

Transplantation and Mental Retardation: What Is the Meaning of a Discrimination?

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The issue of transplantation for patients affected by mental retardation (MR) has been and continues to be a matter of discussion. The recent policy of the Veneto region, a highly populated area in northern Italy, indicates that patients with MR are not eligible for any transplant of solid organs, indicating intelligence quotient (IQ) <50 as absolute and IQ <70 as a relative exclusion criteria. In the present study, we review current conceptualizations of MR, along with the current knowledge on transplantation in this population. Finally, we will review the international guidelines on this matter and discuss the social, ethical and political significance of such policy, arguing that it discriminates persons affected by MR.

Key words: Equity, ethics, transplant

Received 02 November 2009, revised 07 December 2009 and accepted for publication 24 December 2009

Introduction

The recent policy of the Veneto region, a highly populated area in northern Italy, indicates that patients with mental retardation (MR) are not eligible for any transplant of solid organs, indicating intelligence quotient (IQ) <50 as absolute and IQ <70 as a relative exclusion criteria (1).

Transplantation clinicians operate according to their own judgment or follow specific guidelines. To our knowledge, this is the first time that a political institution, such as the Veneto region, states that people with MR should not have access to solid-organs transplantation.

The issue of transplantation for people with MR has been and continues to be a matter of discussion. In 1995, in the USA, the case of Sandra Jensen raised a public debate on this issue. Jensen was a 34-year-old woman with Down syndrome who was affected by a severe congestive heart failure. She maintained a good level of autonomy

in her daily activities. Her family physician indicated that she needed a heart-lung transplantation. Such a decision was approved by her health insurance. However, the two transplantation centers suggested by the health insurance company denied the transplantation. They justified their decision on the basis that Down syndrome represents an absolute exclusion criterion for transplantation. After much public outcry and exhausting opposition, one of the transplantation centers eventually decided to perform the transplantation (2).

By the 1980s, it was recognized that the automatic exclusion of people with MR from access to organ transplants represents a clear form of discrimination. Nevertheless, as suggested by Author Robert M. Veatch 'it has become always more common to see that the decision to transplant a patient with mental retardation is made on some general criteria such as likelihood that the organ will benefit the patient, predicted length of life of the graft and of the patients following transplant, ability to follow a complex anti-rejection drug regimen, and ability of a family support network for the patient' (3). Such argument has provided a platform to an insidious and hidden discrimination. This provided us to comment upon this delicate and important issue.

Health is a right also for people with disability

The United Nations Organization in its 'Convention on the Rights of Persons with Disabilities and Optional Protocol' indicates that 'States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (4). States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: (a) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons; (b) require health professionals to provide care of the same quality to persons with disabilities as to others, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; (c) prevent discriminatory denial of health care or health services or food and fluids on the basis of disability'.

Since 1990, the American Disability Act has prohibited the discrimination of people with disability with regard to the access to health (5).

In Italy, the Constitution (article 32) declares that 'the Italian Republic protects the health as a fundamental right of each single man/woman and of the community'. The article 32 of the Italian Constitution has been the guiding principle of the 'Sistema Sanitario Nazionale' (National Health Public System) that was instituted in 1978 and that guarantees preventive care and treatment to all Italian citizens, regardless of age, race, social and economical status, and (above all) IQ.

International guidelines

International guidelines addressing solid-organ transplantations for patients with MR vary according to the organ to be transplanted.

According to the International Society for Heart and Lung Transplantation 'mental retardation or dementia may be regarded as a relative contraindication to heart transplantation (Level of evidence: C)'. They state that 'there is general agreement, however, that heart transplantation should be reserved for those patients most likely to benefit both in terms of quality of life and survival. The major ethical argument for the use of psychosocial criteria is the same as for medical criteria, such as allocating scarce donor organs to those most likely to benefit. However, there are fewer data on the reliability and validity of psychosocial criteria and on the ability of such evaluations to predict outcome after transplantation. Care must be taken to ensure that psychosocial factors predictive of outcome are not confused with judgments of an individual's social worth' (6).

