



Inclusive Approach to Pediatric Renal Transplantation

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Abstract

With advances in surgical techniques, organ transplantation has emerged as the established therapy for treating a variety of end stage organ failure conditions. Correspondingly there has been a rise in the demand for transplantation in the clinic, consequently creating a highly competitive environment for patients waiting to receive a transplant. An inevitable outcome of this is the implementation of restrictive criteria in order to prioritize the transplantation cases. Given the complexity of the decision making process in the case of pediatric patients, children often become the innocent targets of such restrictive criteria, especially in the presence of other health complications like mental and/or physical disabilities. Our group proposes an approach that replaces the currently established restrictive criteria towards transplantation with a system based upon inclusivity. This approach suggests a revision of criteria that must be met in order to receive transplantation as opposed to rejecting cases based upon disability, thereby creating a system that allows all patients an equal opportunity for receiving transplantation.

Keywords: Pediatric; Renal Transplantation; CNS

Introduction

Organ transplantation is now the established therapy for treating end stage organ failure in kidney, liver, lung, small bowel, and heart conditions. Transplantation is seen by the public in a positive light, as evident in the national support for widespread tissue and organ donor requests [1]. Patients on the waiting list for a kidney transplant know that they are in a competitive environment, where the available supply does not match the need for transplantable organs. When demand outstrips supply, restrictive criteria are often sought to narrow the numbers downward to allow a more harmonious situation. However, when such restrictive criteria are introduced, the most disadvantaged people in our society may be the individuals who are hurt the most. As children have less of a political representation in a politicized health care delivery system such as Canada's, this young population would be ripe for allowing restrictions to be introduced, thereby disadvantaging them in such a competition. Nevertheless, on the whole, the general public has insisted that all Canadians be treated fairly and have expressed displeasure when they see the disadvantaged having restricted access to certain aspects of health care. Particularly, children who are mentally challenged, or have other congenital or acquired deficits, might have further restrictive criteria in accessing such sophisticated care needs as renal transplantation. Physicians practicing in the transplant field have often received negative comments from various sides of the medical world where competition for resources has now become a focused reality. Individuals who see transplantation as one of the programs which must be seriously curtailed in the new concept of "minimally acceptable care", as espoused by the newer generation of ethicist [2]. This is an acceptable ethical code as it allows curtailment of expensive care to be seen in the glare of an "Ethical Light". Allocation of scarce resources are rationed by considering the parameter of social worth, which is a familiar domain known to physicians in North American Nephrology. This is evidenced by its use in the early days for allocation of scarce dialysis facilities in some areas of North America until the sound of the suffering became too loud [3]. However, in such an environment the weakest in our society are at risk as they often lack a voice at the decision level of care [4].

Bioethics of Renal Transplantation in Disadvantaged Children

One of the major advances in Nephrology over the past three decades is the ability to electively dialyze very small infants with acquired or congenital renal disease [5,6]. This presumes that these children have a future life; a life in which there is some quality. Furthermore, it assumes that they will be able to fulfill their educational and social needs in addition to availing treatment for their renal deficit [7]. There are children born with inadequate renal function or lesions that will eventually lead to renal failure, while others acquire it during a later postnatal age. Taking into account the graduates

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from our highly successful neonatal units demonstrates that some have developed renal failure due to traumatic and non-traumatic events around their early lives. Special programs for these children are therefore required to enable them to blend into the mainstream of life. This requirement is especially relevant if they have congenital defects, or damage to their central nervous system in addition to renal failure. Our aim is to have these children achieve educational and societal goals comparable to their peers [8]. When these mentally and/or physically disadvantaged children have renal failure there is often an automatic impulse to question the costs involved. Moreover, medical personnel also frequently vocalize a degree of futility to transplant a child who is perceived to be “not of value”. The charges for over-use of expensive technology are less likely to occur with the intellectually normal “photogenic” poster child who slides into renal failure. Nevertheless, the success in rescuing these neonates has now become standard therapy.

Our transplant group believes it is important to evaluate whether disadvantaged children are treated fairly, and within the law, before allowing or disallowing them access to renal transplantation. Furthermore, we also have to consider whether we are prolonging the suffering of a child who perceives periodic and unremitting therapies such as dialysis and surgical intervention through transplantation as a torture. In such cases, if the intellectual inability of the child does not allow them to understand that such therapy is actually life-prolonging, it makes any intervention appear as an unwanted intrusion. It is noted that renal transplantation is not only life-prolonging but is also a long term commitment to care for the life of the patient [9]. If the patient does not have a supportive environment and is unable to appreciate that renal transplantation is life-prolonging and involves a long term commitment to care, then there is little chance of success. In this way our inclusive program aims at dealing with these issues by providing therapies that satisfy legal as well as ethical criteria.

