

Ethical aspects of clinical care for children with end stage renal disease and mental disability

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Multi-disciplinary team with experts from different cultural, social and ethnic background, just like the patients they look after, should be responsible for children with chronic kidney disease and, especially, for children with end stage renal disease. The members of this team should meet and discuss various ethical issues and dilemmas on a regular basis. They should cooperate and respect each other's different and specific roles. Therefore, difficult ethical decisions should not be left to the responsible clinician but, instead, should be made within the team. Appropriate ethical decisions need to be supported by facts. The parents viewpoint is crucial and it is very important to ensure their understanding of the information [1]. The responsible clinician (usually pediatric nephrologist) should discuss the child with other members of the multi-disciplinary team, comprising of nurses, psychologists, social workers, dieticians, play therapists, teachers and others, when appropriate. The child should be discussed with primary care pediatrician or general practitioner as well, when necessary or appropriate, in order to gather more information about child's family or social background [2].

Technical advances in the area of renal replacement therapy (RRT) can provide life sustaining therapy for many children, including young infants and children with other severe co-morbidities, who would have succumbed to the primary renal disease some years ago. This brings several important ethical dilemmas, such as: initiation of RRT in children with severe co-morbidities or in the newborn, withdrawal of RRT in children, management of

non-adherence with prescribed therapy and the influence of non-adherence on further decisions about listing for renal transplantation, living related transplantation in the presence of a big risk of disease recurrence in the graft, and others [2].

All the members of medical personnel taking care for sick children are bound by their professional codes of behaviour, regardless of their obligations under the law [1]. The United Nations Convention on the Rights of the Child, adopted by General Assembly resolution 44/25 of November 20, 1989, significantly contributed to focus the physician's attention towards promotion of the child's best interest. Convention states, among other things, that the best interests of the child must be a primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies. In addition, the convention guarantees every child who is capable of forming his/her own views, the right to freely express those views in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child [3]. What follows from this is the right and duty of a clinician to obtain a child's agreement for diagnostic and therapeutic procedures but after a thorough evaluation of a child's maturity, their ability to understand various procedures and their risks [1]. In addition, the United Nations Convention on the Rights of Persons with Disabilities in Article 25 specifies 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].

Consent is usually not a problem in pediatric practice because it is normally given by the parents, according to their parental responsibility. It has become increasingly important to involve children who are capable of understanding information in the consent process. This is mandatory for children who are over 16 years old in Great Britain, for example, but age limit may be different in other countries. However, younger children, with ability to consent, also have the right to consent to and refuse medical procedures. But the law grants no rights for the child to refuse these procedures, proposed by clinicians. It may be reasonable to address a court of law to resolve

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difficult issues in these circumstances [1]. On the other hand, the law is often silent or ambiguous in directing what has to be done [2].

Guidelines of the American Society of Transplant Physicians state that cognitive impairment should only be considered a contraindication to transplantation when it is so severe to impair compliance with essential medication regimens and a caregiver was unavailable to compensate for the individual's limitations. However, they acknowledge that support by their family or other caregivers can often compensate his/her lack of cooperation in the treatment process [5]. European good practice guidelines for renal transplantation do not consider mental disability as contraindication for renal transplantation. Guidelines of the Canadian society for transplantation recommend that children, who are candidates for renal replacement therapy, should not be excluded as unsuitable for renal transplantation solely on the basis of decreased cognitive or physical capacity. These guidelines emphasize potential benefit in quality of life for children and members of their family and recommend decisions to be made mainly in a sense of protection of a child's best interest. Similar recommendations were proposed by the United Network for Organ Sharing (UNOS) / Organ Procurement Transfer Network (OPTN) Ethics Committee Report. European Society for Urology guidelines do not consider mental disability as contraindication for renal transplantation, if a patient is able to understand the treatment procedures and cooperate with them. Italian Society for nephrology, on the other hand, classifies mental disability among possible contraindications for renal transplantation, if a patient is not able to understand the complexity of this kind of treatment. However, the latter guidelines do not discuss about the possibility that a caregiver, willing and able to care for the patient, could compensate a patient's lack of ability to cooperate in the treatment process. One of the Italian regions considered explicitly mental disability as contraindication for solid organ transplantation in 2010: with IQ value below 50 as absolute and with IQ value below 70 as relative contraindication [6].