With regard to liver transplantation, the guidelines of the American Association for the Study of Liver Diseases state that 'children with mental retardation pose significant logistical and ethical challenges' (7).

A consensus report from the Pulmonary Scientific Council of the International Society for Heart and Lung Transplantation states that the presence of MR represents a contraindication for transplantation. The report states that transplantations should not be provided on the basis of 'the documented non-adherence or inability to follow through with medical therapy or office follow-up or both, untreatable psychiatric or psychological conditions associated with the inability to cooperate or comply with medical therapy, absence of a consistent or reliable social support system'. Interestingly, the report clearly states that nonadherence must be documented (8).

The European Best Practice Guidelines for Renal Transplantation do not consider MR as a contraindication to renal transplant although they suggest that 'in general, being poor compliance common and one of the most frequent

causes of graft loss, a psychological evaluation may help to predict patient compliance with post-transplant treatment care' (9). According to the guidelines of the American Society of Transplantation 'the potential recipient should have sufficient cognitive ability to weigh risks and benefits of the surgical procedure and understand the need for lifelong immunosuppression. Individuals who demonstrate difficulty with attention, assimilation or memory should be referred for a formal neuropsychiatric assessment of cognitive function. A cognitive deficit should not automatically exclude a patient from transplantation. The severity of the deficit must be considered for its effect on the potential recipient's ability to consent to the procedure and to comply with the need for lifelong immunosuppression and medical follow-up' (10).

The guidelines of the Italian Society of Nephrology indicate that MR may be considered a contraindication to renal transplantation when the patients are not cognitively able to understand the complexity of the transplantation process (11). The ethical committee of the Organ Procurement and Transplant Network/United Network of Organ Sharing has recently stated that patients should not be excluded from renal transplantation because of MR (12).

Overall, it seems that none of the guidelines operating in the field of solid-organ transplantation consider the MR an absolute contraindication to transplant. In addition none of the reported guidelines consider the IQ as a measure to decide which patients should be transplanted.

Definition of MR and IQ

The case of MR is unique in medicine. While this condition is very frequent, with a prevalence ranging from 1.5 to 4% in different countries (13), current conceptualizations and definitions of such condition are largely considered unsatisfactory (14). In fact, the construct of MR suffers from several areas of weakness.

Diagnostic criteria for MR include IQ below the average and impairment in social-adaptive skills. Different classification systems indicate different IQ cutoffs as inclusion criteria: 70 in the *Diagnostic and Statistical Manual of Mental Disorders, IV text revision* (DSM-IV-TR); 69 in the *International Statistical Classification of Diseases, Injuries and Causes of Death-10* (ICD-10) and 70–75 in the American Association on Mental Retardation (AAMR) guidelines. Therefore as a consequence of minor variations in the IQ the same subject might be classified as having or not having MR, depending on the criteria used. However different tools used to measure IQ might provide different results depending on the instruction formats and the subject's neurocognitive profile, ethnicity and socioeconomic status (15). A similar issue is present with the regard to the second definition criterion, that is, the presence of limitations in social/adaptive functioning. Again, the definition of such limitations differs across classification systems. Moreover, different methods, providing different results, might be used to test their

presence. As a result a subject may or may not be classified as having MR depending on several factors, including the classification system considered and the methods and tools employed in the clinical assessment.

A second problem inherent to the definition of MR involves the construct of intelligence. While the conceptualization of MR is founded on the concept of intelligence, we still lack an internationally established definition of intelligence (16). Current debate opposes the 'general intelligence' approach (17) to the 'multiple intelligence' approach (18). In the framework of such a debate, the use of intelligence measurement to classify patients is even more controversial. Standardized instruments such as the Wechsler Adult Intelligence Scale/Wechsler Intelligence Scale for Children (WAIS/WISC) IQ are based on a nonuniversally shared idea of intelligence, provide scores that are variable over time and are often culturally relative (19). Moreover, international standardization of IQ instruments is extremely limited and we still lack worldwide data on IQ distribution.

