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Class of 2017

Avoiding a Formulaic Approach to Transplant Decision Making

Perhaps surprisingly, most kidney donations from minors go to adults rather than to pediatric patients (Monaco & Morris, 2005). Being a donor carries certain risks, including a perioperative morbidity rate of 15.2% (Bruzzone *et al,* 2005) and a very low risk of developing renal failure (Paramesh *et al,* 2007). At the 2004 International Forum on the care of the Live Kidney Donor, participants came to the consensus that individuals under the age of 18 "should not be used as living kidney donors" (Monaco & Morris, 2005). Part of the rationale for this agreement was the demonstration that donations from minors did not lead to significantly better outcomes than from adult donors. Though no doubt conceived with good intentions, a policy of this nature strips minors of any say with respect to donating part of their body.

For a child to make a decision as important as donating an organ to a parent, it is my opinion that they must be able to make the decision free of any parental input. In order for a minor, defined in Alberta as any person less than 18 years of age, to make independent healthcare decisions, they must be deemed a 'mature minor'. Within Alberta, the *Family Law Act* ("FLA") governs medical decisions involving minors (*Family Law Act,* SA 2003, C F-4.5). The FLA purposefully neglects to define a specific age or circumstance for mature minor consideration, rather the statute leaves a great deal open to discretion based on individual cases. There have been numerous court cases involving the medical consent of mature minors elsewhere in Canada, with the Supreme Court judgment in *A.C. v Manitoba* (2009 SCC 30) being the leading authority. Essentially, the Court reaffirms that there is no particular age of capacity; rather, each case must be evaluated on a sliding scale of scrutiny, with the degree of scrutiny elevating alongside the severity of the proposed medical intervention. Some of the factors that are considered include (*A.C. v Manitoba* at paras 95 and 96):

- Is the decision a true reflection of his or her core values and beliefs?
- Are there any existing emotional or psychiatric vulnerabilities?

- Do they have the intelligence to understand the potential consequences of their decision?
- What is the potential impact of the adolescent's lifestyle, family relationships and broader social affiliations on his or her ability to exercise independent judgment?

The Court provides an excellent framework for discerning the medical autonomy of a minor, which is useful to inform a medical professional's ethical assessment of a child's decision to donate an organ. To fully explore the decision making process of a child donating an organ to a parent, it is perhaps advisable to first evaluate the child's capacity to make independent decisions, then consider the pertinent circumstantial factors surrounding the decision.

While mature minors should unquestionably be in charge of their medical decisions, one of the hardest measures to assess in a family situation is the presence of coercion. The question states that the daughter "appears" to be making the decision in the absence of coercion; however, the pressures faced by the potential donor may not be overt or even intentional. A child may fear some exclusion or rejection from the family if they did not go through with the operation, even if there were no grounds for such an assumption. It would be of paramount importance to speak with the daughter alone and provide her with a medical alibi for not proceeding with the transplant. The ability to be completely blameless would hopefully free her to decide without any fear of reprisal. If the daughter still wished to donate a kidney to her father at this point, it seems more likely that it is truly in line with her core values. It is entirely reasonable that the support and promotion of her family's health and well-being is something crucially important to her. In such cases it would directly oppose the notion of patient-centered care and collaborative health care to refuse her wishes.

Nevertheless, awarding mature minor status requires more than just a true desire to proceed with the procedure. It is equally, if not more important, to verify that the child is free of any emotional or psychological ailments and is capable of meaningfully understanding the consequences of the

operation. As a fourteen year old, it is likely that the daughter has had some exposure to biology and anatomy and is more than likely intelligent enough to grasp the nature of the operation. It would be the physician's responsibility to have a discussion with the daughter to explain the procedure, potential complications, and the consequences of living with a single kidney to ensure her understanding. There seems to be some debate in the literature as to the long term effects of living with a single kidney, with some studies claiming increased risk of hypertension and a reduced glomerular filtration rate (Kiberd, 2013), while others cite no serious detrimental sequelae from a unilateral nephrectomy (Monaco & Morris, 2005, Haberal *et al* 1999, Paramesh *et al,* 2007). Live kidney transplants only began being used in the early 1950s (Watson & Dark, 2012), so it seems reasonable to assume that the truly long-term effects will need much more time to be elucidated - the patient deserves to be aware of this. Careful assessment of the mental state of the daughter would also be essential. Any concerns regarding depression or other psychological conditions could cloud her ability to make a rational decision and should raise red flags for the transplant committee. If the young woman appears clear of mind and is able to effectively convey back her understanding and awareness of the operation and its risks, then it would be ethical to consider her an adult with respect to the procedure.

Given the appropriate mental considerations, there remain several social factors that need to be examined. Perhaps the most important piece of information that has been neglected up to this point is the mother's wishes in the matter. The mother, assuming she is a legal guardian for the daughter, must be included in the decision making process as her dissent may present a significant obstacle to the procedure or bring about legal ramifications if the daughter is not found to be a mature minor (Ross, 1994). It would also be crucial to assess the family life of the daughter: whether she has siblings, her feelings of safety at home and the presence of familial support and care following her operation. To those who still remain convinced that any organ donation from a child to an adult is exploitative, consider that "a person's needs and best interest do not exist in a vacuum, but must be evaluated

alongside of the needs and interests of other intimate persons" (Ross, 1994). It may be extremely painful for the young daughter to watch her father suffer through end stage renal failure. The ability to help rid him of that great burden could be extremely empowering and a strong motivation. In fact, interviews with donors who gave kidneys to living relatives indicated that "they would go through the same procedure again to help their families" (Haberal *et al* 1999). The emotional and compassionate considerations inherent in such a life-altering decision should not be downplayed in a physician's ethical assessment of the situation at hand.

Generosity is an attribute that many parents strive to instill in their children. Indeed, it is a value highly espoused by religious influences, "Give, and it will be given to you" (Luke 6:38) and, from personal experience, also encouraged in the public school system. Despite this positive exposure to the concept, many adults are taken aback by altruistic acts. Indeed, the participants at the International Forum on the care of the Live Kidney Donor would deny adolescents the ability to donate their kidneys. Perhaps the strongest argument against this outright ban can be framed in the scope of risk assessment. Approximately 8% of patients waiting for kidney transplants die every year, with an average wait time of three to five years (Paramesh *et al,* 2007). Whereas the risk to a child who serves as a kidney donor is roughly the same as allowing them to learn how to drive according to Lainie Friedman Ross in his book, "Children, Families, and Health Care Decision Making". From the daughter's perspective, she can roll the dice on her father's life, or take the keys to the family car and drive. In the same sense that all patients are individuals, every transplant decision faced by a minor is highly personal. A bright line, formalistic approach to permitting a minor to donate an organ is neither desirable nor ethical, as it ignores the need for a case-by-case assessment and fails to give due weight to the human factor that is inevitably entwined with familial transplantations.

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