Liver transplantation and mental retardation

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Abstract

Mental retardation has been a controversial relative contraindication to organ transplantation. We present a case report of a 54 year old man with alcoholic cirrhosis and mental retardation who was sent for evaluation for liver transplantation. We discuss the ethical considerations of transplantation in the mental retarded patient. (Acta gastroenterol. belg., **2002**, 65, **131-132**).

Key words : liver transplantation, mental retardation.

Introduction

Organ transplants in potential recipients with mental retardation raises concerns about compliance, longevity and quality of life after transplantation (1). Wide discrepancies in criteria used and rates of patients refused on psychosocial ground are discovered (2). It seems sensible not to transplant patients in whom the mental retardation process is still developing (eg. Alzheimer's dementia). On the contrary patients in whom the mental retardation process is the consequence of a congenital anomaly or defect in which no further deterioration is expected, should be evaluated for transplantation.

Case report

A male 54 year old patient with the fragile X syndrome was seen in the out patient clinic for evaluation for liver transplantation. He suffered from an end stage alcoholic liver cirrhosis which was complicated by portal hypertension (ascites and oesophageal varices, Child Pugh B).

When the diagnosis of cirrhosis was made, three years before consultation, he stopped drinking alcohol. At the moment of consultation, he was still working as an aid in a building company. He lived with his sister who had taken care for him for a great part of his life. Medication (propanolol and spironolactone) had always been taken as described : under supervision of his sister, compliance was excellent.

After psychological examination his intelligence quotient was 45. The patient, when explained, did not understand the purpose, consequences and possible complications of transplantation.

However, because of the presence of a reliable primary support person, we decided to discuss about this patient and the indication for a liver transplantation. Psychiatric analysis could not find a contra indication for transplantation : there was no ongoing alcohol abuse and addiction. The family of the patient and the primary support person (patient's sister) were in favour to go on with a pretransplant work-out. After advice of the ethical board and in the absence of other medical contra indications, we decided to list this patient for a liver transplant.

Discussion

Historically medical care for patients with mental retardation has substandard. Only in the last 30 years have significant improvements been achieved in the quality of medical management of these patients (3). However, the recent case of Jo, a Down's syndrome child who was initially refused a heart and lung transplant has raised the issue of rationing health care (4). The conflict between the physician's duty to the individual patient and the societal need to maximize the use of finite resources is particularly acute in organ transplantation. Because of the limited number of donor organs available for transplantation, difficult choices must be made in terms of recipient selection. Often physical and medical evaluation are straight forward. On the contrary, there is considerable disagreement among different centres and programs considering rejecting or accepting a patient on psychosocial grounds.

In a survey performed in 1991, the proportion of patients rejected for transplantation on psychosocial grounds ranged from 0% to 37% with an average of 5.6% in the United States and 2.5% in non-U.S. programs. More than 70% of all programs excluded patients on the grounds of dementia, active schizophrenia, current suicidal ideation, history of multiple suicide attempts, severe mental retardation, current heavy alcohol abuse and current use of addictive drugs. Lack of consensus was found for some exclusion criteria (eg. mild mental retardation) (2).

However considering transplantation in patients with mental retardation, good results were published in a group of patients listed for a renal transplantation. In that single centre experience even patients with significant mental retardation (IQ < 70) were found eligible for transplantation. Only cooperative patients supervised by

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a reliable long-term caregiver, with long life expectancy and able to take medication under supervision, were accepted as candidates, independent of the IQ level. One and 5 year patient and graft survival were 100%. Compliance with immunosuppressive treatment and clinical follow-up was excellent in all of the recipients (1).

However when the mental retardation is still progressing (eg like in patients with Alzheimer's disease), it is obvious that the decision to list the patient for a transplantation depends upon the expected outcome of the mental process. In those cases, a careful case per case evaluation should be done, considering the outcome of the patient without transplantation and the outcome and evolution of the mental deterioration.

Apart from concerns considering outcome, there are broader ethical issues. Is patients' ability to understand the transplant process important ? Although there is an understandable reluctance to submit a mentally handicapped person to a process they cannot fully understand, many young children are transplanted after a decision is reached on their behalf with their family (5). Case reports of renal transplants in Down's syndrome (6) and assessment of children undergoing bone marrow transplantation (7) are encouraging and report no problems with compliance in their selected patients.

Because organs are scarce, one can argue that these organs go to the best recipients. However, ethical unacceptable criteria are financial possibilities of the patients and also contribution(socially, financially, economically...) to the society (8).

In our patient, medical criteria for transplantation were present (Child Pugh B liver cirrhosis with complication, abstinence of alcohol abuse of more than 6 months). Since quality of life is better after transplantation than in a patient with an end stage liver cirrhosis, regardless the severe mental retardation and the impossibility for the patient to understand the consequences and risks of a liver transplantation, we think this patient is eligible for a liver transplantation. The presence of his sister as a reliable support person that will take charge of the administration of immunosuppressive medications, and compliance with clinical follow-up is of paramount importance.

In conclusion, regardless of the IQ, cooperative mentally retarded patients able to take oral medication under supervision, with a solid support network and long life expectancy should be evaluated for transplantation.

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