The Inclusive Approach

The IWK Health Center is a tertiary care referral center for assessment and management of children with renal disease from the four eastern provinces of Canada, which according to the latest census reports is comprised of a combined population of 2.3 million people. Moreover, the center is the only pediatric dialysis and renal transplant program in eastern Canada, which means that we are assessing virtually all referred children with renal disease in this part of the country. IWK's pediatric transplant program is part of a larger adult program based at Dalhousie University's teaching hospitals. Over a 47 year period, we have performed approximately 173 transplants in 144 patients from infancy to 18 years of age. Of these 144 patients, 84% were considered to be developmentally age appropriate with no significant cognitive abnormalities, physical handicaps, or evidence of complications associated with any other organ system involved. The remaining 23 transplant candidates (16%) had either cognitive impairment or visual handicap. These 23 children comprised 10 who were blind, 12 with significant cognitive impairment affecting development and learning potential and a child with congenital chloride losing enteropathy with both blindness and cognitive impairment. Currently, there are 6 children on our renal transplant wait list comprising of 2 children with significant cognitive impairment. Of these children one has Joubert Syndrome complicated by CNS involvement, intellectual disability, and a past history of psychosis that was medically controlled, while the second child has cerebral palsy and learning disabilities. Restricting access

to dialysis and transplantation from children with end stage renal disease and cognitive deficits or blindness raises complex ethical and legal issues. This represents discrimination against children with mental and/or physical disabilities and reflects our society's prejudice against its disadvantaged members. In the pediatric population, this issue is further complicated as decisions made by health care givers are agreed upon by parents or guardians without full representation of the child's rights and/or wishes. The only just solution to this issue then is to assure that all children, despite physical and/or mental handicap, have equal access to dialysis or renal transplantation as one of the several treatment options. The merits of dialysis and/or transplantation must be considered in relation to other treatment options for this group of patients including: withdrawal of treatment and death. Similar to children without physical and mental challenges, the guidelines and considerations for groups must be equal to that offered to children without disabilities.

Pressures on the health care system have accentuated a conflict and competition between a child's fundamental right to access dialysis/transplantation versus the pressures which limit access to dialysis/transplantation such as (i) shortness of organ supply, (ii) the cost of health care and expensive technology and procedures, (iii) criticism of competing families, (iv) professional perceptions, and (v) the anticipated impact on quality of life. Regulating this interaction is thus the key ethical and legal issue reflecting the views of our society. Furthermore, this evolution of laws and positions on ethical and moral dilemma strongly reflect society's values and limitations.

All children assessed in our center are offered the options displayed in (Table 1). The challenge is to make the best decision that reflects the child's rights and includes both, the family and the child, in the decision making process. This format allows protection of the child's rights guaranteeing access to every child in the program. The family is informed that their child is eligible for any of these therapies (Table 1) followed by further discussions focused around which therapy is best for their child. This approach is attainable with most care-givers and can be carried out either at the local or at the central level; however, the process of informing at the local level can create conflict if all options are not presented with sincerity, honesty and with the child's rights protected. Since the year 2000, advancements in medical technology for detecting neonatal disorders has led to the availability of better diagnostic tools such as ultrasounds and genetic screening. These have significantly led to improved perinatal health care resulting in a reduced number of patients who exclude themselves from active therapy. In reviewing the 5 children that excluded themselves from active therapy in our program, a conflict between North American exclusion criteria and our approach to dealing with these patients became apparent. We determined that children's rights, guaranteed by the Canadian Charter of Rights and Freedoms, were in direct conflict with exclusion criteria developed by most centers that provide dialysis and renal transplantation. This issue was therefore addressed by the development and implementation of inclusion criteria for pediatric patients entering our end-stage renal program. These criteria included: 1) families were expected to accept transplantation as the eventual goal for all children offered chronic dialysis, 2) the patient or parent were required to understand the perceived benefits of dialysis and/or transplantation and articulate this understanding to a psychiatrist independent of our transplant team, and 3) children must not have a medical condition which could deteriorate with immunosuppressant therapy. Only when all therapy options are offered, we contend, can physicians truly say

Table 1: Care pathways available to children with end stage renal failure.

(1) Dialysis alone inclusive of provision of palliative care dialysis goals
(2) Peritoneal dialysis or hemodialysis to optimize goal of renal transplantation
(3) Preemptive renal transplantation
(4) Conservative medical treatment of symptoms of end-stage renal failure.

to a family that they have been informed and are equal partners in the discussion of their options. Moreover, if certain therapies are restricted to certain children, a parent may carry the guilt of never offering their child an option that may have benefited him or her the most. However, palliative care has always been presented as a possible option in our program. Nevertheless, after considering all treatment options, potential complications, and potential benefits, the parents usually find it easier to decide the appropriate course of treatment.

