favorable without any major problems, due to the fact that we held a joint conference with other departments monthly.

Conflicts of interest

The authors declare that they have no conflicts of interest.

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