MR and transplantation results

A recent review reported that survival rates of MR patients after a renal transplant were 100% 1 year after the transplantation and 90% 3 years later. These rates are similar to those of patients nonaffected by MR (1-year and 3-year survival: 95% and 90%, respectively). In general, an adequate posttransplant medication compliance has been reported when patients had support from family members or concerned caregivers (20,21). Such data should be interpreted with some caution because the sample sizes were small and there may be some bias in favor of positive outcomes (for instance, trend to report successful cases more commonly than unsuccessful cases). Nevertheless, these results provide a strong argument against the exclusion of people with MR from access to transplantation. Whether or not one considers the outcome criteria as ethically acceptable, the outcome argument does not provide any foundation for the exclusion of persons with MR from access to transplantation. Unfortunately, few results are available for other solid-organ transplantations. Overall, it is suggested that more cases of solid-organ transplantation in mentally retarded patients should be reported in literature in order to gain a broader perspective on this issue before drawing definitive conclusions. Currently, there is no scientific evidence or compelling data suggesting that patients with MR should not have access to organ transplantation. The above-mentioned results were related to the presence of effective social support networks. This implies that the patient's intelligence level *per se* does not necessarily affect an adequate compliance to posttransplant medical regimen.

Why patients with MR are usually excluded from access to transplantation

The following four arguments are usually reasons why patients with MR are excluded from solid-organ transplantation:

- 1) Reduced life expectancy. This is a belief and not a reality. It is well known that 80% of people affected by Down syndrome live 50 years or more (in 1929, the life expectancy in the population was 9 years). In any case, since worldwide patients aged more than 65 years may be candidate to transplantation, such argument falls short.
- 2) Reduced or absent cognitive skill to comply with complex posttransplant, antirejection medication regimens. This is true, but compliance is increased by family and social support, as reported in the above-mentioned studies.

Moreover, according to this argument children without MR should not be eligible to solid-organ transplantation. In addition, with regard to renal transplantation, how is it possible to assume that an end-stage renal disease patient, who is compliant to hemodialysis, will not be compliant to renal transplantation procedures?

- 3) Inability to understand the process of transplantation. If we accept this argument, patients with MR should not receive any kind of therapy or medical treatment at all. The same is true for young children without MR.
- 4) Lack of improvement of quality of life. It is usually accepted that transplantation should be reserved for those patients who are more likely to benefit in terms of quality of life. Indeed, a recent Japanese study involving 25 patients with MR who underwent renal transplantation reported that all persons providing primary support for patients were satisfied with the transplant and believed that quality of life was improved in both transplant recipients and themselves (22).

Nevertheless, it has been suggested that caregivers should prioritize quality of health over quality of life. In fact, from a medical ethics standpoint the issue of quality of health is more relevant than that of quality of life, as health is the primary goal of medical care (23). As highlighted by Spagnolo, all human lives must be considered of the same value from an ontological standpoint. Ontology, the study of the being, holds that life is a supreme good that cannot be measured and consequently cannot be graded. On the opposite, health can be assessed and graded. Physicians are constantly establishing whether the health of their patient is improving or declining. However, the value of human life cannot be measured, and is not determined by the quality of an individual's life at a particular time point (23).

Conclusion

IQ is not a reliable measure of mental retardation. Lack of a reliability in the construct of intelligence, the insufficiency of normative data, the inconsistency across measurements procedures and the variations in diagnostic

classification systems dramatically limit the solidity of the construct of MR, providing a very controversial and questionable foundation to any clinical and medical decision.

Keeping in mind the international guidelines, the results of the solid-organ transplants performed in patients with MR and the declarations of the United Nations Organizations and of the American Disability Act, it is difficult to accept that patients with MR are excluded *a priori* from solid-organ transplantation. Every patient deserves an individual evaluation, as declared by the surgeon who operated on Sandra Jensen 'we never should judge through generalizations'. With regard to Italy, it is surprising that a political institution such as the Veneto Region delivered official guidelines that are discriminatory against people with MR, in infringement of the principles of the Italian Constitution and of the United Nations.

Acknowledgment

We would like to thank Tanika Baptiste for her crucial assistance in the manuscript preparation.

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