When such an inclusive approach is utilized by the health care team, a joint conclusion, involving both the parent and child, can be made more effectively. Furthermore, we noted that this is the preferred approach as the families appreciated that all options were made available to them. Retrospectively we reviewed all families with children over one year of age who had other medical co-morbidities, and did not choose dialysis or transplantation. These families, in conjunction with the transplant team, decided that dialysis and transplantation would not be an acceptable alternative, and therefore did not fulfill the inclusion criteria. This group consisted of three children with congenital hydrocephalus with spinal cord involvement, one with Zellweger syndrome, and a fifth child with Bardet Biedl syndrome. All 5 of these cases had significant delay and cognitive impairment; the children would not even allow the most rudimentary of investigation to be done without expressions of terror. Their condition on presentation was very poor with tremendous demands already burdening the family. There was no perceived gain to the child's well being and the intervention options were seen as inflicting pain and terrorizing the child. If exclusion criteria were to be institutionally enforced, legal representation for such a child would be a necessary option. Additionally, there were also other unexpected issues wherein some families had unrealistic expectations on what would be achieved by renal transplantation. For instance, such families often hoped that renal transplantation would lead to marked improvement in the non-renal components of their child's health, particularly in relation to central nervous system conditions.

Each parent who selected palliative care as an option for their child had two predicative phases of interaction with our team. Typically, on the first meeting, these parents were prepared for confrontation with the nephrology team to advocate for their child's right to dialysis and transplantation because they perceived that their child deserved access which was being denied by the medical establishment. Once they were informed that their child was eligible for any of the four therapeutic approaches (Table 1) they typically rethought their position and actively participated in the difficult discussion of whether their child's needs would be best met thorough palliative care. This was often the first time either parent had discussed the possibility of their child's death, either by themselves or with the medical team. Initially parents reported apprehension in discussing the option of palliative care as they felt the child/partner would have a differing opinion. However, when all the options were openly discussed, it was noted that the parents were very reasonable and thoughtful in making a decision. In one isolated case, a parent became hostile and confrontational towards the transplant team when the local authorities prejudged

the condition of their child and said that their child was ineligible for any end stage renal therapy. However, this child, who had Bardet Biedl syndrome, was eligible for transplantation when evaluated by our team, as we had no such exclusion criteria. The child received a successful transplantation, but succumbed to an acute illness at a later date. Our program's approach to this difficult challenge, and the principles within our inclusion criteria, allow us to abide by two important rights of children guaranteed in Section 7 and 15[1] of the Canadian Charter of Human Rights and Freedoms:

Section 7: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

Section 15(1): "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, color, religion, sex, age, mental or physical disability."

These two rights make it clear that our health delivery system does not have the legal right to exclude any Canadian child access to therapy. Nowhere in the charter does it state that money is a criterion for excluding an individual from what is now considered to be equal access to care. Use of appropriate inclusion criteria, based on the principles noted above, has allowed us to participate in good treatment decisions for our children with the support and contribution of their families. In 1984 Alper warned us that in the process of becoming a successful business, hospitals, and by implication, health professions, may compromise the quality of caring that has been crucial in gaining public trust, and is the most important aspect of personal institutional identity in the healthcare field [10].

In a review of the current practices of United States Transplant Centers, Bia et al. [11] noted that there was no policy regarding the use of mentally retarded people as donors at 46% of their centers; 31% accepted a donor with a low IQ and 7% to 10% accepted a donor with a borderline retarded or retarded status if they were functionally independent. Six percent accepted organs from severely retarded donors, who presumably would not be able to understand the donation process. Although no such data was available in Canada, this does not exclude a similar pattern. It is worth noting that Canadians have used their provincial Tissue and Organ Retrieval legislation, which has wide latitude to cover all situations. When a literature search was performed in Canada no data was forthcoming. If such individuals are a donor source, should society not recognize their fundamental right to receive organs when they are significantly contributing to the donor pool? In the United States of America, the use of psycho-social criteria to assess candidates for organ transplantation may violate the 'Americans with Disabilities Act (ADA) [12]. The ADA prohibits discrimination on the basis of disability or on the basis of eligibility criteria that disproportionately affects persons with disabilities. If the courts were to interpret such laws in a way that deny or permit a lower priority ranking on a waiting list, and the candidate is individualized and not based entirely on generalized predictors, the prediction of diminished benefit will have to be based on scientifically valid criteria.

As shown in a study by Ubel and Loewenstein, the public places a high value on giving everyone an equal chance at receiving scarce resources, even if it results in a significant decrease in the likelihood that available organs will save some people's lives while jeopardizing others [13]. The authors of this study felt that there was a conflict

between the aims of outcome research and cost-effectiveness studies being promoted by Health Care organizations and the values that the general public places on fairness. The exclusion or inclusion of a patient therefore has to be on medical need and the possible outcome of such a procedure on the child's overall well-being, and not on a cost analysis or government perceived political framework. Society has to see to it that such aims are met and that our government lives within its own legislation and the standards of fundamental justice.

Conclusion

Pediatric healthcare is focused on the acquisition of assets inclusive of somatic growth, education, employment, and psychosocial development. In contrast, adult medical practice tends to focus on mitigating loss of assets including health, employment, and other crucial parameters. We contend that all children must have access to care despite physical or mental handicaps and therefore exclusion criteria should be replaced with appropriate inclusion criteria with more emphasis placed upon providing healthcare based on the needs of the child.

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