There is often a competitive environment for patients waiting to receive a transplant due to increased demand for transplantation in clinical practice. As a consequence, restrictive criteria were implemented in order to make priorities in the transplant waiting list. Children can become "victims" of these criteria, most commonly in the presence of mental disability or other health issues. Therefore, some centres propose instead inclusive approach to pediatric renal transplantation in order to avoid rejecting children due to mental or other disabilities. In this way a system, allowing all patients equal opportunity for receiving a transplanted organ, could be created [7].

Several studies from different countries proved good survival of kidney grafts as well as patients with mental disability, with similar treatment outcomes as in patients with normal intellectual abilities. The quality of life of

these children and their caregivers has improved. There were 16% of children with mental disability among children with first kidney transplantation between years 2008 and 2011, according to UNOS data. The principles of equal access and justice demand that these children should be treated in the same way as other children [6]. A recent study showed similar graft survival and acute rejection-free survival rates between children with intellectual disability and those without. According to these findings, there is no apparent contraindication to renal transplantation in pediatric patients with intellectual disability, according to authors, and these children should be considered transplant candidates if they have an adequate social support network [8].

Several factors have to be considered in ethical decisions in clinical practice, such as: activities should always aim to provide the child's best interest, need to gain all the available relevant information, avoidance of second hand or unproven information, discussing the issues with the whole family, respect the opinions of all other team members, try to reach a consensus whenever possible, consideration of the child's palliative and terminal care and offering a support for affected persons among parents as well as among medical personnel [1]. Principal bioethical axioms that have to be considered are respect for autonomy (what are the patient's wishes), beneficence (balancing between benefits and harms of the treatment), non-maleficence and justice (are the patient's requests fair and able to be satisfied?). However, we can do the best we can and yet, sometimes, there is no ideal solution [1, 2, 9].

The ethical dilemmas encountered in clinical practice have grown under the influence of technological advances and increasing availability of information. Multi-disciplinary team work is of utmost importance in clinical practice that can help to solve ethical issues. Sometimes ethical dilemmas about further treatment remain open even after obtaining necessary information, whether inside a team or between child's family and a team. It makes sense to address ethical committees in these case. In addition, medical professionals have to address ethical problems more systematically. Therefore, training in biomedical ethics should be part of the education for all team members [1].

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Author Contributions

Matjaž Kopač – Conception of the work, Design of the work, Acquisition of data, Analysis of data, Interpretation of data, Drafting the work, Revising the work critically for important intellectual content, Final approval of the version to be published, Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

Guarantor of Submission

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Data Availability

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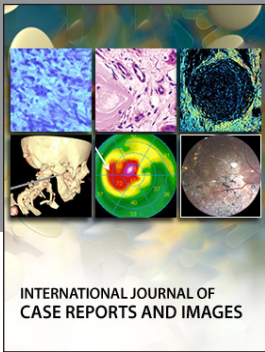
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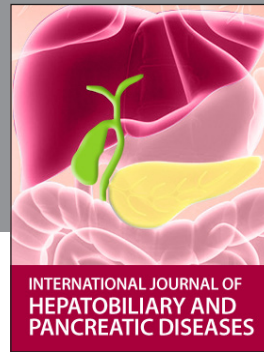
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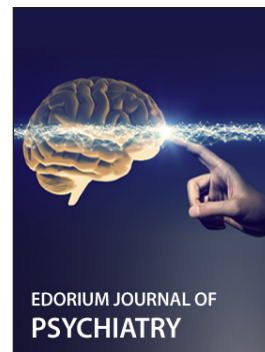
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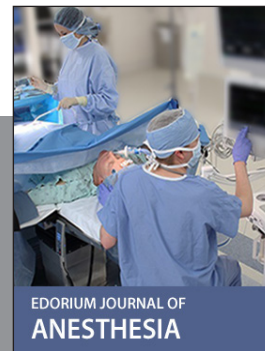
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